Is a user-generated social media campaign for the symptoms and consequences of vitamin B12 deficiency an effective tool for creating awareness of the health issue?

A Bulgarian case study

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ABSTRACT

This study aims to analyze the effect of an improvised user-generated health awareness campaign which was based on a personal narrative and first-hand experience with the B12 deficiency symptoms in babies and toddlers. The campaign was conducted in 2015 with a follow-up video in 2016 and shared through social media outlets, informing about the topic and empowering individuals to take responsibility for their own or their child’s health by providing information that could serve as a guideline for early diagnosis and intervention and by presenting an outlook of how people with similar issues manage the condition.

The impact of the campaign is being qualitatively and quantitatively accessed by interviews with medical professionals and respectively survey data from a national survey and statistics from the YouTube console. In consideration has been taken the trust the respondents have in the medical service and the usual access to health information both online and offline.

The quantitative data were collected using a national online survey in which 1185 individuals took part. It aimed to additionally identify the general public attitude towards medical service in and the awareness about the vitamin B12. Four people participated in the interviews, divided into two groups - parents of children, who had symptoms similar to those, shown in the videos; and health practitioners who have seen the videos and comment on its qualities as a self-diagnosing material as well as the effect that attention to the issue created on their medical practices.

The results confirmed that the personal narrative of a campaign could help to create identification and thus be more persuasive and with further increased sharing potential of the message through social media. The concrete campaign reached cumulatively over 167,000 people through YouTube, which is around 2.4% of the population of Bulgaria and possibly creating a lasting impact on the public attitude towards vitamin/mineral and other deficiencies.

We found out that social media and YouTube could serve as an impactful medium for disseminating health-related information online when accurate and persuasive information is being used. When addressing a wide audience with little or no prior knowledge of the subject the personal narrative or testimonial could create more impact than a neutral fact-providing material.

KEY WORDS: social media, user-generated health content, narrative health communication, YouTube
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1. INTRODUCTION

“The internet is the single largest source of information related to health care, equivalent to books, newspapers, magazines and mouth-to-mouth sources combined.”
(Cresci et al. 2012)

The creation and exchange of user-generated content are made possible through the advance in information and communication technologies (ICT) and the existence of new media in the form of a group of Internet-based applications which that build on the foundations of Web 2.0 ideologically and technologically (Kaplan and Haenlein, 2010). New media as such provide not only new means for dispersing news but also have a different philosophy from the mainstream channels for circulating information. While the former, “old-fashioned” or now in some sense dated mainstream media channels broadcast controlled content, selected from editors and limited in length to several seconds or minutes, the new alternative in the face of the ubiquitous and a fundamental communication tool of the internet (Bennet and Glasgow, 2009) provides an opportunity for every individual with a camera, keyboard or a microphone and access to internet to create or be a time-limitless broadcasting agency with raw, subjective and unfiltered emotions and content, formed by one’s own point of view. The messages are various - news distribution, entertainment, communication and education, digital labor, but also for disseminating messages important for the communities, societies, and individuals. Thus in such a way Web 2.0 provides a platform for the voice of marginalized to be raised and for creation and expression of empowerment (Wilkins et al. 2014, p.132) and development.

To simply define what communication for development or ‘development communication’ is - it is at heart a social process engaged with sharing of knowledge while considering the interest and goals of all actors involved and aims at the respective social change (Servaes, 2008). One of the many faces of communication for development is health communication or the sharing medical of health-related information online alongside useful tips, new treatments, and individual experiences. (Jackson & Duffy, 1988) Its objective is disseminating knowledge and thus and empowering audiences by giving them the opportunity for a self-motivated change of attitudes and practices for health (and in some cases lifestyle) improvements. It does not propose replacing medicine in terms of exams, testing, adequate and sufficient treatment but rather addresses the subtle and early symptoms; gives insights about existing treatment alternatives or provides social support by one-way communication from someone dealing with the same condition or create a dialogue about the topic.
However, the communication does not provide an improvement in and of itself and that is where interpersonal communication plays a vital role. In the current research we investigate a real-life case, in which there is an interpersonal communication provided by social media, a tool for connection and if there are concrete (measurable or qualitative) development results in the form of empowerment for taking responsibility for one owns health and wellbeing and attempting to take into consideration at least some of the complex elements/components such as culture, societal understandings/settings and behavior (Servaes, 2008).

1.1. Background

Our first daughter, Anastasia was born perfectly healthy in 2013. By the age of 6 months she was developing normally and meeting every milestone. Around the 8th month she started to smile less, to eat less and the development started to get delayed. She became increasingly irritable, started losing balance. We got her tested and found out she had severe anemia for which we (I and my husband) consulted multiple medical practitioners and specialists. She was diagnosed with iron-deficient anemia. When I asked were vitamin deficiencies among the commissioned tests the doctors answered negatively.

After 10-day treatment with iron supplement, her levels increased above the critical threshold but her sleeping patterns changed dramatically with up to 22 hours of sleep. Again we consulted with medical practitioners to be told that this is normal and is a “decompressing mechanism” that follows the improvement of her health. After several days she started having eye twitching. We researched what this could mean, found out it might be epilepsy and contacted neurologist. During a hospital stay all the medical tests for epilepsy came back negative, not a single one confirming the tentative diagnosis. Nevertheless her final diagnosis was “symptomatic partial epilepsy” based only on this one symptom – the eye twitch. For us this could not answer the other symptoms like developmental regression and especially the excessive sleep. We searched for second and these opinions only to have our concerns dismissed. We started our own research, I in English and my husband in Russian and we cross-checked the available information in medical journals and online blogs. We had a list of all the symptoms and eventually we found out that we had 19 of 20 symptoms for B12 deficiency in toddlers. We got Anastasia tested (in Bulgaria there is a free access to paid medical testing) and we proved severe deficiency. Upon returning to the hospital and the medical practitioners however, we were denied treatment on the grounds that “B12 deficiency is a non-condition”. Again we searched for second, third

Vitamin B12 deficiency is regularly being misdiagnosed as Alzheimer’s disease, multiple sclerosis, heart disease, a neurodevelopmental disorder, Parkinson’s disease, depression, or other mental illnesses (Pacholok and Stuard, 2011; Mukku et al. 2018) and in some cases optic failure (Larner 2004) While these conditions might take years to develop, in babies or
toddlers the undiagnosed deficiency could swiftly lead to critical and permanent neurological damages as the brain and neurological system had not been adequately formed yet. The misdiagnoses, in this case, vary from failure to thrive (Chalouhi et al., 2008) to epilepsy with many neurological disorders in between (Fiedler et al., 2008). The continuous wrong interpretation of medical tests is in some cases caused by the low levels of iron, which mask the most searched-for sign of megaloblastic anemia. (Abu-Kishk et al., 2009)

Despite that, the medical literature provides information about the neurological consequences of the lack of adequate vitamin B12 levels and the crucial importance of urgent treatment and correction of the deficiency in many studies the mothers of the children are reported to be vegetarians or strict vegans which can mislead medical doctors while talking through the symptoms. In reality, there are multiple conditions that are not related to the nutrition and/or supplementation and could lead to vitamin B12 deficiency, including genetic ones. In such sense, it is crucial to focus on early screening of symptoms and signs in order to ensure timely and adequate treatment and prevention of permanent damages.

The issue with vitamin B12 deficiency is not only a Bulgarian one but prevalent worldwide (Loyola, 2007; Loikas, 2007) and with the increase in popularity of unsupplemented vegetarian and vegan diets the rate of would be significant, although the diet is only one of the many factors causing deficiency (Pacholok & Stuart, 2011).

As our family has been directly and critically impacted by the misdiagnosis of vitamin B12 deficiency, we were committed to resolution of the issue by ourselves and thus ‘more acquisitive of information pertaining to the problem, selective in dealing with information and transmissive in giving it to others’ (Kim & Grunig, 2011, p.125) and as a consequence we became active in dissemination of important information that could assist in other cases where health care practitioners are failing to address the underlying cause of the symptoms and that would usually lead to misdiagnosis (Kim & Grunig, 2011). What is more, it could serve as a rough guide for early screening and prevention of permanent neurological damages, especially in babies and toddlers (age 0-3). We felt that our moral obligation is to share what we know and what we have learned along the way and if it could help save the health of only one child our efforts would be worthwhile.

I have been video-blogging since September 2014 but due to privacy concerns, I did not include our daughter Anastasia in the movies. However, after the treatment for vitamin B12 deficiency, I decided that in order to prepare the audience for the upcoming important message, along with my ‘sit-down’ videos with tips and tricks, I needed to start filming daily videos in which I began to include Anastasia and show what our everyday routines look like with her, where we went, what we ate, thus deliberately creating more intimacy and a parasocial relation between me and the viewers (Horton and Wohl, 1956), which would
subsequently give more influence to our medical story. I would repeatedly mention that we were visiting rehabilitation centers but I would not specify why. I wanted the online ‘world’ of people who watch my videos to get to know her after and outside the condition to minimize the bias and stigma towards a ‘different’ child.

Several months after the treatment and the several courses of rehabilitation, when the emotions had subdued and Anastasia was already known as simply an adorable little child, the self-styled social media campaign was launched in the form of two videos, published on the video-sharing platform YouTube in June 2015. In the videos, I told the full story of the multiple misdiagnoses that she received, including a full description of all and short videos of some of the symptoms, what tests were made how and when the issue was adequately addressed, what was the treatment and how the development of the child to-date is. Later, the first two videos were complemented with a new material about my physical and neurological symptoms as an adult.

1.2. Objective

This study investigates the effect of social media use for health communication, namely using the personal narrative story as a basis for a YouTube video awareness campaign for the symptoms and consequences of B12 deficiency in children for whom an immediate response and treatment is of crucial importance for a favorable outcome. Such information dissemination in our experience could (and has) helped to decrease the number of misdiagnoses and medical errors sometimes leading to crippling and permanent physical and mental conditions as severe as death, caused by chronic or acute B12 deficiency.

The most important matter, however, is that especially in babies and small children there is a very short window for a reaction before the neurological damage - only months, weeks or sometimes even days before it gets permanent and the timely access to information is of crucial importance. (Pacholok & Stuart, 2011)

This study aims to fill in a gap of research about the video blogging as a tool for raising awareness about health issues in recent years2 and most particularly in Bulgaria3.

