WhatsApp In Health Communication: The Case Of Eye Health In Deprived Settings In India

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Abstract

The aim of this study was to explore the use of WhatsApp in developing a community based practice of eye health promotion in a deprived locality bordering a metropolitan city in India.

Globally, 285 million people are visually impaired, a quarter of whom live in India, which results in lower employment and lessened productivity. The national blindness prevention strategy aims at eyecare promotion through health behaviour change achieved by raising awareness. Traditionally, health behaviour change has been achieved through conventional communication platforms like radio and television-. The recent exponential development in social media technology, ubiquitous and inexpensive, offers significant potential for two-way communication in real time with a wider audience, including those from disadvantaged groups. WhatsApp, an inexpensive social media platform which is widely used in the Indian subcontinent, may offer an important channel for eyecare related health communication. Importantly, no study has systematically evaluated WhatsApp in promoting health communication on eye care in India, specifically in its largely deprived population.

This qualitative study used WhatsApp (as an interventional tool) to create an information resource link on basic eye care between a tertiary city based healthcare provider and the deprived community, resident in the fringe of the city. WhatsApp use was facilitated by specially selected local women trained in information usage to disseminate contextual audio-visual information on eye care through multiple 'educational' sessions. Perspectives of 10 healthcare providers, 10 community health advocates and 30 women participants from the deprived community, were qualitatively explored. Changes in health behaviour of the deprived community members were also assessed. A thematic analysis was performed to systematically interrogate data to create meaningful themes.

This study confirmed the presence of a significant information gap on eye care on the face of high disease burden. The use of WhatsApp was supported unanimously by healthcare providers and community health advocates as an acceptable, feasible and cost-effective two-way communication tool, although concerns were raised about its hidden costs, privacy and security issues. Acceptability of WhatsApp based information dissemination amongst the study participants was high with reported benefits of increased awareness of eye diseases, their preventative management, remedial measures and the availability of affordable eyecare services. Additionally, study participants found WhatsApp technology appealing and intuitive. The resultant increase in self-confidence, consequent to heightened awareness, boosted social empowerment and enabled study participants to challenge prevalent social and cultural norms.

In conclusion, this study demonstrated that WhatsApp can be effectively used as a suitable vehicle of information dissemination on eye care in mediating a behavioural change in deprived settings. Findings from this study may be considered in developing policies that develop and disseminate eye care information. The wider implications and impact of this study lies in disseminating healthcare information related to other important public health issues to the marginal population.

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Dedication

This thesis is dedicated to the memory of my parents and mother-in-law who taught me to value life selflessly over personal needs. This thesis is also dedicated to all those women who may benefit from my study, not just only in matters of eye health or any health issues, but in all aspects of their life.

CHAPTER 1. Introduction

1.1 Introduction

Whilst, health behaviour change may be communicated using traditional platforms like radio and television (Finkelstein et al., 2012), social media, accessed through ubiquitous mobile technologies offers significant potential for two-way communication with a wider audience, including disadvantaged groups (O-Adewuyi, 2016). It has the potential to educate and empower (Whitehead and Seaton, 2016a). Social media based online forums allow patients to air questions, grievances, suggestions and to provide mutual support. Social media can also be used in identifying areas of need for information, monitoring the response of the public to health issues and communicating appropriate health messages to targeted communities. Social media have also been used in disease surveillance, health education, tracking and monitoring of disease outbreaks as well providing cost-effective communication in real time (O-Adewuyi, 2016). However, to date, research into social media in healthcare has been limited, and is restricted to major platforms such as Skype, Twitter and Facebook (Moorhead et al., 2013; Weng Marc Lim, 2016). In the Indian subcontinent, where communicating information about good eyecare practice is an important issue, WhatsApp, another social media platform which is inexpensive and widely available, may offer an important channel for eyecare related health communication. Importantly, no study has systematically evaluated WhatsApp in promoting health communication on eye care in India, specifically in its largely deprived population.

1.2 Context of the study

Worldwide, 285 million people are visually impaired out of which 39 million are totally blind. Quite strikingly, 90% of the visually impaired population resides in the developing world. Eighty percent of this blindness is preventable (*WHO | Visual impairment and blindness*, n.d.)(*Universal Eye Heath: A Global Action Plan 2014 - 2019*, 2013). A multitude of socioeconomic risk factors results in a high prevalence of visual impairment in the developing world (Jaggernath et al., 2014). Disability resulting from visual impairment results in lower employment and lower productivity.

Consequentially, beyond the individual and the society, visual impairment has a far-reaching influence on global socio-economic development.

India has almost a quarter of the global burden of vision impairment and this poses a major challenge for India's healthcare agenda (Nair, 2015). The policy of the Government of India, in public-private-partnership with non-governmental organisations, is to provide eye care services through primary eye care settings; this includes raising awareness through health education (Misra et al., 2015a). Primary Eye care services in India are delivered through two major models – fixed facility service provision (hospital based) and mobile dispensing services (mobile dispensary and tele-ophthalmology). Mobile dispensing services are still in a relatively early stage of development (John et al., 2012), and there is considerable scope for the development of additional technology-based solutions to address the unmet need for eye healthcare advice and support.