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1 Deficit of Vitamin B12 YouTube playlist: https://www.youtube.com/playlist?list=PLkMEjoBsZtv4fV0utKVCCgVvMSsZYBvYd
2 Many studies that research the role and place of blogging and video-creating are already dated because this type of media develops and evolves on almost a weekly basis.
3 Bulgaria is a country on the verge of the Global North, as a part of the European union but still having many traits from the oriental having been 500 years under ottoman ruling and also from its communist past until 1990.
1.3. Research questions

In the current study, we want to address the following research questions.

1. What are the advantages of using personal narrative in communicating health-related information?

2. Is social media, in particular, YouTube an effective medium for health communication from the general public’s perspective?

3. What are the viewers’ reactions to educational entertainment versus facts in personal video blogs aimed at creating awareness about a certain health issue?

1.4. Hypothesis

In order to set boundaries for my research, I started with an initial hypothesis “If the general public (represented in the participants in the questionnaires) has got lower trust in the quality of the received medical care, they could be more susceptible to unofficial or “alternative” sources of information which a YouTube video is.”

1.5. Research design

The qualitative (e.g. intent of future behavior, engagement with the issue and spreading of information) and quantitative (measurable reach) results of the video and additional blog-posts were analyzed to research the overall campaign impact.

1.6. Relation to communication for development

The current study is viewed through the lens of health communication, which, although relying on multidisciplinary approaches shares the same objectives with communication for development, namely to ‘engage, empower, and influence individuals and communities’. (Schiavo, 2013, p.6) and in a broader sense may be viewed as one of the many aspects of development communication that persuades people to change thus leading to improvement of the lives of individuals and societies. (Tufte & Mefalopulos, 2009)

The transitions in health communications began in the early 1960s as a reaction to the change in the communication for development paradigms. Then, attempting to address risky sexual behaviors, the Global North countries created a plan of stages of change or linear models for changing behavior. These models are placed within the understanding that people who are given knowledge would change their attitude, thus presumably the change in attitude would lead to a change of their practice/ behavior. These initial health theories
were commonly known as ‘knowledge, attitude and practice’, or ‘KAP studies’, and were
subject of extensive criticism about the faults in the concept that behavior change would
occur in isolation, without considering the various factors such as the individual, the
community, and society. (Durden & Govender, 2012)

1.7. Limitations of the current study

During my research on multiple occasions I felt pressed by the word limit and available time,
and I believe the study would have been immensely enriched by a more thorough and
interdisciplinary approach including not only media for development studies, but also
sociological and psychological perspectives such as overcoming resistance to persuasion
(Knowles and Linn, 2004) or comparing the communication modality, (i.e., written, audio or
audio-visual material) that makes a message more effective (Chaiken and Eagly 1983).

A limitation in measuring the impact of the individual’s own social media awareness
campaign is that we cannot draw a clear border between has been achieved by the
campaign in question and what is a result of subsequent campaigns (conducted via national
television, blogs, a book tour with lectures and webinar), especially due to the fact that the
first campaign has been used as a "living example” and I, as its creator have been a part of
the latter campaigns and events.

The involvement of me, as a researcher in the study is significant which I tried to balance out
by providing impersonal quantitative data (statistics). Additional shortcomings that need to
be considered about the data gathering are that the social media accounts are followed and
the videos in the YouTube channels are watched by people who are already personally
involved with the family history of the researcher and the specific episode of vitamin B12
deficiency, so they have most probably seen the videos and followed up the rehabilitation.
Further, the interviewees were picked, based on previous connections or interactions with the
researcher. Further, to-date I continue to share information about the deficiency of vitamin
B12 symptoms, as well as another macro- and micronutrients, which makes the boundaries
of the campaign blurry.

Further, a mistake was made in the design of two questions in the online questionnaire
(Section 4 - Questions N20 to N28) where initially there was no option “I don’t know/I cannot
answer”. In the comment section, a respondent noted that in this case people might not
know the right answer but guess as the question is required for answering. There were
already 600 replies (of total 1185) when the mistake was corrected, thus the replies from this
section should be considered with caution.
Some of the questions could have been designed differently in order to return a more comprehensive or simple for answering and an easier for the understanding reply. For example Question N8: Do you receive full and exhaustive information from your medical practitioner about your condition, including dietary guidelines, exercises, and lifestyle? Has a scale from 1-10 where 1 is ‘never’ and 10 is ‘always’. A better alternative would be categories like ‘never’, ‘rarely’, ‘usually’, ‘always’ or similar.

All four interviews were conducted in written form as preferred by the respondents who wanted to answer in their own spare time. This has some advantages of the thoughts being clearly and orderly formulated but, on the other hand, the method lacks the spontaneousness and nonverbal cues of the interviewee as well as the opportunity to ask additional questions or the flexibility for the researcher to guide the conversation in new directions.

The analysis of the contents of videos along with the quality of the movie (including production features light, angle, setting, posture, the direction of gaze etc.) was beyond of the scope of this research.
2. LITERATURE OVERVIEW

In this chapter, we will discuss the theoretical background and previous knowledge on the subject of development communication and what is applicable to the current case.

2.1. Communication for development

If we can define 'communication for development and social change' as the use of tools to share information improve connectivity in order to improve and advance states, communities and/or groups of individuals (Servaes, 2008, p.14), and identifying what are the obstacles for development and who are targeted as main beneficiaries (Schech & Haggis, 2000).

What exactly is considered an improvement, however, differs for each class, culture and historical period of time for there is no unifying, overarching paradigm of development (Nederveen Pieterse, 2010). The participatory aspect of development requires the community to take steps in identifying what is needed for development – what are the issues that need to be corrected and adjusted. In a broader sense, this is the exact meaning of the health awareness campaign, the subject of the current study – a mix of ‘grassroots and social media activism’ (Murthy, 2018; Valenzuela, 2013) to identify an issue and to create and implement steps for overcoming it (sharing of know-how) in order to create a meaningful impact on the lives of the community members.

Interesting viewpoint is discussing the conflict between behavior change communication and social change communication (Salem and Sullivan 2008; de Mooij 2013; McKee et al. 2014) which, due to time and space limitations are beyond the scope of this study.

2.2. Participatory media

The term ‘participatory culture’ had been introduced by Henry Jenkins (1992, quoted in Jenkins et al. 2013) to depict the creation of (new) culture and social interactions among fans in order to distinguish them from other types of observers. According to Jenkins (2013) if a piece of information “doesn’t spread, it’s dead” (p.1) and the role of the public had been transformed from mere spectators to people who are ‘shaping, sharing, reframing, and remixing media content in ways which might not have been previously imagined’ (p.2).

The advance in ICT has brought platforms that facilitate an immediate sharing of ‘media artifacts’ (Jenkins et al, 2013 p.2). The more important question, however, is not how the media is becoming increasingly more shared but why and ‘the spreadability paradigm assumes that anything worth hearing will circulate through any and all available channels, potentially moving audiences from peripheral awareness to active engagement (Jenkins et al, 2013’, p.7)
2.3. Social media and health communication

The leading strategy for public health communication has been to disseminate “messages of enlightenment” to high-risk groups of people by using the top-down approach without necessarily reaching out for a dialogue. Indeed that is the essence of communicating health information. The bottom-up or horizontal approaches would not only question the medical authority (which in some cases proves to be necessary due to medical errors (see 2.6 below) but poses the issue of creating misinformation (Chen et al., 2013; Hughes, et al., 2009; Kim, 2009; Orizio et al., 2010).

Because the core of social media is to provide space for conversations among audiences, in the context of health information dissemination and promotion, the engagement of the audience with the health messages could lead to different outcomes - including increased awareness of the issues, sense of sociality in terms of association or belonging, engagement in the programme, etc. (Neiger et al., 2012). Social media campaigns differ from mainstream media especially in the element of interactivity and possibility for active communication, including such in real time (Owen & Humphrey, 2009). What is more, social media could be more efficient in organizing people due to the creation of networks and the information sharing within those networks (Paek et al., 2013) thus suggesting the capacity of social media to be used as an important tool for health campaigns.

“Perhaps nothing is more human than sharing stories, whether by fire or by “cloud”...” argues Jenkins, Henry et. al (2013, p.3) in a quest to explain not just how information and stories but why. In such sense testimonials (i.e. personal stories) are more influential than the mere presentation of facts (Braverman, 2008) as confirmed by the opinions shared in the surveys for the current study, because they are relatable. For this project, we will investigate the relationship between personal experience shared online as a part of empowering knowledge serving as informal and ‘grass-roots’ communication for development.

In the online world the user-generated content becomes an alternative source of information (Wyrwoll 2014, p.2) but there is so much of data (Adams, 2010) that one can hardly make any use of it (Bush, 1945, p.38) And to add to that in a research from 2017 shows that the vast majority of the content contains misleading information (Knight, van Leeuwen, Roland, Moll, & Oostenbrink, 2017) and that the videos with inaccurate information have a larger view count than the factual and correct ones (Garg et al., 2015) This is what we want to test with the specific campaign in the study - is it informative enough for patients and correctly presented according to practitioners.
What is more, the unprepared patient or general public might not know how to process the information (Adams, 2010) and when uncertainty about the symptoms is strong, psychologist talk about cyberchondria - the online correspondent of hypochondria (Fergus, 2013) In the interviews we will get the point of view for the concrete videos from the medical representatives with vast clinical experience with vitamin B12 deficiency.

To add to the issue, more often than not attention is put on the effect the technical quality plays in the judgment of the overall quality of the material. Non-professionals as patients or parents could be misled by the appearance of the video (picture and sound quality, setting and light) and ascribe that to the quality of the clinical example itself. (Knight et al. 2017)

To address the issue, according to Knight et al. (2017) assert that medical practitioner should voice their concerns about the accuracy of information presented online and discuss with patients or parents reputable sources of advice. During the interviews, I asked two medical practitioners what their view and opinion about the video materials and the provided information in the frames of the vitamin B12 awareness campaign. I invited them to comment on the possible changes or improvements that would make the current or future materials better and inquired if they would recommend the videos to students and patients as a source of first-hand information about the symptoms, reaction to treatment and further rehabilitation.

### 2.4. Effectiveness of Entertainment-Education Strategy

Entertainment education (EE) is viewed as an new and arguably effective health communication strategy (Singhal et al. 2003; Lee 2004; Cody and Sabido, 2008, Woudhuysen, n.d.). It is considered to be more effective means of persuasion due to its narrative structure for as or as Sartre puts it ‘a man is always a teller of tales, he lives surrounded by his stories and the stories of others’ (1938, p.61).