Traditionally, media platforms such as radio and television, have been used as preferred communication channels by healthcare providers for achieving a behaviour change in the target population (Finkelstein et al., 2012). The access and appeal of social media in the developing world has increased exponentially with the availability of increasingly affordable mobile technology and cheaper internet service provision. This has resulted in wider access to target audiences and increased engagement, especially with the disadvantaged population (O-Adewuyi, 2016). Social media has created a new form of communication platform by transforming monologue into dialogue (McMullan, 2011). Bridging geographical, time and social barriers and bypassing traditional media, social media has provided access to local communities in their own language. More specifically, educating and empowering people with health information is one area where social media has been exceptionally useful (Whitehead and Seaton, 2016b). The traditional vertical system of sharing health information from sources of scientific authority, passed down to the public through local authorities and clinicians, risks being made obsolete by emerging technologies that facilitate rapid horizontal and vertical information sharing (O-Adewuyi, 2016). Currently available online forums allow patients to air questions, grievances, and suggestions and to provide mutual support. Social media can also be used in identifying areas in need for information, monitoring the response of public to health issues and communicating appropriate health messages to targeted communities. Social media have also been used in health education, disease surveillance, tracking and monitoring of disease outbreaks and provide cost-effective communication in real time (O-Adewuyi, 2016). However, research into the role of social media in healthcare has been limited and is restricted to Twitter, YouTube and Facebook (Moorhead et al., 2013; Weng Marc Lim, 2016). Importantly, the role of social media remains largely unexplored in health communication in eye health research.

As is seen in many developing countries including India, geographical areas of extreme socioeconomic deprivation are often juxtaposed between areas of affluence. In these areas of abject poverty, with higher levels of prevalence of communicable diseases, a lack of knowledge and access to the basic eye care services, renders this population more vulnerable to eye ill-health and its incumbent detrimental effects. Such communities are often ignored as they lie hidden in the shadow of the more affluent neighbouring areas. WhatsApp, a relatively new social media platform, is widely available, free to use, inexpensive and provides instant audio-visual, two – way messaging capabilities. WhatsApp is widely accepted in the Indian subcontinent and has a further reach in the general population, particularly in the rural communities, over other social media platforms. Its presence and usage is particularly evident in the deprived sections of the society, where the acquisition of cheap smartphones can provide a vital link between healthcare providers and the ‘hard to reach’ deprived population. However, the potential of WhatsApp, in eye health information dissemination remains largely unexplored.

Considering the potential of WhatsApp and the unmet needs of the deprived community, this study intends to explore the use of WhatsApp in developing the community-based practice of promoting eye health in a deprived locality bordering a large metropolitan city in Eastern India.

1.3 Research question

What are the potential benefits and barriers associated with WhatsApp as a tool for enhancing community-based practice in eye health in deprived semi-urban settings?

1.3.1 Aim

To contribute to the theory and practice regarding the benefits and barriers of WhatsApp usage in supporting eye health care in deprived semi-urban settings.

1.3.2 Objectives

1. To conduct a literature review of the uses of social media in health care
2. To profile the demographic context of the deprived community, including their access to information on eye health
3. To gather insights into healthcare provider's and community advocate's views on the benefits and barriers associated with health communication via social media for eye health
4. To explore the nature of communication and attitudinal change associated with the adoption of WhatsApp for eye health
5. To propose a conceptual framework of the communication and attitudinal change associated with the adoption of WhatsApp for eye health
6. To propose a conceptual framework of the benefits and barriers associated with the adoption of WhatsApp for eye health

1.4 Approach

The research commenced with a literature review of the uses of social media in healthcare. This review identified the key themes in previously research. and has two main foci – social media usage by health providers and social media usage by end users. The review particularly focussed on the benefits and barriers of a social media based health communication strategy from the perspectives of key stakeholders (healthcare providers and end users). The literature review identified a knowledge gap on the use of social media in dissemination of health information on eye care in deprived communities (***Objective 1***). Additionally, factors that influence end-user engagement with health communication using social media were also identified.

Next, the focus shifted to the members of the deprived community and their access to eye health. To understand the socioeconomic profile of the deprived community, and their existing beliefs and opinions about eye health, semi-structured interviews were conducted. Care was taken in the design of these interviews to frame the questions in a way that community members could relate to. In terms of understanding the potential impact of the study and any later initiatives into eye health, this stage generated useful insights into the wider circumstances of the community, which might impact on their ability or willingness to engage to social media based eye health promotion (***Objective 2***).

The next stage of the research was to scope the context and benefits and barriers of using social media in health promotion amongst healthcare providers and community health advocates through semi structured interviews. This offered useful insights into key aspects of the context of the study, including current social media usage amongst the healthcare providers, and views in promoting eye health using social media, its benefits and perceived barriers in implementation (***Objective 3***). This stage also facilitated the identification of specific medical and allied professionals who would support the later stages of the study, by assisting with access to deprived community members, and providing required technology support

In order to explore the change in communication and attitude as a result of the implementation of WhatsApp based information portal on eye care, a focus group interview of end users (members of the deprived community) was conducted. The objective of this stage was to learn about the processes associated with accessing WhatsApp based eye care information, its perceived benefits, the extent of word of mouth in the collective spread and assimilation of new advice received, their future use intentions and changes they intend to make as a result of the app interactions, and their perceptions of the barriers associated with use of this new form of communication (***Objective 4)***. This stage of the research formed the basis for proposing a framework of the communication and attitudinal changes in the end users associated with the adoption of WhatsApp (***Objective 5***). Finally, this stage, in conjunction from information obtained earlier (Objective 3) helped in proposing a conceptual model of the benefits and barriers associated with the adoption of WhatsApp for eye health from the perspectives of healthcare provider and end users (***Objective 6***).