The entertainment education is an interesting topic which we will touch upon only briefly because the three videos of the campaign are not entirely build upon the entertainment and are rather informative sharing of personal experience with a health issue. The elements of EE are evident in the other videos of the video creator where educational information (e.g. vitamin D3 deficiency) is mentioned as part of lifestyle videos but not completely relevant to the specific three videos of the campaign.

### 2.5. YouTube, participation, and empowerment

Although some scholars consider all media essentially social for they are part of a society (Fuchs, 2013, p.4), the mere use of social media does not constitute a dialogue because it
could be rather a one-directional presentation of information (Wilkins et al., 2014) The participatory approach, on the other hand, aims to create dialogue and discussions in order to facilitate ‘meaningful knowledge generation and exchange’ (Wilkins et al., 2014).

“The medium is the message” argued Marshall McLuhan (1964, p.7) in the sense that every medium has its own characteristics that shape the communication and relations and the for YouTube participation is not only a buzzword, it is ‘the core of the business’ (Burgess and Green, 2013). And although YouTube is, in essence, a public (and corporate) platform for video sharing each individual channel is ‘owned’ by the video creator and thus when a video-creator is a part of community, they have equality and horizontal power relations with the other members of community, represented as viewers and in practice, participatory.

YouTube is more than television – it has dual characteristics of a platform for simultaneously top-down sharing of popular culture and a bottom-up stage for creativity and multifaceted nature of a ‘high-volume website, a broadcast platform, a media archive, and a social-network’ (Burgess and Green, 2013) and the second-most-popular not only a website but also search engine worldwide and a steadily growing source of unmoderated health-related information (Madathil, et al, 2015).

The YouTube following has its own subculture, where the video-creators are real-live people and not merely media personalities and beyond the monetary compensations for their digital labor, receive ‘a sense of community, esteem, and/or belonging to those who share a common interest’ (Gregg, 2009, p.209) This, so called “capitalizing intimacy” by the micro-celebrities as put by Tobias Raun (2018) builds upon the exposure that the platform creates, thus representing or being form of the mediatization of the Web 2.0, where everyday life and culture are intermixed with user-generated content (Hepp, 2013, Hjavard, 2013). The ‘perceived genuineness’ of a creator is what will attract or pull away the audience (Jerslev, 2016, pp 5245-5246; Marwick, 2015, p. 346) – audience or following, that is built gradually by investing of emotional labor of ‘revealing personal information, sometimes to the point of extreme discomfort and vulnerability (...) using real emotional affect when presenting oneself and interacting with others’ (Marwick, 2013, p.196)

Researchers have previously studied the use of YouTube for health information dissemination (Briones et al. 2012; Desai et al. 2013; Kim et al. 2010; Yoo and Kim 2012) and the results confirmed the persuasiveness of such type of media content thus affirming the intricate role of YouTube as an agent in creation of ‘meaning, value and agency’ (Burgess and Green, 2013).

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4 ‘Micro-celebrity describes the state of being famous to a niche group of people’. (Raun, 2018, p.104)
The YouTube space mimics interpersonal relationships and the para-social relations in several ways – both are deliberate, provide company and are built based on social attraction (Perse and Rubin, 1989). Yet Schramm and Hartmann argue that the third point is not a requirement for there are people who are motivated to watch a media person by mere dislike. (Schramm and Wirth, 2010).

Unfortunately due to limited space and time we cannot engage on a deeper level on the self-disclosure (Utz, 2015) and intimacy as an important factor impacting to ‘both the form and content of the videos and the relation between the creator and the audience’ (Raun, 2018, p.101).

2.6. Health communication and the possibility of a medical error

A research by John Hopkins University showed that the third leading cause of death in the USA is “medical error” although occasionally being omitted in reports (Makary and Daniel, 2016). Medical error as such is described as

“an unintended act (either of omission or commission) or one that does not achieve its intended outcome, the failure of a planned action to be completed as intended (an error of execution), the use of a wrong plan to achieve an aim (an error of planning), or a deviation from the process of care that may or may not cause harm to the patient.”

(Makary and Daniel, 2016)

The reasons for medical errors might be many and multifaceted – inadequate training or expertise; lack of experience; personal or health issues of the medical professional that interfere with the process of finding the diagnosis, etc. The unfavorable outcomes, however, do not differentiate the reasons for the mistakes.

To add more, there is also a time lag between the discovery of new knowledge and its integration in medical practice which might cause unnecessary harm to the patients as argued by Chan et al. (2017). Sometimes the integration of new clinical discoveries may take even decades as a research done in 2011 by Institute of Public Health, University of Cambridge reports that the average time between a medical discovery and its implementation into general practice ranges between 17 to 23 years (Morris et al., 2011). And while there is a real issue with new theories and understandings which have not been evaluated enough and might pose danger for patients safety (Cameron, 2016) some of the already known facts are not always well established in the medical practice.
In the case of smaller countries, the period could be even longer due to the lack of translated materials - as not all researchers and studies are being translated in Bulgarian, for instance; and additionally because not all of the medical professionals are fluent in English.

A basis for the creation of the video - the campaign is the presupposition that when “armed” with accurate and thorough information people could be less likely to adopt the first suggested treatment and instead feel empowered to search for second opinions, alternative treatments, etc. It provided a summary of well-researched sources about the symptoms of vitamin B12 deficiency in toddlers and adults as well as valuable personal insights and know-how applicable to the specific conditions in Bulgaria (directions to clinics and medical laboratories as well as a way for ordering highly-absorbed forms of vitamin B12 from abroad, etc.).
3. THEORETICAL FRAMEWORK

The findings of the current study will be evaluated upon the communication for development and in particular with health communication through social media as a way for improving the well-being of communities and individuals. The difference between the literature overview and the theoretical framework consists in the focus. While in literature overview we explained certain concepts and set the background of the study, the current chapter gives us the frame that will guide our discussion.

A specific development communication strategy is a unique fusion of functions and elements depending on the specific needs. (Wilkins et. al, 2017) but there is also a blend of several functions of the communication for development: the informational material serves both as an educational communication – in terms of providing of new ideas, knowledge or skills; for building certain capacities (general or applicable to personal life) and influencing behaviors; but also allowing for participation and dialogue (Wilkins et al, 2014).

Although multiple theories to analyze the video campaign (e.g. media for development, ICT for development, participation for development) may have been appropriate I chose to opt for health communication as it is most eminent considering the main topic and the target outcomes of the information disseminated by the YouTube clips but I will also briefly touch on entertainment education as a part of the communication strategies that were to a certain extent involved in the project.

3.1. What is health communication?

In the era where social media has increasing importance, healthcare communication can have many forms and structures. First, social media becomes a platform for sharing and receiving of information, used both by medical practitioners and patients as well as the general public (Giustini 2006; Fox et al. 2009; McNab 2009a and YouTube as a platform for video publication and an important search engine and community network has been used for sharing of different health stories (Fernandez-Luque et al. 2009; Chou et al. 2011).

Health communication is a feature, branch or one of the many ‘faces’ of the communication for development and it is dedicated to

‘influencing, supporting, and empowering individuals, communities, health care professionals, policymakers, or special groups to adopt and sustain a behavior or a social, organizational, and policy change that will ultimately improve individual, community, and public health outcomes.’ (Schiavo, 2013, p.3)
“To this end, health communication inquiry is usually problem-based, focusing on identifying, examining, and solving health care and health promotion problems.” (Duffy and Jackson, 1998)

For health communication information is the most important capital in healthcare and health promotion ‘because of it essential in guiding strategic health behaviors, treatments, and decisions’ (Kreps, 1988). Here health information is understood as the ‘knowledge gleaned from patient interviews and laboratory tests that are used to diagnose health problems.’ (Duffy & Jackson 1998).

Yet, in the context of health communication, the meanings and importance are “located in the realm of the community and not in the realm of health outcomes imposed by external experts” (Dutta, 2008, p.56).

It has a multidisciplinary nature, including medicine, psychology, sociology, media and communication studies etc. and in some ways, it overlaps with social marketing (Cho, 2011). For disseminating of the message it engages different communication channels (e.g. personal interaction and conversation, mainstream media channels, including written, audio and audio-visual sources, social media, etc.) to reach out to the target audience. (Schiavo, 2013, Duffy & Jackson 1998) as well as strategies for designing effective messages and communication (Cho, 2011; Parvanta, & Harner, 2010; Thompson, 2003).

3.2. History of health communication

Development per se has been broadly compared to modernization, as a process of economic and social change (Schech & Haggis, 2000; Scott, 2014). What exactly is considered an improvement, however, differs for each class, culture and historical period of time for there is no unifying, overarching paradigm of development (Nederveen Pieterse, 2010). And with the cultural turn and the change of paradigm in development communication, the focus became the needs of the communities there came two leading schools of thought arose - the first was classified as behavior change communication (BCC) and the second - social change communication. The former is a rather didactic approach aiming at promoting positive health outcomes, grounded on existing theories and models of behavior change, while the latter is an ‘integrated’ and inclusive one that includes media, interpersonal communication, and advocacy.
3.3. Types of health communication

There are different classifications of health communication in the different disciplines and according to (Wright et al., 2012) the types are as follows:

- **persuasive/behavioral communication** - explaining new ideas and practices to particular audiences;
- **risk communication** - communicating the seriousness of an issue and advising on possible paths and solutions;
- **media advocacy** – using mass media to "advance social and public policy initiative";
- **entertainment education** - involving diverse media channels such as TV, radio, internet, and etc. to deliver a message about health-related issues.
- **interactive health communication** – the use of media outlets for patient-professional interaction to provide support and/or guidance
- **development communication** – addressing general health issues or behaviors in communities
- ‘influencing, supporting, and empowering individuals, communities, health care professionals, policymakers, or special groups to adopt and sustain a behavior or a social, organizational, and policy change that will ultimately improve individual, community, and public health outcomes.’ (Schiavo, 2013, p.3)

The campaign of interest in this research involves elements from all the listed but most prominently relied on interactive health communication for it uses online platforms and social media; risk communication – informing on the risks of the vitamin B12 deficiency; arguably media advocacy – giving voice to the patients and signaling concerns in the medical system and finally entertainment education.

Health communication as a subject in itself employs different theories and elaborate models that are used for health promotion and disease prevention programs include:

- Ecological Models
- The Health Belief Model
- Stages of Change Model (Transtheoretical Model)
- Social Cognitive Theory
- Theory of Reasoned Action/Planned Behavior

A thorough analysis according to the different models is an interesting topic yet due to limited time and space it was beyond the scope of this project. (Health Promotion and Disease Prevention Theories and Models. (n.d.))