1.5 Researcher’s motivation

At a personal level, graduating from a background in Geography has been instrumental in stimulating the researcher’s interest in human behaviour in the societal context. Furthermore, she was trained in educational methods and skills whilst undertaking higher training in education (Bachelor (BEd) and Masters in Education (MEd)). Whilst undertaking postgraduate training in environmental management, she has been motivated to understand the differences in environmental awareness amongst individuals from different socioeconomic backgrounds and its detrimental effects on health outcomes. Moreover, she remains motivated by the differences in information seeking behaviour from individuals belonging to different socioeconomic backgrounds. Whilst undertaking a Masters in Information Science (MSc), she became interested in the use and functionality of information portals as a means to address this lack of awareness. She became increasingly aware on the potential usage of social media as a communication tool. Widespread adoption of cheaper mobile phone technology and easier access to social media platforms influenced her to consider this as a potential medium of information dissemination in developing countries like India, from where she begun her journey. The researcher was also aware of the impact of blindness on the society, and its particular significance in the developing world. During a recent brief stay in India, she became acutely aware of the wider consequences of blindness and other eye health issues, often preventable, that resulted from a lack of access to appropriate information in these ‘hard to reach’ deprived communities. As she came across the unmet needs of such marginalised population, she felt that they may benefit from the widespread availability of tailormade and relevant information, effectively disseminated through a widely available and cheap social media platform, such as WhatsApp. This background and inner conviction has been a central motivation in her exploration of the reach of social media as tool of effective information dissemination on eye care to the deprived community.

1.6 Thesis structure

This section provides an overview of the thesis and introduce the reader to the steps undertaken in carrying out this research.

Chapter 1. Introduction

This chapter provides the context of the study, its aims and objectives, the rationale behind and the researcher's motivation. This section also provides an overview of the thesis.

Chapter 2. Research Context

This chapter details the rationale for undertaking this study, highlighting the global burden of visual impairment and blindness, its variation by geographical region, socioeconomic parity, age, gender, area of residence and ethnicity and the impact of visual impairment on individuals, families and society. It also discusses barriers in accessing eye care services, particularly in the context of a developing country like India. This is followed by a detailed discussion of the remedial measures undertaken globally, and in India. Finally, geographical context of the study is discussed along with introducing the healthcare provider and the study population.

Chapter 3. Literature Review

This chapter outlines the forms of social media platforms used, discusses the domains of health communication and critically reviews published research on the use of social media in health communication. Subsequently, key themes thus identified are discussed from the perspectives of healthcare providers and end users. Finally, it discusses determinants influencing end-user engagement with social media in health communication.

Chapter 4. Research Methodology

This chapter commences with a brief introduction to research paradigms with particular relevance to this study. It provides the rationale behind the 'interpretative' paradigm chosen for this study. Various research approaches, deductive and inductive, and approaches undertaken in research pertaining to information science - quantitative, qualitative and the mixed methodology are discussed. The rationale for adopting a qualitative case study based approach for this study is outlined and the methodological stages adopted for this study is described. Details of the processes associated with participant selection, face-to-face semi-structured interviews, focus group interviews, the interview schedule, details of conducting and recording interviews and the nature of data collected. Justification for using

WhatsApp as the social media platform for information dissemination and the details of educational sessions and the assessment sessions are also provided. Subsequently, the chapter describes the theoretical basis of thematic analysis, and its implementation in this study. Theoretical basis of the methods employed in ascertaining research quality is discussed along with its application to this study. Finally, the chapter touches on the ethical considerations and steps taken to make this study fully compliant.

Chapter 5. Findings and analyses

This chapter details the research findings from this study. Descriptive statistics have been included to highlight key sociodemographic attributes of healthcare providers, community advocates and the deprived community members. It details the key themes and subthemes identified from this study. This includes the presence of information gap on eye care and the barriers in accessing information, eye health promotion using social media and particularly, the benefits and barriers of the use of WhatsApp in health communication on eye care as envisaged by healthcare provider and community health advocates. Finally, the chapter discusses the findings from the assessments of learning outcomes, the communication and attitudinal changes identified post adoption of WhatsApp based health communication strategy on eye care, the benefits and barriers identified by the members of the deprived community.

Chapter 6. Discussion

This chapter discusses the significance and implications of the research findings in the context of existing literature. It highlights this study’s contribution to the body of research knowledge on WhatsApp based health communication on eye care for deprived communities in India. A framework of communication and attitudinal changes in the deprived community that was associated with the adoption of WhatsApp for eye heath is also proposed. Finally, a conceptual model of benefits and barriers in the adoption of WhatsApp in eye care related health communication is proposed.

Chapter 7. Conclusions and Recommendations

This final chapter concludes the research, highlighting the study findings, including the benefits and barriers in a WhatsApp based healthcare communication strategy in eye health in the developing world settings. It summarises the answers to the research questions and how this study met its objectives. It also details the study's contribution to further existing knowledge, and to the methodology, theory and practice of eye care with practical implications for public health policies and healthcare providers. Finally, the chapter acknowledges the study limitations and makes recommendations for future research in healthcare communication using social media.

Chapter 8 (References) details all references cited in this study using Manchester Metropolitan University Harvard Style.

Chapter 9 (Appendices) presents the information used in this study like the interview questionnaires, study information document for participants, consent forms and ethical approval documentation.

CHAPTER 2. Research context

2.1. Introduction

This chapter aims to provide a summative account to the research context of the problem being investigated; it introduces the reader to the global problem of blindness and visual impairment with particular emphasis on India, the emerging new world of social media and the geopolitical context of specific regional location of India studied.

2.2 Global context of eye diseases, blindness and visual impairment

Globally, it is estimated that 2.2 billion people have blindness or vision impairment; of which, at least a billion would have been preventable (*World Report on Vision*, 2019; *Vision impairment and blindness. WHO Fact Sheet*, 2019). Recent estimates indicate that globally, moderate or severe distance blind impairment and blindness results from unaddressed refractive error (123.7 million), cataract (65.2 million), glaucoma (6.9 million), corneal opacities (4.2 million), diabetic retinopathy (3 million), and trachoma (2 million), as well as near vision impairment caused by unaddressed presbyopia (826 million) (Bourne et al., 2017). This is however widely considered as an underestimation, particularly reflecting a lack of data in children as most countries with the high disease burden, lack robust data capturing systems. Despite this limitation, recent estimates indicate that India has the largest number of people with blindness and visual impairment in the world, at around 8.3 million (Stevens et al., 2013). This forms a compelling ground to undertake this research in India. The following sections in this chapter describes the common eye conditions that may result in vision impairment and its risk factors, the impact of visual impairment on the individual, the family and the society, the magnitude of the problem in India, and the measures undertaken to address the problem in the global and Indian context.

2.2.1 Vision impairment

Vision impairment is said to be present when an eye condition affects the visual system and one or more of its vision functions (*World Report on Vision*, 2019). This definition is compliant with the explanation of the term ‘impairment” provided by the International Classification of Functioning, Disability and Health (ICF), as forwarded by the World Health Organization (World Health Organization, 2001). ICF uses ‘impairment’ to denote a problem in the function or structure of a person’s body due to a health condition (World Health Organization, 2001). This definition is also in accordance to the International Classification of Diseases 11th Edition (ICD 11) that is widely used as an international resource for disease classification (*WHO | International Classification of Diseases, 11th Revision (ICD-11)*, n.d.). Visual acuity has remained the primary tool in the assessment of visual impairment in population studies, which may be classified as a mild, moderate or severe distance vision impairment or blindness, and near vision impairment (*World Report on Vision*, 2019). However, at a clinic level, other tests may also be employed to determine and quantify vison impairment that include field of vision, contrast sensitivity and colour vision (*World Report on Vision*, 2019)

Common eye conditions resulting in vision impairment and blindness

Refractive errors implies blurred vision from the impairment of focussing the light accurately on retina and may result from abnormal eye shape or length. Many types of refractive errors exist that include difficulties in seeing distant objects (myopia or near sightedness) or seeing nearer objects (presbyopia or far sightedness), the latter being common beyond the fourth decade of life. Mostly, such refractive errors are amenable to correction by appropriately configured glasses or contact lenses (*World Report on Vision*, 2019). Cataract refers to cloudiness of the lens that leads to a blurred vision. Although, a child may be born with or develop one in childhood, the risk of developing cataracts increases with age. Cataracts are usually treated surgically. In glaucoma, increased pressure in the eye leads to pressure damage of the optic nerve and consequent loss of vision. Management is largely using medications to reduce this pressure but surgery may also be indicated. Corneal opacity arise from a number of conditions including infection and injury, that scars the cornea and makes it cloudy thereby obstructing the passage of light. Treatment is largely preventative and in refractory cases, may involve corneal transplant from cadaveric donors. In diabetic retinopathy, damage to the small blood vessels of the retina secondary to high blood glucose content in diabetes, results in abnormal proliferation and leakage leading to impairment of light passage. Treatment is preventative control of diabetes and laser ablation strategy. Trachoma is a type of bacterial infection that results in scarring and inward turning of the eyelids ultimately resulting abrasive corneal scarring and blindness (*World Report on Vision*, 2019).

Risk factors for common eye conditions that results in vision impairment and blindness

Multifactorial risk factors may play a part in the causation of common eye conditions that lead to visual impairment and blindness. This include age related changes, genetic makeup, lifestyle changes and risk taking behaviours, a variety of infections, and various underlying health conditions like diabetes and hypertension (*World Report on Vision*, 2019)

Aging may result in the increased prevalence of presbyopia, cataract, glaucoma and age-related macular degeneration (Chiang et al., 2018). Genetics may have role to play in a number of conditions that include glaucoma, certain retinal degenerative conditions and some forms of refractive errors (Miller et al., 2017; Dias et al., 2018). Ethnicity may be regarded as a non-modifiable risk factor that is associated with some eye disorders like glaucoma (Jonas et al., 2017). Lifestyle risk factors like smoking maybe associated with increased prevalence of age related macular degeneration and cataracts (Prokofyeva et al., 2013; Mitchell et al., 2018). On a similar note, heavy alcohol consumption may lead to early onset cataracts and macular degeneration (Gong et al., 2015; Chong et al., 2017). Nutritional deficiencies, like a lack of vitamin A, may result in a multitude of eye problems including dry eyes and night blindness (Gilbert, 2013). The prevalence of ocular injury related visual impairment increases with certain high risk occupations and certain type of contact sports.