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3.4. Designing and implementing a process for a health campaign

As with any campaign, the formal project management (Wright et al., 2012) would include
1. Planning and Strategy selection - identifying what is the main issue and prepare the research and/or information collection. Then we need to select the target audience in order to tailor the message to them. At the end of the first stage, the results would be defined goal, objective, and planned or expected the outcome.
2. Selecting the most appropriate channels and approach through a creative process.
3. Preparing the materials and testing them on focus groups to fine-tune the contents in order to create the most impact.
4. Implementation – conducting the actual campaign.
5. Assessment - evaluating the planned and actual outcomes, gathering feedback from the audiences and comparing its consistency in different settings.
6. Reevaluating the overall success of the program to accommodate what has been learned in the process, including recommendations how to achieve better results.

3.5. Challenges for health communication

To be effective health communication should be not only tailored to the specific community or group of individuals but also should “speak” their language with carefully created messages and multiple approaches with ultimate goal of social change which, Melkote and Steeves (2001) argue that is not always achieved according to plan because it is a ‘complex, disordered, unstructured and often uncontrollable process’ (quoted in Durden & Govender, 2012)

And while the theory is complex and multifaceted for formal and official campaigns and programs, the subject of this research is an improvised attempt at creating awareness for a health issue and some of the aspects are not being considered or applicable (e.g. applying a specific theory).

For evaluating of the user-generated health awareness campaign I adapt some points for the planning of a health campaign (BBC), as given in “Communication for Better Health” – a Populations report by Johns Hopkins Bloomberg School of Public Health (2008):
“EFFECTIVE BCC PROGRAMS:

- **Use a proven process.** Following a sound process helps ensure results. Typical steps consist of analysis, strategic design, development and pretesting of messages, implementation and monitoring, and evaluation.

- **Apply theory.** Theories of behavior change help programs develop appropriate strategies and messages that will resonate with the audience.

- **Rely on research.** Research provides information that guides program design, monitoring, and evaluation.

- **Involve the community.** When community members help design and guide BCC programs, programs are more capable of addressing the community’s concerns and needs. Also, the community strengthens its capacity to identify and address health and social problems.

- **Develop relevant and creative messages and materials.** Messages should make clear the benefits of the recommended behavior that the audience values. Programs need to tailor messages and materials to the interests of different audiences and their readiness to change.

- **Address both the individual and the larger society.** Both individual behavior change and social change are necessary to achieve sustained improvements in health.

- **Combine communication channels.** Using a mix of mass media, interpersonal communication, and community approaches increases the influence on behavior.

- **Plan with scaling up in mind.** Expanding activities to reach more people and more areas works best when it is planned from the start.

- **Develop and sustain capacity for the future.** Training, education, and working partnerships build capacity. Also, with technical assistance, individuals and local organizations can learn how to carry out effective BCC programs.”
4. METHODOLOGY AND METHODS

For the purpose of this research, I chose to apply mixed methods - both qualitative and quantitative methods for data gathering, combining the results under the overarching Case Study approach as the latter is appropriate in the social sciences and for a real-life phenomenon (Yin, 2009).

4.1. Methodology

The overarching research approach that we use for analyzing the collected data for the current Degree Project is the Case study methodology for we are discussing a particular but complex case, set within not only health communication but also in social media. The campaign itself is created and executed not by a professional in the medical field. Theoretically, although there is not a single, unified and clear definition of what Case Study is in terms of scope and characteristics (Blatter, 2008), still a case study may be generally described as an ‘approach in which one or a few instances of a phenomenon are studied in depth’ (ibid). The writing style in case studies is ‘informal, perhaps narrative, possibly with verbatim quotation, illustration and even allusion and metaphor’ (Stake, 2009, p.24) However, I find it particularly applicable to my Degree Project because it is not limited to only social science but also explores the practical sides of issues or phenomena. As Yin argues, a case study is practical to use when the questions asked are ‘how’ and ‘why’ (quoted in Sharan, 2014, p.45).

Among the limitations of the Case Study is its tendency to subjectivity based on the individual (and possibly biased) point of view of the researcher (Sharan, 2014, p.52), making a claim or conclusion based on their preconceptions, or, as Stake, 2009 states that ‘Naturalistic generalizations develop within a person as a product of experience (...)They seldom take the form of predictions but lead regularly to expectation’ (Stake, 2009, p.22).

In research for social sciences, one of the most commonly used methods for data gathering is Surveys (Given, 2008) and for the purposes of this project I opted for two of the specific methods, namely Online questionnaires - for collecting a larger and quantitative database and Interviewing - for qualitative analysis, although some parts of the questionnaires used for the current research would provide some additional qualitative input as well.

First, I chose Interview method, as it aimed to gain the particular personal perspective and experience of the respondents with a special focus on the medical practitioners. The latter would provide a different point of view at the subject of the campaign and its effects as well as their professional judgment of the issue but would not be ‘visible’ or easily distinguished in a generalized questionnaire aimed at a larger public. I wanted to confirm (or deny) the
correctness of the presented information about vitamin B12 in the videos, the facts, claims and whether our personal experience is a “typical case” scenario.

The process of interviewing was discussed with the respondents several weeks before the actual questionnaires had been sent. Each of the respondents was given the choice how it would be the most convenient for them to answer - via Skype video connection, phone conversation or in written form. All of the respondents preferred the written form. This, however, has its limitations - the interviews had to be done in a structured manner with pre-written questions and with limited to none in-depth interviewing with cues and guiding from the researcher’s side. Further, the non-verbal signals and spontaneity of the answering were lost. Additionally, some of the respondents were not following the questions and answering them but rather telling a story about them and others did not respond in time and needed to be reminded of the project. Yet again, the written responses could be more well-thought, organized and edited before sending, thus arguably more accurate.

Next, Survey via Online questionnaires was preferred for a quantitative research method as it can easily cover large audiences and triangulate the results from the interviewing to more generalized observations. The larger the sample size of respondents, the more representative the outcome of the research, hence online recruiting of respondents was found as the most appropriate option considering the already built audience of the researcher as an established video-blogger.

Another advantage of online surveys is that there was a need for less time investment in organizing because the data was automatically collected in tables with no need for filling out paper forms and then manually transferring the data. The time savings apply to the process of surveying itself as it is fully accessible, available internationally and at the leisure of the respondent.

Additionally, to gain better understanding of the campaign’s impact and reach, we will make use of quantitative measures to analyze the measurable dimensions of the video, showing statistics of both publicly available metrics such as view count, engagement in terms of likes/dislikes, comments and shares; as well as privately accessible by the creator of the video statistics including demographics profiles - age, sex and playback location.

4.2. Design

To begin with, I provide a quantitative analysis of the video reach by presenting official statistics from the YouTube creator console and analyze was the actual reach and engagement of the public and who is the video most appealing to in terms of demographics.
Next, in order to qualitatively evaluate the impact of the videos, I give a brief summary of what were the initial and subsequent reactions from the audience and how did people engage with the message, based on the **public comments under the materials and mine account as a video creator – about the private messages, emails and phone calls**. This qualitative text analysis would be included as a secondary method, complimenting the interview and surveys.

Further, to add to the understanding of spread and change of attitudes I evaluate the impact analyzing the data from surveys in which 1185 individuals participated online.

The survey was created online using Google forms - an automated survey platform that simultaneously sorts out both data input in tables but also automatically creates visual graphics and charts. Once again, similarly to the interviews, the questions were initially written in English, and subsequently translated in Bulgarian and then were separated in seven different sections in order not only to create some kind of organization but not to look overwhelming to the respondents. The majority of the questions were ‘required’, i.e. one needed to fill them out to advance to the next section.

Participants were invited to participate by publishing information about the survey on the social media channels of the researcher - the public Facebook page of the vlog (10,000 followers) and the video-blogging (vlogging) channel on YouTube (the main channel ‘AGLEU mama’ in which the campaign videos were published counts, 50,000 subscribers, to-date and the additional ‘casual’ vlogging channel is with 22,000 subscribers). It was directed towards anyone aged 18 years and above in order to limit participants who would fill it out for entertainment. Finally, to ensure ethical use of the information, all of the data was anonymous. Additionally, it was stated at the beginning of the questionnaire that by its filling out people agree that the results would be used for a project for Malmo University.

Finally, to triangulate information of the questionnaires, I analyze the **interviews** I conducted with from representatives of both sides - first with medical practitioners (N=2) in order to evaluate what was the effect on their practice, both positive and negative and next, with parents (N=2) who have used the said vitamin B12 deficiency videos for guideline on initial self-diagnosing.

The interviewees were selected on the basis of availability and previous contact with the researcher. The parents are people who had been in close contact with the researcher for the period of symptom observing, through diagnosis and treatment and until recovery.
5. RESULTS

In this chapter, we will present the data gathered through the different methods described in the previous chapter.

5.1. Video statistics

The first video of the improvised, user-generated awareness campaign for the deficiency of vitamin B12 is named “False epilepsy or how we saved our daughter’s life” while the captions on the thumbnail read “Medical errors that cripple - Our story - Part1”

With the choice of title and captions, I wanted to address the misdiagnosis that almost leads to a fatal outcome and to engage not only mothers and parents but also people who might have suffered misdiagnoses with possible permanent consequences or people who have not previously assumed it was likely having high trust and respect for the medical profession.

The video ends with

‘Professor H. upon looking at her CAT scanner data: “Yes, indeed there are changes in the brain but it does not look to me like epilepsy.” ‘I asked him “B12 deficiency?”’ and he said “YES”.’

‘We knowing or being directed towards what was the issue with Anastasia did not mean that the medical doctors were willing to cooperate.’

In Part 2 of the video series I explain in details the path we went through in finding a medical laboratory to test such young child and when after having definite results how we were forced to self-medicate due to lack of support from all of the medical practitioners we met. To conclude, I gave more information on how our child is advancing developmentally since the treatment.

The Part 3 in the series was filmed a year after the first two videos as an answer to multiple questions what were my symptoms of B12 deficiency and what are the symptoms of adults (as they differ from those of babies and toddlers).