Infections involving the eye may result from bacterial, viral, fungal and parasitic elements and can result in long term scarring and other permanent damages resulting in visual impairment (Azari and Barney, 2013; Lansingh, 2016). Environmental determinants like household air pollution and a lack of basic sanitation and hygiene may result in increased prevalence of eye disorders (West et al., 2013; Yang et al., 2013; Stocks et al., 2014). The presence of certain underlying health conditions is associated with an increased prevalence of eye disorders. These include, but are not limited to diabetes (Becker et al., 2018), rheumatoid arthritis (Murray and Rauz, 2016), and being born premature (Kim et al., 2018). Additionally, long term usage of certain medications like steroids may result in an increased prevalence of cataract and glaucoma (Bielory et al., 2006; Bielory and Bielory, 2014)

It is to be emphasised here that many eye disorders are multifactorial in aetiology and genetic susceptibility, together with environmental determinants, may closely interact together in disease progression and modification. For example, in myopia (short sightedness), genetic susceptibility may interact with lifestyle changes (intensive near vision activity as a risk factor and longer time spent outdoors as a protective factor) to influence disease onset and progression (Morgan et al., 2012). Importantly, access to good quality eye care remains an important risk factor in prevention or prompt institution of effective treatment (Ramke, Gilbert, et al., 2017; Wong et al., 2018).

2.2.2 Variation of eye disease by geographical region (countries and continents), socioeconomic parity, age, gender, area of residence and ethnicity

Globally, eye disorders have an uneven prevalence with some regions and countries being disproportionately affected. The likelihood of acquiring common but serious illnesses like measles, rubella (German measles) and vitamin A deficiency and its associated eye problems, is higher in African and Asian children (Sherwin et al., 2012; Wirth et al., 2017; Orenstein et al., 2018). Trachoma, a highly preventable disease, remains a major problem in 44 countries including Africa, Central and South America, Asia, Australia and the Middle East (Lansingh, 2016). Myopia prevalence peaks in the high income countries of Asia-Pacific region (53.4%), closely followed by the countries of East Asia (51.6%) (Holden et al., 2016). Estimates from China and South Korea indicate myopia prevalence rates in adolescents as high as 67% and 97%, respectively (Pan et al., 2015). Africa and Latin America shares a higher prevalence of age related eye conditions like glaucoma (Tham et al., 2014). Interestingly the incidence of glaucoma continues to be high for ex-pats from these regions residing in developed nations like the US (Quigley et al., 2001). Age related macular degeneration, on the contrary, affects over half of the Caucasian population aged 45 – 85 years of age in Europe (Wong et al., 2014).

Visual impairment, such as that affecting distance vision, shows a higher prevalence in the low- and middle-income regions that is estimated to be four times higher than in high-income regions (Bourne et al., 2017). Similarly, the prevalence of bilateral blindness in low- and middle-income regions of sub-Saharan Africa and South Asia is eight times higher than in all high-income countries (Ackland et al., 2017). Similar trends are noted for unaddressed near visual impairment in low- or middle-income countries (Fricke et al., 2018).

Eye disorders vary by the age of onset with certain conditions like retinopathy of prematurity (Blencowe et al., 2013), myopia (Pan et al., 2015), and amblyopia (West and Williams, 2011) being more prevalent in childhood. In contrast, the prevalence of presbyopia, cataract, age-related macular degeneration and glaucoma increases with age (Prokofyeva et al., 2013; Jonas et al., 2017; Fricke et al., 2018; Mitchell et al., 2018). On a different note, cataract and trachoma are higher among women, particularly in low- and middle-income countries (Lewallen et al., 2009; Lansingh, 2016). Mirroring the age and gender specific prevalence trends of eye disorders, visual impairment tends to be influenced by age and gender. The prevalence of distance visual impairment is higher in older age groups and in women (Bourne et al., 2017; Fricke et al., 2018)

Certain eye diseases like trachoma are seen more in poor and rural communities with inadequate access to potable water, sanitation and healthcare (Stocks et al., 2014; Lansingh, 2016). Rural communities may face greater barriers in accessing healthcare due to long distance to travel and poor infrastructure (Fletcher et al., 1999; Liu et al., 2018). For example, cataract surgery coverage tends to be less amongst rural inhabitants as compared to their urban counterparts (Ramke et al., 2017), whereas, in contrast, childhood myopia tends to be higher in the urban population (Holden et al., 2016). Similarly, visual impairment and blindness tends to be higher in the rural population (Xu et al., 2006).

Indigenous populations and ethnic minority groups may have a disproportionate burden of eye disease and visual impairment prevalence. Indigenous Australians, Kenyans and Mexicans have a higher prevalence of visual impairment as compared to the general population (Mathenge et al., 2012; Jimenez-Corona et al., 2015; Foreman et al., 2017). In high income countries, ethnic minority populations like those of African American and South Asian descent may have a higher prevalence of visual impairment (Sivaprasad et al., 2012; Frick et al., 2015).

2.2.3 The impact of visual impairment on individual, family and the society

Visual impairment, through its consequent disability, has an impact that goes beyond the individual and the family. Disability here refers to the impairments, limitations and restrictions that a person with an eye condition may face whilst interacting with the environment – physical , social and attitudinal (*World Report on Vision*, 2019). These difficulties and experiences include issues in everyday life situations like attending school or places of work. The disability is also determined by the likelihood of accessing quality eye care, assistive products (such as spectacles), and rehabilitation services as those with access issues are more likely to have greater limitations in everyday functioning and higher disability (World Health Organization, 2001; *World Report on Vision*, 2019).