The statistics showed that the overall reach of the campaign is significantly larger compared to the expectations that YouTube algorithm might set (see APPENDIX 1). Cumulatively the videos have gained the following numbers:
### Table 1 Cumulative video statistics for the three videos

<table>
<thead>
<tr>
<th></th>
<th>Video 1</th>
<th>Video 2</th>
<th>Video 3</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total views</strong></td>
<td>73.511</td>
<td>47.930</td>
<td>45.468</td>
<td>166.909</td>
</tr>
<tr>
<td><strong>Comments</strong></td>
<td>184</td>
<td>188</td>
<td>85</td>
<td>457</td>
</tr>
<tr>
<td><strong>Likes</strong></td>
<td>1877</td>
<td>1.799</td>
<td>883</td>
<td>4559</td>
</tr>
<tr>
<td><strong>Dislikes</strong></td>
<td>27</td>
<td>12</td>
<td>18</td>
<td>57</td>
</tr>
<tr>
<td><strong>Shares</strong></td>
<td>505</td>
<td>312</td>
<td>543</td>
<td>1360</td>
</tr>
<tr>
<td><strong>Video added to playlist</strong></td>
<td>132</td>
<td>102</td>
<td>196</td>
<td>430</td>
</tr>
<tr>
<td><strong>Total watched minutes</strong></td>
<td>637.329</td>
<td>514.514</td>
<td>204.219</td>
<td>1.356.062</td>
</tr>
<tr>
<td><strong>Average view duration</strong></td>
<td>8:40 (39.7%)</td>
<td>10:43 (38%)</td>
<td>4:29 (39%)</td>
<td>39%</td>
</tr>
<tr>
<td><strong>Demographics</strong></td>
<td>Female 93.0% Male 7.0%</td>
<td>Female 93.2% Male 6.8%</td>
<td>Female 91.1% Male 8.9%</td>
<td>Female 92.44% Male 7.56%</td>
</tr>
<tr>
<td><strong>Subscribers gained</strong></td>
<td>118</td>
<td>101</td>
<td>60</td>
<td>279</td>
</tr>
</tbody>
</table>

The subscription status has not played a significant role as there are significantly more views from people who do not or did not previously followed the channel.

This can be interpreted in two different ways. First, people who have seen the video and found it helpful, are sharing it through social media (i.e. Facebook, Messenger, etc.) and the videos gain views beside the people who are already following the channel. The second and additional source of views would be using YouTube as a search engine. Depending on the algorithm, different internet, and YouTube users, respectively, receive tailored search results. The results for “епилепсия” (‘epilepsy’) or “витамин B12” (‘vitamin B12 deficiency’) return the said videos on the first or among the first results. Same is valid for google searches.

The most reached group was that of females in the age group 18-24 who are arguably the most digitally literate, reliant on the internet as an important source of information matching the profile of the video creator.

### 5.2. Personal messages, emails, and phone calls

Starting immediately after publishing the videos, with a second peak a year later when I gave some in-depth interviews for the national television show “Na Kafe/Over a coffee” where I
once again told our story from my pregnancy and the birth of Anastasia to recent days, I received dozens of messages. The overarching theme was in essence:

'We saw your story, we fight the system as well, we have been misdiagnosed multiple times and now we took the matters in our own hands. You are a mother and not a doctor but you understand us more than any medical practitioner ever did. Tell us what to do'.

I would briefly tell how Anastasia was and how she had recovered and then we would discuss what the age of their child was (as there is the biggest chance to reverse the damage up to 3 years and then it gets permanents, so the younger the child the better chance for recovery they had). Then we will discuss what were their symptoms, what tests did they do or not do, is there any progress with the treatment they had been prescribed. They would ask for the specific tests we did, where they could have them made and what were the prices. Further, if there is any possible overdose or side effects of vitamin B12; what doses we used for what period of time; when were to be observed the first results. Almost all of the people were interested if we could recommend a medical professional who would give them a thorough exam and adequate treatment, while at the same time expressing their disappointment with the doctors met before.

In almost all of the communications, we had at least three contacts, in some of the cases up to 30, including e-mails, personal messages on social media, phone, and video calls. One of the most important aspect in dealing with the condition for the people or parents was the emotional support (Fergie et al., 2016) from someone that had been in the same situation but also equally important, multiple repetitions of what needs, will or could happen with the health condition of the child if the decline was indeed caused only by the vitamin B12 deficiency.

5.3. Messages in the comment section

The comment section below the videos can provide data which as Jeffries (2011) describes as ‘ethnographic goldmine’ for an interesting qualitative analysis, which however will not be included in this project due to limited space and the similarities with the surveys.

5.4. Online surveys

The online survey was first presented to a small focus-group of three people to test the questions and whether they were easy to understand as well as to measure the time required for filling out the forms. Some minor corrections were made before a post about the questionnaire and its aims were published on the Facebook page of the researcher. Due to
the algorithm of Facebook which favors personal profiles and connections to Official pages, the post reached a small percentage of the total followers of the page (10,000) but was shared in closed Facebook groups discussing Vitamin B12 deficiency symptoms and treatment and got 118 responses. A week later the project was announced in my lifestyle YouTube vlogging channel and got a much larger reach (nearly 14,000 views). In total, the questionnaire was open for responses/participation for 30 days and got 1185 replies.

Although initially not planned as such the comment section of the questionnaire provided plenty of high-value (N=15 ) thorough comments that would contribute to the qualitative analysis.

5.4.1. Demographics

From a researcher’s perspective, I wanted to collect a wide range of diverse profiles. We wanted to gain an understanding of who is interested in the videos and the shared information is the initial target group of the campaign being reached (i.e. mothers and women in an active age in all the locations in Bulgaria). The level of education would roughly suggest the most appropriate language that is needed in creating those kinds of messages - should it contain specific terms or should it explain in a conversational style.

5.4.2. Findings

- The general findings of the questionnaires show that the respondents do not have optimal levels of trust in the quality of medical care they receive, including the overall lack of individual approach to the needs or conditions of the patients as well as focus predominantly on the symptoms rather than the cause of an illness or condition.

- A vast majority of the participants had been misdiagnosed at least on one occasion that has led to a hindered treatment and what is more, rarely receive full medical testing until reaching a clear and comprehensive diagnosis.

- The most common follow-up to what it felt like or perceived by the patient as a wrong diagnosis was looking up for a second opinion, followed by self-medication. For different reasons, a significant portion of the people gets tested in medical laboratories without medical direction.

- Three-quarters of the respondents reported high interest in receiving more information about health topics, including early symptoms and diagnostics, ways of treatment and managing of a condition, yet only one-fifth of the people receive
sufficient information by their medical practitioner about their state, further steps, diet, physical activity, and lifestyle.

- Medical specialists (cardiologists, neurologists, etc) are listed as a most trusted source for medical information followed by “self-researching of medical literature” and a significant portion of people state that they trust someone else’s experience.

- The participants listed YouTube videos as the second most often used source for health information right after “Medical websites and online journals in Bulgarian”.

- Evaluating the general awareness of the sign and symptoms of vitamin B12 deficiency among people of different ages, I found out that despite not being confident in the details (e.g. what is the deficiency being mistaken for, what is “masking”, and the most high-risk group of individuals), the majority of people answered correctly about the most common misconceptions about the vitamin deficiency – the symptoms were different in children and adults, only food is not sufficient for ensuring there are adequate levels of the vitamin as well as the need for immediate correction of the deficiency and the appropriate treatment.

- Considering the video campaign itself, a vast majority of the respondents have seen at least one of the three videos and over three quarters have seen all of them. For over a half of the participants, a similar situation with misdiagnosis seems it possible in their life and that such events could happen for other health conditions or issues.

- Asked about their personal preference of personal narrative versus presentation of information and facts most of the people reported that they find a personal story more engaging. Further, almost all of the participants are content with the knowledge in the videos and found it clearly presented, making it easier for the identification of possible symptoms of vitamin B12 deficiency. To add, almost all of the people found additional value in the materials given in the description boxes of the videos (including a list of symptoms, link to blog posts with more information by the video-creator, etc.) and a majority regard the comment section as useful.

- Once again, almost all of the people who have seen the videos, report that they felt more inspired and empowered to ask for second, third and next opinion and/or medical tests until reaching a definite diagnosis.

- As for actual experience with B12 deficiency, some people had already been tested, while others plan to do so. Of those who had low levels of the vitamin, some have been treated under medical supervision and an almost equal part had been self-treating with supplements, while both groups report different levels of alleviating of
the symptoms. Further, a half of the respondents are getting tested periodically as a control measure and the majority of people do intend to ask for testing for deficiencies as a part of the diagnostic process.

The final question (N=35) was not a required one and asked for additional comments, questions or input that has not been covered in the questionnaire.

In total there were 119 responses, which we could divide into five general categories:

<table>
<thead>
<tr>
<th>Type of comment</th>
<th>Number of comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Showing appreciation for the videos or wishing support to the project</td>
<td>63 (52.1%)</td>
</tr>
<tr>
<td>Commenting on the healthcare system in Bulgaria or related to experience with medical errors or misdiagnoses</td>
<td>15</td>
</tr>
<tr>
<td>Commenting on experience with vitamin B12 deficiency</td>
<td>14</td>
</tr>
<tr>
<td>Asking health-related questions or giving suggestions for future videos</td>
<td>14</td>
</tr>
<tr>
<td>Random (including smiles or general comments about life)</td>
<td>13</td>
</tr>
</tbody>
</table>

Table 2- Comment categories of the online survey

We have some thorough, well-written replies that give us additional qualitative information about the trust in and experience with the health system, about the campaign and further about the philosophy and content of the channels that the videos were published in and that continue to provide information about different health- and lifestyle topics.

"After informing myself in details about the deficiency of vitamin B12, I tried to engage the attention of the medical practitioners whom I had contact with and to ask for more information. Unfortunately, in most cases, I was denied attention. Even laboratory testing of vitamin B12 levels had been declined on multiple occasions. I don’t have free access to laboratories as I live abroad and the labs work only with medical prescriptions or directions."
Another participant in the survey wrote:

“My observations [for the situation] in Bulgaria are the same - having an issue with anemia, my mother was denied testing of levels of vitamin B12 on meaningless grounds. Yet in Bulgaria, everyone has a free [paid] access to medical testing and they could get tested on one's own initiative. That is a great advantage. I have noticed that doctors very often neglect vitamin B12, [tend to] order basic tests that are by no means telling of the health condition, there is a lack of detailed medical testing.”

“I feel that the case with Zornitsa and her daughter gave publicity to what the deficiency of vitamin B12 is, what is it mistaken for and what are the consequences. And it gave the courage to mothers and parents to ask for five or ten opinions until finding the truth. Rarely in Bulgaria if something is not shown in media or if, God forbid, happens something bad, we would be informed enough from our general practitioners about a certain illness, medical tests, etc.”

5.5. Interviews

The interviewed medical representatives confirmed the correctness of the information presented in the three videos from the YouTube awareness campaign about the deficiency of vitamin B12 and two parents whose children have been diagnosed as a result of this campaign have shared their experience with the deficiency and their opinion on the importance of the awareness campaign.