Impact of visual impairment on the individual

Visual impairment has serious consequences across the life course of the individual (Cupples et al., 2012). Early onset visual impairment may result in language and communication development disorders in preschool children (Mosca et al., 2015). It has also been implicated in affecting cognitive function in childhood (Bathelt et al., 2018)and the development of autistic patterning (Wrzesińska et al., 2017). A study from the Royal National Institute for the Blind People (RNIB) explored how visual impairment affects the educational attainments of secondary school students (Chanfreau and Cebulla, 2009). The authors reported all children with visual impairment entered secondary school with lower attainment than other pupils; the effect is compounded if the pupil has concomitant other special educational needs. Age and degree of vision loss also affected perceived self-concept and self-esteem among children than their normal sighted peers (Augestad, 2017). Overall, there is long lasting effect of visual impairment on adaptive behaviour and quality of life of the children (Bathelt et al., 2019) and their parents (Lupón et al., 2018).

Visual impairment significantly affects the quality of life in adults and is highly feared amongst the general population (Vu et al., 2005; Brown and Barrett, 2011). A survey of American adults exploring patients perceptions of visual impairment revealed loss of vision as the worst possible health outcome and was ranked worse than loss of hearing, memory, speech, or a limb (Scott et al., 2016). Specifically, a loss of quality of life was rated as the top concern, closely followed by a loss of independence. Adults with visual impairment have less employment and productivity (Frick et al., 2015; Naidoo et al., 2019) and higher rates of mental illness including anxiety and depression (van der Aa et al., 2015). Managing other medical conditions and self-medication also becomes difficult for persons with visual impairment (McCann et al., 2012). In the elderly population, visual impairment may result in social isolation (Evans, 1983; Hodge and Eccles, 2013), walking difficulties (Swenor et al., 2014), a higher risk of falls and fractures (Hong et al., 2014; Crews et al., 2016) and greater chance of being cared at nursing homes (Friedman et al., 2004; Owsley et al., 2007). Visual impairment is also closely associated with significant cognitive decline (Bowen et al., 2016; Guthrie et al., 2018), and with harassment due to violence and abuse, including bullying and sexual violence (Banks et al., 2017; Brunes and Heir, 2018; Brunes et al., 2018). The prevalence of motor vehicular accidents in visually impaired persons remains high (Rubin et al., 2007). The overall cumulative effect of unaddressed visual impairment can be disproportionately large on social and economic well being (Cumberland et al., 2016).

Impact of visual impairment on family members and carers

The impact of visual impairment is evident on family members, friends, and carers, who are often involved in providing crucial physical, emotional and social support (Bambara et al., 2009). This support may be provided in a variety of ways including assistance with day-to-day living, emotional support, financial help to buy assistive devices at home, facilitation of attendance at medical services, and financial support for carers (Bambara et al., 2009). Such support has been associated with positive outcomes such as improved adaptation to vision impairment (Reinhardt et al., 2009), fewer depressive symptoms (Cimarolli and Boerner, 2005), enhanced uptake of rehabilitative services (Watson et al., 1997) and overall, greater life satisfaction (Reinhardt, 2001; Cimarolli and Boerner, 2005). In contrast, such high intensity support is often associated with carer fatigue associated with higher risks of physical and mental health conditions (Strawbridge et al., 2007; Dada et al., 2013).

Impact of visual impairment on society

Visual impairment has a far reaching effect on the wider society as it impacts on employment, quality of life and caretaking requirements (*World Report on Vision*, 2019). Vision impairment and blindness, is ranked third for years lived with disability in the Global Burden of Disease (GBD) Study (GBD 2017 Disease and Injury Incidence and Prevalence Collaborators, 2018). Official economic estimates suggest that the annual healthcare cost of vision impairment ranges from US$ 0.1 billion in Honduras to as high as US$ 16.5 billion in the United States of America (Eckert et al., 2015). The annual global financial burden on loss of productivity due to visual impairment is estimated to be US$ 244 billion and US$ 25.4 billion for uncorrected myopia and presbyopia alone respectively (Frick et al., 2015; Naidoo et al., 2019). Interestingly, a disproportionate economic burden of visual impairment is noted in East and South Asian countries (Naidoo et al., 2019).

2.2.4 Barriers to accessing eye care services

Despite advancement in eyecare over the century, the use of eyecare services has been patchy and is determined by the availability, accessibility, affordability, and acceptability of such services (*World Report on Vision*, 2019). The subsequent sections briefly outline the impact of access to quality eye care on visual impairment.

Availability of eye care services

Shortage of trained human resources that includes ophthalmologists, and allied ophthalmic personnel, such as optometrists, opticians, orthoptists, ophthalmic assistants, ophthalmic nurses etc, has been one of the biggest challenges in the delivery of eye care (Palmer et al., 2014; Gilbert and Patel, 2018; Resnikoff et al., 2019). This shortage varies by country's economy, and is particularly noted in the low- and middle-income countries. It also varies by rural residence where there is an acute shortage of trained staff. Even where staff is available, services are often limited by the lack of essential ophthalmic equipment (Patel et al., 2010). Due to sociocultural issues with eye donation, there is a shortage of corneal graft tissue that severely impedes the corneal transplant programme. The harsh reality of the matter is that much of the eye care in low and middle income countries is delivered through secondary or tertiary hospitals, which are principally located in urban areas, which also adds to inequity of access (*World Report on Vision*, 2019).

Accessibility to eye care services

Gender, socioeconomic status, and perceived cost of eye care can be powerful deterrents in accessing eyecare. Women in low and medium income countries are less likely to have the same access to eye care services as men. This may related to a range of socioeconomic and cultural factors, including limited financial decision-making power and minimal experience in travelling outside their community amongst women (Mganga et al., 2011; Ramke, Gilbert, et al., 2017). In addition, disabled people face greater challenges in accessing eye care services (Chan and Yap, 2016). Socioeconomic disadvantage (Fotouhi et al., 2006; Tafida et al., 2015), poor eye health literacy (Muir et al., 2006, 2008), a lack of knowledge of locally available services, together with homelessness and refugee status (Balarabe et al., 2014; Bal et al., 2019) may all acts as barriers to access. Furthermore, a perceived high cost burden of treatment and a lack of benefit (Khanna et al., 2018), may also hinder access to eye care services. Thus, self-medication and the use of traditional and spiritual remedies have been the mainstay of therapy, often with unwanted consequences (Gilbert et al., 2010). There's also a misconception amongst older people that visual impairment is part of the normal aging process (*World Report on Vision*, 2019)

Affordability of available eye care

The directs and indirect cost of eye care often acts as a barrier in accessing eye care in a timely manner. Direct costs arise from the treatment itself including medicine usage, purchase of vision aids, contact lenses, as well as transportation related expenses (Ramke, Petkovic, et al., 2017). It has been estimated that in low and middle income countries, 50% of people reside more than an hour of travel time to the city (as compared to less than 10% in the developed world) and this may act as an important barrier in accessing eye care services (Weiss et al., 2018). Also, a lack of health insurance coverage results in a low uptake of eye care services in the private fee paying sector, and this is particular important in geographical areas with lacking freely accessible government care facilities (Braithwaite et al., 2018, 2020). Indirect costs include those associated with non-attendance at clinic appointments as a result of concerns regarding the loss of income associated with the time spent to travel to eye care service points. (Melese et al., 2004). In some circumstances, non-attendance may reflect much deeper financial problems; basic living needs requirements may be prioritised over eye health concerns.

Acceptability of eye care

Finally, and very importantly, acceptability from the patients perspective is an important factor in considering barriers in accessing eye care services. Mistrust may be directed to the cost or quality of treatment provided, particularly if it is provided at a subsided cost for fear of being mediocre or ‘less good’ (Congdon et al., 2011). Other factors that affect acceptance of eye care include prior cosmetic belief (Adeoti, 2009), and pre-existing linguistic and gender biased, ethnic and cultural perceptions (Cooper-Patrick et al., 1999; Turner et al., 2011).

2.2.5 Addressing and improving eye care globally

The World Health Organization (WHO) has been at the forefront in addressing the unmet needs of blindness and other forms of visual impairment. The most recent global initiatives revolve around two flag ship projects; Vision 2020 and Universal Eye Health. Although it is beyond the purview of this research to discuss these programmes in detail, a brief discussion of these keys schemes is undertaken in the following sections.

Vision 2020

Launched in 1999 by the WHO and International Agency for the Prevention of Blindness (IAPB), Vision 2020 is a global initiative that aims to eliminate avoidable blindness by the year 2020 (*VISION 2020: The Right to Sight*, n.d.; *WHO | What is VISION 2020?*, n.d.). Vision 2020 works closely with twenty international non-governmental organisations involved in eye care and prevention and the management of blindness and provides guidance, and technical and resource support to countries that have formally adopted its agenda.

Universal eye health: A global action plan 2014–2019

Following the discussions held in the 66th World Health Assembly (2011), the WHO in close consultation with its member states and international partners, developed an action plan, also known as Universal Eye Health, for the prevention of avoidable visual impairment for the period 2014–2019 (World Health Organization, 2013). The Universal eye health plan ambitiously envisages "a world in which nobody is needlessly visually impaired, where those with unavoidable vision loss can achieve their full potential and where there is universal access to comprehensive eye care services" (World Health Organization, 2013). The global target of this plan is a reduction in prevalence of avoidable blindness and visual impairment by 25% by 2019. This is to be achieved by the collection of good quality country-specific data on visual impairment and training of additional eyecare professionals including nurses, optometrists and ophthalmologists to address shortages and equity of access. This plan aims to provide comprehensive eye care that is funded and integrated into the existing healthcare and covers all major causes of visual impairment and its rehabilitation. Furthermore, the plan aims to eliminate social and economic obstacles to access of eye care by ensuring addressing point-of-care payment arrangements, particularly making it free for the deprived communities.

2.3. Visual impairment and blindness in the context in the Indian subcontinent

There is a paucity of good quality data on the state of eye health for the whole country, although recent global estimates indicate that India has the largest number of people with blindness and visual impairment in the world, at around 8.3 million. (Stevens et al., 2013). Prevalence estimates show that over the age of 50 years, 3.6% were blind and 4.4% had severe visual impairment (Neena et al., 2008). Estimates also indicate that the disease burden is more in the rural population (8.2 % vs 7.1 % urban), in women (9.5 % vs 6.5% males) and amongst the older (> 70 years) population (20.6% compared to 1.3 % in people aged 50-54 years) (Neena et al., 2008). Furthermore, the prevalence of blindness was found to be significantly higher among people from lower socio-economic backgrounds. It is also estimated that almost 88.2% of blindness is avoidable and that the major cause of blindness is due to untreated cataracts (81.9%) and to uncorrected refractive errors (7.1%)

(Neena et al., 2008). Despite this large disease burden, the prevalence of cataract blindness, showed a downward trend (Murthy et al., 2008). However with increased life expectancy, this reduction in cataract blindness is offset by an absolute in increase in total blindness in the older population (Murthy et al., 2008). Additionally, acknowledging the effect of substantial advancements in cataract surgery over the past decades in reducing disease burden, there is an urgent need to consider other causes of blindness and visual impairment (Rao, 2015). It is however important to highlight that these figures are over a decade old and there remains a lack of research reporting on current disease prevalence in India.