Doctor Hadil Kathom (Appendix II-A), who is pediatrician and genetics specialist and is the medical practitioner with arguably the most clinical experience with the concrete issue in Bulgaria states that just as presented in the videos if there were not taken adequate measures or in the presence of the wrong diagnosis.

“(…) it would lead to severe changes of the neurological system related to neurological developmental delay, seizures, anemia, severe cases of dermatitis, diarrhea with the following malabsorption, etc.”

Asked about the positive and negative effects of similar media health awareness campaigns, both user-generated in social media and on mainstream media, doctor Kathom stated that there is a definite positive impact on the early diagnostic, prevention or timely treatment of vitamin B12 deficiency, however, there are some negative aspects as:

“(…) the increase of self-medication, the exchange of [layman] advice and consultations in internet-groups, which in some cases is dangerous.”
Further, doctor Tatjana Shabanova (Appendix II-B), who is a retired pediatrician, currently working states that ‘there is nothing more powerful than personal stories’. She appraises the content and says that each of the symptoms is described ‘logically, thoroughly and completely’ and she is recommending the videos to fellow colleagues and patients for reference to a real case:

“Because I am a pediatrician and I meet every day many children and mothers, I constantly quote you and I recommend them to watch your videos - they are extremely valuable for me - detailed, visual and instructive.”

For a point of view of the patients, I interviewed two mothers of children who had been tested for deficiency of vitamin B12 yet the cases are extremely different to one another. While the baby of Elka Shopova has had a severely low level “lower than the minimum levels the laboratory could detect, <30pg/ml” the child had virtually no negative consequences because the mother found it at the very early stage before it had impaired the child’s development. Interestingly, the mother says it was ‘by accident’ (Appendix II-C) She was sent a link to one the video materials about vitamin B12 deficiency in YouTube when discussing with a friend hers the low haemoglobin levels in babies at the age of about 6 months and that it is not always the case of low blood iron. She got the information when the baby was only 2 months old and decided that she would insist on or order herself vitamin B12 levels as a part of the 6-month routine testing.

The other parent in the study, Magi Ruseva has a major difference in the case of the other parent and child. The son of Magi has had already neurological manifestations of the vitamin B12 deficiency, he is roughly at the same age of Anastasia⁶, and, living in the same town, has gone the same paths of diagnostics with a similar diagnosis to the one, presented in the videos – epilepsy. Once again the parent has stumbled upon one of the videos on social media and later contacted me as a video-creator. Initially, Magi chose to self-medicate and this has decreased the occurrence of seizures but only after medical interventions in the clinic (under the care of doctor Kathom) the seizures disappeared. The child has still some developmental delays but the treatment for epilepsy has been canceled as it was not the correct diagnosis (it has been given despite “all of the visual imaging, medical tests and the electroencephalography” being normal. Diagnose autoimmune epilepsy [and treatment] 4 anticonvulsant drugs. Magi shares the video materials with other people who might be interested or have similar symptoms:

“I am immensely grateful for the publicity given to this issue. Its presenting in media and the sharing of personal experience. I try to give it special attention, I share with our

⁶ Our daughter and the protagonist of the awareness video series.
pediatrician and visits to other medical specialists about the initial cause of the condition. This way we helped to four of my friends to recover and to all of my family members who turned out to have vitamin B12 deficiency."
6. DISCUSSION

In the current study, we discuss the effectiveness of a user-generated campaign sharing personal narrative through video social media platforms as a tool for creating awareness of a health issue or condition.

While in the past people shared their knowledge and experience with people who they personally knew, in recent times everyone who is interested is invited to use the shared information and create and as a consequence user-generated content can influence societies, communities, and individuals in ways not previously seen as possible. (Wyrwoll, 2014)

The results from this study confirm what other researchers have found out – that with the advance of ICT technologies and the new landscape of exposure to information there is also the change in the way health communication is viewed. “E-health” is the new phenomenon of people not being only patients but also consumers and producers of health knowledge (Hardey, 2001) and there comes the rise of ‘informed patients’ or ‘lay experts’ (Ziebland and Wyke, 2012). What is more, the abundance of information leads to a change of perspective and responsibility for one’s health form the health-care provider to the person or ‘patient’ themselves (Harris et al. 2010).

Evaluating the effectiveness of the campaign based on the replies in the questionnaires - we can deem the planned goal as accomplished – to encourage individuals to take the power in their own hands by researching information, looking for further professional opinions, demand more medical tests and the results show that people report feeling ‘more inspired’ or supported to take actions.

The questionnaire further tested my initial hypothesis that the trust in health care system could be a precondition for a possible increase in the persuasiveness of the informal channels of advice. We found out that in Bulgaria very little people have confidence in the medical care they receive which could possibly lead to a heightened susceptibility to alternative opinions and treatments of which the internet (and YouTube) nowadays is abundant with.

In the subculture and community of YouTube, the para-social relationships between creators and viewers are essentially based on stories and a narrative of a life – with the creator sharing personal views about subjects but also events that have shaped them which minimizes the uncertainty about the content creator (Berger and Calabrese, 1975). The significance comes from the fact that the process and effect of telling of stories are considered to be more effective means of persuasion due to the human nature that tries to make sense of the surrounding world and create an order and security in it by creating
narratives (Bolton, 2006, p.204). This persuasion has a fundamental importance in the domain of medicine as well as researchers have already shown (Greenhalgh & Hurwitz, 1998; Engel et. al., 2002; Brody, 2003; DasGupta & Charon, 2004) and the relate-ability of a character or story (i.e. they present things that are the same in ‘real life’) is further enhancing the effects of influencing the audiences. Here, the reported high levels of identification and transportation in the narrative reported by the participants in the questionnaire could be attributed to the demographic profile of the viewer which is closely correlating with the profile of the video creator – same age group, sex and for many of the viewers – being a mother – which are preconditions to increasing the persuasiveness of a message by creating transportation and identification effect.

Transportation is described as mental and affective engagement in the story of events unfolding whereas identification is an intense cognitive and emotional relation with the characters of the story (Cohen 2001, Green and Brock 2000) To evaluate that in the online surveys we attempt to weigh the transportation and evaluation by asking the respondents to self-assess, as they play a role in an effective EE message because the audience is immersed in the entertainment, while awareness and education happen simultaneously but not in the foreground of the experience. (Quintero Johnson et al. 2013) Although the topic of transportation and identification, resistance, and persuasion are deep and interesting they would require a more thorough research that is beyond of the scope of this project.

The participants in this study were highly interested in receiving more information about a certain condition or changes in lifestyle and the second most trusted source after a medical specialist (cardiologist, pulmonologist, etc) is said to be own research of the topic. Yet, the medical platforms with information translated in Bulgarian are the most common answer but there is an issue that I as a philologist have noticed on multiple occasions. Because there is no Bulgarian equivalent of WebMD or other peer-reviewed or moderated medical sites, the information provided in the quoted in the survey online pages is either inaccurate as such or wrongly or partially translated (often by online translating bots) and is in some cases is even showing a completely different information to what is available as knowledge and data in English and other languages. During our research of vitamin B12, we found out that in Bulgarian in 2015 there was a very little information about the symptoms in babies and children along with the fact that in the Bulgarian sources was given that the vitamin is highly toxic and easy to overdose which is the total contrary to the truth. Not cross-referencing with information from other sources, however, one can be misleading and driven to negative consequences.

The next most elected answer among the respondents was “Platforms for video sharing - YouTube, VBox7, etc)” to little surprise as YouTube is not only the second most used search engine but the video format makes possible the easier creation of para-social relationships between the viewer and the video-creator, to some extent similar to those in the television
format but much enhanced with the possibility for social interaction via the comment section.

In the comment section of the Questionnaires, a person commented their preference of the exact way the information in the awareness campaign in question is presented

“Your videos are not only the first source of information about the deficiency of vitamin B12 that I stumbled upon but also about the functional medicine (and many other topics ...) You are the reason for me to be interested more in similar topics and to research them additionally by myself. However, if the channel was dedicated only to “serious” issues I doubt that I would find or follow it with the same interest. What I like in the published content is how easy and entertaining are your videos. (...) The acquiring of useful information is in passing and by the way. (...) And your videos are a great balance between useful and entertaining. (..)”

as well as other important or useful information in the video channels – as a part of the conversation and shared experience about a topic (including vitamin or mineral deficiencies and alternative ways for diagnostics such as Functional medicine (Schimmel and Penzer 1997; Bland 2014; Vasquez 2016). Such introducing of knowledge can be viewed as a form of entertainment education (EE) - a new and arguably effective health communication strategy (Singhal et al. 2003). And while educators recognize that understanding in the learning is realized with the connection of the elements in stories (Doyle, 1997) and for the purpose of this study we will limit the understanding of entertainment education to using narratives to convey a message, although there are many different approaches (Sherwood 2003; Willoughby et al. 2018; Lee 2004).

In the end, I will attempt to formally apply or compare the suggested markers for a successful health communication (or BCC) program discussed in section 4.5. to the vitamin B12 awareness campaign to understand the differences.

The campaign was created by a “layman” or informed person and did not follow the formal process of strategic planning, pretesting of messages; nor did it apply theory as the implementation was rather intuitive. It did rely on copious amounts of previous research about the topic and the personal narrative and experience provided added value. Involving the community in the initial phases was minimal – however, the video-creator herself could be viewed as a part of a community who had identified an issue and communicated it along with the possible and proven solutions.

Yet, the strong features of the campaign were relevant and tailored to the audience messages taking into consideration cultural factors, shared the previous experience with the health care in Bulgaria, as well as the personal profile of the presenter. It is debatable if it
addresses society besides the individual but creating “buzz” around an issue assists in demanding and achieving policy or social changes, i.e. changing of the reference range for vitamin B12 deficiency, making it a routine testing, etc. The additional strong element was the combination of communication channels – first, the video materials were supplemented with written blog posts and external links with more information, and secondly, the materials were shared by the viewers on different social media platforms.

I would argue that the video campaign is suitable for ‘scaling up’ due to the potential of social media to create ‘viral’ content without regards of when it has been published. For it is the personal story it cannot be dated and can always provide useful information and social and peer support. To this day I continue to receive messages, emails and telephone calls from parents or patients asking for help.
7. CONCLUSIONS

This chapter concludes the thesis by answering the research questions and recommending future research triggered by questions generated through the process of the study.

The studied health issue awareness campaign about the dangers of vitamin B12 deficiency is based on health communication as a communication for development strategy and has traits of all of the general types of health communication (Wright et al., 2012). It uses both social media and an interactive health communication by providing a two-way communication through the comment sections, as well as with personal messages, emails and other forms of personal contact with the creator who has the role of informed patient, providing know-how and support for health issue who they have experienced. Using narrative constructions it has connection points with the entertainment education, making the knowledge easy to understand the persuasive message.

To gather both quantitative and qualitative data I used mixed methods, including surveys in the form of structured interviews, online questionnaires as well as statistics about the reach of the videos of the awareness campaign for vitamin B12 deficiency in which beyond my role as a researcher I am the video-creator as well. I chose to present it as a Case study due to its dependence on geographic, cultural, demographic factors.

Finally, we need to address the research questions:

What are the advantages of using personal narrative in communicating health-related information?

The data from the surveys confirmed that both in understanding and in practice the impact and persuasiveness of a personal narrative and story are stronger than those of mere representation of facts. That is because humans are in essence storytellers and a person who is living in the same setting and culture becomes relatable and their story more poignant and effective - a real-life experience shared through social media is more relatable and hence impactful than a simple statement of facts and statistics about a health issue. In fact, other studies show that an internet user does not distinguish between content that has been produced by professionals and one coming from other users when containing sufficient information about self-management and lifestyle. (Fergie et al., 2016)

Further, a personal narrative diminishes the persuasive resistance, thus increasing the impact of further actions or intents of actions. The adequately chosen profile of the presenter, i.e. one that is corresponding to the target group is of crucial importance to the receiving or understanding of the message.
Is social media, in particular, YouTube an effective medium for health communication from the general public’s perspective?

In concordance with previous studies, the current research proved YouTube to be an effective platform for disseminating of information for health issues, having reached significant audiences and having created engagement in terms of commenting, and reacting to the video materials and the video format itself being found more appealing to the audiences and with a great sharing potential (Kite et al., 2016); and the latter was confirmed by the number of shares of the videos from the campaign in social media. This has several implications – first, the narrative and previous para-social relations with the video-creator have created a higher trust environment; secondly, being available in time-dependent situations or in search of “fact-finding” (i.e. description of symptoms, testing or treatment). (Fergie et al., 2016) as well as providing emotional and peer support from people with similar experiences or conditions (Giles and Newbold, 2013; Ho et al, 2014;)

There are multiple benefits of using social media for health communication, including increased accessibility to information, important especially for vulnerable social groups that have no access to quality health care (Lariscy et al. 2010; Kontos et al. 2010), thus providing the former with alternative (or even main) source of information, taking into consideration that it can be presented in other formats that a written text thus reaching even people or community where the literacy is low. But also of extreme importance are the beneficial social and emotional support that it can provide (O’Dea and Campbell 2011; Lupiáñez-Villanueva et al. 2009; Moen et al. 2009; Takahashi et al. 2009) and the potential for further interactions and connections with people who share the same condition or lifestyle.

Qualitatively viewed, the long-term effects of a health issue campaign or even a blog-post or video are much intertwined and multifaceted. One cannot measure in figures the impact a timely diagnosis had on a person’s life by preventing physical, neurological and mental impairment and conditions. Additionally online word-of-mouth has the power to expose wrong-doings thus further to beneficially influencing communities by driving social/community or even political changes. Even if not wholly applied to vitamin B12 deficiency the notion and idea that no diagnosis is final until all paths are explored could have positive implications for future health care decision-making and outcomes.

What are the viewers’ reactions to educational entertainment versus facts in personal video blogs aimed at creating awareness about a certain health issue?

The general public’s attitude towards educational entertainment is of acknowledging it as an undemanding and pleasing way to be presented with important information. The knowledge of medical issues and practices is no longer a prerogative to medically trained professionals but has entered the social network of connections where it can be “accessed, assessed and
reappropriated” (Nettleton and Burrows, 2003, p.179) What is needed, however, is a translation from highly professional jargon to simple every-day or ‘layman’ language for which informed patients of “layman” experts could provide assistance.

To conclude, YouTube has some weaknesses for the dissemination of important messages per se because as a query-dependent search engine, on one hand, it requires a specific search term which the viewer might not know how to define (Wyrwoll, 2014, p.4) or even look for. Yet, on the other hand, a video channel can be viewed or followed in some sense as a magazine or television programme in which the video creator is the executive producer and they get to decide on the content and its presentation. This way the information might become a part of the educational entertainment and the messages would be not intrusive but nevertheless present, creating exposure to a subject and long-term impact.

7.1. Further research and recommendations

In the current study, we reviewed an awareness campaign dedicated to a ‘curable’ condition that is aimed towards recognizing the symptoms and ensuring prompt diagnosis and treatment. What is interesting is to analyze similar campaigns directed towards permanent health or genetic condition, e.g. Down Syndrome, autism, etc. How did people’s perceptions change, how did it influence the life decisions of parents who got a diagnosis, is there a support network and how effective it is.

For future health communication campaigns, I would recommend a partnership between social media influencers who have previous experience with creating engaging video content as well as already built-up following - with a medical practitioner who has experience in a certain domain. One of the best-practices is an honest conversation about a topic of interest for the video-creator (hence relatable to their public).

One of the points, raised by doctor Kathom in the interviews is the importance of a ‘presenter’ of the information. According to her the national television awareness campaign for vitamin B12 deficiency “due to an inappropriate choice of a presenting person lead to a rejection from the medical community.”.
REFERENCES:


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Morris, Z. S., Wooding, S., & Grant, J. (2011). The answer is 17 years, what is the question: understanding time lags in translational research. Journal of the Royal Society of Medicine, 104(12), 510–520.


Utz, S. (2015). The function of self-disclosure on social network sites: Not only intimate, but also positive and entertaining self-disclosures increase the feeling of connection. Computers in Human Behavior, 45, 1–10.

https://doi.org/10.1037/t34487-000


APPENDIX 1 - Lifetime statistics of the videos in the campaign
(35 months after publishing)

As of May, 12th 2018, Part 1 of the series following the multiple misdiagnoses (duration 21:50 minutes) is placed as follows:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Views</td>
<td>73.511</td>
</tr>
<tr>
<td>Comments</td>
<td>184</td>
</tr>
<tr>
<td>Likes</td>
<td>1877</td>
</tr>
<tr>
<td>Dislikes</td>
<td>27</td>
</tr>
<tr>
<td>Shares</td>
<td>505</td>
</tr>
<tr>
<td>Video added to a playlist</td>
<td>132</td>
</tr>
<tr>
<td>Total watched minutes</td>
<td>637.329</td>
</tr>
<tr>
<td>Average view duration</td>
<td>8:40 (39.7%)</td>
</tr>
<tr>
<td>Demographics</td>
<td>Female 93.0% Male 7.0%</td>
</tr>
<tr>
<td>Subscribers gained</td>
<td>118</td>
</tr>
</tbody>
</table>

Table 1 – Statistics for video 1

The video engagement is typically calculated as:

- **Views per subscriber**: On average the view count of a video constitutes about 14% of the number of subscribers. In our case, as of 15.5.2018, it is 73511 to 51000 or 144%. We must note, however, that the video is published 35 months ago and these are the cumulative views. Nevertheless, the number is impressive.

- **Likes per view**: The figure is calculated by dividing the number of likes to the total views. 0.025 or 2.5% of people who have seen the videos gave it a positive vote. Additionally, the likes of dislikes are 98.6% to 1.4% respectively.

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7 The average view duration is that usually on the platform it is close to the mean values for the platform but it decreases every time one gets back to the video to ask or answer a question in the comments or to search for the specific moment they want to see again.

8 How to use YouTube analytics to measure viewer engagement by Dane Golden http://tubularinsights.com/YouTube-analytics-viewer-engagement/
- **Comments per view:** The activity in the comment section is relatively low - 0.0025 (dividing 184 comments to 73511 views) - 0.25% or 1 of every 400 people who watched the video created or engaged in virtual conversation.

- **Or grossly simplified:** number of interactions and interaction per views - first we sum up the number of all the comments, likes, dislikes, shares and adding to playlists to get a total of 2752 interactions; or divided to the number of views - 0.037 or 3.7% - nearly 4 in 100 people interacted somehow with the video.

Finally, the subscribers gained figure indicates how many people decided that they want to see more from this video-creator, based on the material they are watching (Burgess and Green, 2009)

The video is seen mostly by women (93%) and predominantly by the age group (18-24 years).

![Figure 1 Video 1 Age and sex of the viewers](image)

The viewers who are not subscribed to the channel are almost twice the number (views N=47,961, 65%) to those who follow the channel (views N=25,514, 35%) although the subscribers have a slightly longer view duration.

<table>
<thead>
<tr>
<th>Subscription status</th>
<th>Watch time (minutes)</th>
<th>Views</th>
<th>Average view duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not subscribed</td>
<td>403,222 (63%)</td>
<td>47,961 (65%)</td>
<td>08:24</td>
</tr>
<tr>
<td>Subscribed</td>
<td>233,911 (37%)</td>
<td>25,514 (35%)</td>
<td>09:10</td>
</tr>
</tbody>
</table>

Table 2 – Subscription status of the viewers

The share function is used most commonly for Facebook messenger (28%, N=140 out of 505), followed closely by undisclosed social media sites given as “other” with 27% (N=130)
and thirdly is again a Facebook option for sharing (on personal page or friends wall) with 21% (N=106).

Figure Video 1 Most used social media platforms for sharing

An interesting metric is the geography of the viewership and their subscription status for both videos. The movies had been watched in over 50 countries and judging by the average view duration it was not by accident but rather they were seen by Bulgarians abroad or by people who speak or understand Bulgarian due to similarities in the languages (as it is with Serbians, Macedonians, sometimes Russians and other Slavic languages).

Figure 3 - Video 1 International viewership by countries (top 25)

Part 2 of the video-series which contains details about the actual diagnosis and treatment (duration 28:01 minutes) had received
Compared to the first video, the second part has received a lower number of views but it could be due to the fact that only people who are interested in the details of the treatment continued watching. This is confirmed by the data for engagement which shows higher involvement and interaction.

- **Views per subscriber:** 94%

- **Likes per view:** 0.375 or 3.75% Likes to dislikes. Additionally, the likes of dislikes are 99.3% to 0.7% respectively.

- **Comments per view:** 0.003 - 0.3% or 1 of very 330 people commented

- **Simplified:** A total of 2430 interactions; or divided by the number of views - 0.05 or 5% - nearly 5 in 100 people interacted somehow with the video.

Similarly to video 1, the vast majority of the viewers are again female and in the age group of 18-24 years.
Again, the percentage of non-subscribers is significantly higher than those of subscribers which indicate that many people have found the video accidentally and watched because of personal interest and not because of mere fan-support.

**Part 3**
The last video of the series (the symptoms and experience from an adults point of view with duration 11:38 minutes) was published a year after the first two, so the lifetime statistics are for 23 months and as follows:

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<tbody>
<tr>
<td><strong>Views</strong></td>
<td>45,468</td>
</tr>
<tr>
<td><strong>Comments</strong></td>
<td>85</td>
</tr>
<tr>
<td><strong>Likes</strong></td>
<td>883</td>
</tr>
<tr>
<td><strong>Dislikes</strong></td>
<td>18</td>
</tr>
<tr>
<td><strong>Shares</strong></td>
<td>543</td>
</tr>
<tr>
<td><strong>Video added to a playlist</strong></td>
<td>196</td>
</tr>
<tr>
<td><strong>Total watched minutes</strong></td>
<td>204.219</td>
</tr>
<tr>
<td><strong>Average view duration</strong></td>
<td>4:29 (39%)</td>
</tr>
<tr>
<td><strong>Demographics</strong></td>
<td>Female 91.1% Male 8.9%</td>
</tr>
<tr>
<td><strong>Subscribers gained</strong></td>
<td>60</td>
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</tbody>
</table>

Table 3 – Statistics for Video 3

Figure 4 Age and sex of the viewers for Video 2
● **Views per subscriber:** 89% in 23 months of being published.

● **Likes per view:** 0.019 or 1.9% of people who have seen the videos gave it a positive vote. The likes of dislikes are 98% to 2% respectively.

● **Comments per view:** The lowest comment activity - 0.0018 (85 comments divided to 45468 views) - 0.18% or 1 of very 555 people commented.

● **Simplified:** 1725 interactions; or divided by the number of views - 0.037 or 3.7% - nearly 4 in 100 people engaged with the video content.

As with the previous two videos, women are more interested in the topic and especially in the active age group 18-24 years.

![Figure 5 - Viewership by age and sex for Video 3](image)

Yet again the tendency from the previous clips remains unchanged. People, who are not following the channel have more total views than those who do (73% to 27%) but with slightly shorter average view duration (4:25 to 4:41 minutes)
APPENDIX 2 - Questionnaire

The first section of questions, named “Health service and information” (1-8) aimed to evaluate the trust the respondents place in the health care they receive, their previous experience and the overall attitude as a base for analysis on the underlying causes for looking up and following “unofficial” sources of information such as blog-posts and shared online videos.

The second section “Looking up health information” (Q9-11) explores the sources people would usually use when searching for health-related information.

1. Do you have full trust in the medical services you receive? *

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Rather NOT  Closer to YES

2. Do you consider that most of the medical practitioners you consult have an individual approach towards you and your relatives? *

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Rather NOT  Closer to YES

3. Are you being ordered medical tests by most of the medical practitioners (through National Health Care or paid) until reaching definite diagnosis? *

☐ YES
☐ NO
☐ I cannot answer

4. Have you or your relative been misdiagnosed; which obstructed hindered your treatment? *

☐ NO
☐ YES
☐ YES, more than once

5. What was your next move? (choose multiple if needed) *

☐ I reached for second/third/different opinion from specialist in Bulgaria
☐ I consulted specialist abroad
☐ I used alternative methods for treatment, ordered by a specialist
☐ I self-medicated/self-healed
☐ I did nothing more

6. Have you ordered medical test in a lab without medical direction? (choose multiple if needed) *

☐ YES, by recommendation of a close person
☐ YES, when I suspect I have some symptoms
☐ YES, this is the easiest and fastest way with no waiting time
☐ NO, I follow only medical practitioners advice
☐ NO, I don’t have access to medical laboratory/testing centre
☐ NO, I don’t know what to look for
7. Do you believe that your doctor is looking for alleviating the symptoms or looking for the underlying cause of the illness? *

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<tbody>
<tr>
<td>Focus on SYMPTOMS</td>
<td>Focus on underlying cause</td>
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8. Do you receive full and exhaustive information from your medical practitioner about your condition, including dietary guidelines, exercises and lifestyle? *

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<tbody>
<tr>
<td>Never, I look up more information by myself</td>
<td>I always receive detailed information</td>
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9. Whom do you trust most for health information? (choose more than option if needed) *

- My general practitioner
- Medical specialist (cardiologist, neurologist, etc)
- The experience of a close person or relative with the same or similar condition
- Experience, shared in social media (Facebook, YouTube, Twitter, etc.)
- Own research of medical literature, web sites and/or studies

10. Are you interested in more information about health topics (including early symptoms and diagnostics, ways of treatment and managing of a condition)?

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</thead>
<tbody>
<tr>
<td>Rather NOT</td>
<td>Closer to YES</td>
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11. What are the sources of information you use most often? (choose multiple answers if needed)

- Books and/or magazines in foreign languages
- Books and/or magazines in Bulgarian
- Medical web sites and online journals in foreign language (English, German, Russian, etc.)
- Medical web sites and online journals in Bulgarian
- English or other foreign blogs
- Bulgarian blogs
- Platforms for video sharing (YouTube, Vbox7)
- Recordings of TV shows
- Social media (Facebook, Twitter, Instagram)
Further, in section “Vitamin B12 awareness” (Q12-19) I wanted to examine the overall to-date awareness of the symptoms and treatment of B12 deficiency because it will show a background preparedness for a possible misdiagnosis and it will influence what the next reactions would be in case there is no support from a certain medical practitioner. In other words, if people know what their condition is and/or what they could expect, faced with a disregard, they would be more likely to search for second and further opinions.

12. Are the symptoms in children and adults the same?
   - YES, they are the same
   - NO, they are different
   - I don’t know

13. What will happen if the symptoms are misdiagnosed and no treatment is administered?
   - The symptoms will disappear by themselves
   - The symptoms will get more severe and permanent
   - I don’t know

14. What is the treatment of vitamin B12 deficiency?
   - Medications, including pain-killers or antibiotics
   - Anti-consultants (drugs for epilepsy) or psychotropic drugs
   - Correction of the deficiency of vitamin B12 until alleviating of all or some of the symptoms
   - I don’t know

15. What is vitamin B12 deficiency frequently being mistaken for, which hinders its fixing/correction?
   - Dementia
   - Autism
   - Anorexia
   - Epilepsy
   - Balance issues
   - All of the above and other
   - I don’t know

16. Is anemia a mandatory symptom of the deficiency?
   - YES
   - NO
   - I don’t know
17. What is "masking" the vitamin B12 deficiency?
   - Low blood serum iron
   - High blood levels of folic acid (vitamin B9)
   - Both
   - I don’t know

18. Is it sufficient to consume food that contains vitamin B12 to prevent deficiency?
   - YES, it is
   - NO, because its absorption depends on many factors
   - I don’t know

19. Which is the group with the highest risk to develop of suffer the most negative consequences of vitamin B12 deficiency?
   - Babies, toddlers and small children, because of forming of the nervous system
   - Pregnant women, because they pass on the deficiency to the unborn baby
   - People above the age of 50 because of change in the metabolism and gut flora
   - Vegans or people who do not consume animal products and don’t supplement
   - All of the above
   - I don’t know
   - 

To continue, **questions 20-28** seek to understand the reactions and impressions of the concrete online video awareness campaign by asking about the videos per se and about potential identification and transportation.

20. Have you seen any of the videos above?
   - YES, a part of one or whole one
   - YES, all of them
   - NO, neither of them
   - NO, but I have seen the TV episodes of "Na kafe" ("Over a coffee" - a Bulgarian talk show on national TV)

21. Could you imagine yourself at the place of the person, telling the story?
   1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
   NO, I cannot | | | | | | | | | YES, to a great extent

22. Do you consider that a personal story is more engaging of presenting only facts and statistics?
   1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
   FACTS are more engaging | | | | | | | | | STORIES are more engaging
23. **Do you consider that similar events are probable even for other conditions?**

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<td>NO, it is not likely</td>
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24. **Is the information clearly presented so you could easily identify a possible symptom of vitamin B12 deficiency?**

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25. **Do you find the videos informative enough?**

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26. **Was the additional information in the description of the video useful - list of symptoms, link to blog-posts, etc.?**

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27. **(For those who had seen the video/s) - Did the narrative inspire you to be more demanding and looking for second and next opinion until accurate diagnosis has been reached?**

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28. **Was the discussion in the comment section useful?**

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In the last section “**Searching the underlying cause**” (Q34) I inspect if the respondents are inclined to take control of their health or the health of their children or relatives by insisting for additional medical tests of ordering them by themselves.

34. **Do you intend to look for deficiencies of vitamins, minerals, etc. or overload. e.g, heavy metals as a essential part of a medical diagnosis and treatment?**

- o NO
- o Sometimes
- o YES

35. **Additional comments - Here you can write something that is important to you but has been in the questions; as well as sharing opinion or impressions.**
APPENDIX 3 – Survey participants demographics

The respondents that took part of the survey (N=1185) are as follows:

- **SEX**: 97.7% of the respondents are female (N=1158) and only 2.7% male (N=27).

- **AGE**: The large proportion (50%, N=593) are in the age group 18-24 years; followed by the next most active age group of 25-34 years with 39.4% (N=467); with small representation of 35-44 years old with 8.6% (N=102) and insignificant of groups 45-54 years (1.6%, N=19) and 55-64 years (0.3% N=3).

- **EDUCATION**: The two largest groups are having High School degree (37.9%, N=449), followed by Bachelor Degree (34.1%, N=404); the third most common education level is Master’s Degree with 24.1% (N=286); only 2.9% (N=39) have completed only primary school and 1% (N=12) of all of the people who took part in the surveys have a PhD.

- **LOCATION**:
  - 31.2% (N=370) of the respondents live in the capital of Bulgaria, Sofia;
  - next are towns with 10,000-100,000 residents with 21% (N=249);
  - 152 people (13.2%) live in Varna, which is the town in which the events in the first part of the awareness campaign videos take place;
  - 9.6% live in Plovdiv (N=114); 8% (N=95) are abroad;
  - 5.9% (N=70) are in a large town (with population 100,000-300,000 people); 45 people (3.8%) are in Burgas;
  - 44 (3.7%) live in a village;
  - 30 people (2.5%) are in Ruse As there was option “other”, some respondents chose to put the name of the town or place they live in (N=12)