2.3.1 Eye diseases, blindness and visual impairment in the socioeconomically disadvantaged population in India

Common to many other developing countries, despite significant economic advancements over the past few decades, pockets of poverty exists in India (Gupta et al., 2014). It is estimated that approximately 22% of the population (270 million people) lives in poverty and reflects the largest concentration of poverty anywhere in the world. People from a disadvantaged background carry a much greater risk for blindness and visual impairment (Dandona and Dandona, 2001; Khanna et al., 2007; Ulldemolins et al., 2012). Although the reasons may be multifactorial, a lack of awareness, availability of local eye care services, accessibility and affordability of care, poses major challenge to alleviate this problem (Brilliant et al., 1991; Fletcher et al., 1999; Vaidyanathan et al., 1999; Dandona et al., 2000; Kovai et al., 2007; Marmamula et al., 2011).

2.3.2 Addressing eye care needs in India

National Program for Control of Blindness (NPCB)

In response to the unmet needs of blindness, and in alignment with global initiatives, the Government of India demonstrated a strong commitment by establishing a NPCB in 1976, the first country to do so globally (Verma et al., 2011; Misra et al., 2015b; Vemparala and Gupta, 2017). This is a centrally sponsored programme with an ambitious goal of reducing blindness prevalence from 1.4% to 0.3% by the year 2020. Working in 640 districts in the country, this is the single largest National Health Programme model (Vemparala and Gupta, 2017). The programme uses a decentralized approach cascading responsibilities at the district level through state intermediaries and is based on a successful public-private partnership (PPP) model. The main aims and objectives of the programme are detailed in Table 2.1 (Verma et al., 2011).

The **aims and objectives of the NPCB programme** are:

- To reduce the backlog of blindness through identification and treatment of the blind
- To develop comprehensive eye care facilities in every district
- To develop human resources for providing eye care services
- To improve quality of service delivery to the affected population
- To secure participation of voluntary organizations/private practitioners in eye care
- To enhance community awareness on eye care
- To provide best possible treatment for curable blindness available in the district/region.
- To set up the mechanism for referral coordination and feedback between organizations dedicated to prevention, treatment and rehabilitation

Table 2.1. Aims and objectives of the NPCB

The details of the activities undertaken by the NPCB is beyond the purview of this dissertation, it may suffice to say that in the year 2016 – 2017, 6.5 million cataract surgeries were conducted with a cataract surgical rate of 6000 surgeries per million population (*World Report on Vision*, 2019). During the same period, 32 million children were screened at school, 1.5 million procedures were performed for other eye conditions and approximately 750 000 spectacles were distributed (*World Report on Vision*, 2019). Consequentially, the overall prevalence of blindness has reduced from a reported 1.1% (2001 – 2002) to 0.45% (2015–18) (*World Report on Vision*, 2019). NPCB has been instrumental in establishing 20 regional institutes of ophthalmology (tertiary eye hospitals), more than 3000 primary health care vision centres largely catering for the rural community, develop and support eye banks for corneal transplantation programmes and the development of human resources (Vemparala and Gupta, 2017). Until recently, the NPCB focussed primarily on cataract surgery. More recently, it has evolved to encompass other important eye conditions including diabetic retinopathy and glaucoma (Verma et al., 2011)

Vision 2020 India: The Right to Sight programme

'Vision 2020: The Right to Sight' programme was adopted in India in the year 2004 with an ambitious aim of blindness elimination by the year 2020 (Rao, 2000; *VISION 2020: The Right to Sight - India. A snapshot of our journey 2004 - 2018*, 2018). Vision 2020 aims to address blindness by addressing advocacy, strengthening of existing eyecare and organisational development. This was to be achieved by the establishment of 20000 primary eye care units also known as vision centres that would act as a point of interface of the population with skilled, comprehensive eye care service providers. It was proposed that these vision centres will then feed into 200 training centres and 20 centres of excellence through a 4 tier system.

Enhancing community awareness on eye health

As one of the major objectives, NPCB aims to enhance community awareness of eye care by using print, electronic and social media (Vemparala and Gupta, 2017). Specifically, NPCB has supported awareness programmes that include identification, motivation of potential beneficiaries, information sharing through media, educating voluntary groups, teachers and other community based volunteers including Accredited Social Health Activists (ASHA) identified under National Rural Health Mission (National Health Mission, n.d., n.d.). This aspect of NPCB is particularly relevant to this study and acts as a mainstay on which the focus to increases community awareness on eye health rests.

2.4 Chapter overview

In summary, this chapter discusses the burden of blindness and visual impairment in the global and Indian context. It highlights the variation of eye diseases by region and population and the deleterious consequences of poverty and socioeconomic status on eye health. It also touches upon the various initiatives to address this burden at a global and Indian level and its beneficial effects. As awareness on eye health issues remain very low in the India, this chapter highlights the initiatives undertaken to enhance community awareness on eye health.

CHAPTER 3. Literature review

3.1 Introduction

Social media has been used widely as a health communication platform across various heath care settings. In this literature review, an attempt has been made to critically review the current evidence on the use of social media in health communication, its benefits and factors underpinning its usage. More specifically, this literature review aims to identify and interrogate the current evidence on the use of social media in providing eye health related information. This chapter commences with a brief discussion of social media, its major platforms and usage in the global context with emphasis on its usage in India. Subsequently, the chapter discusses the concept of health communication and its domains. Finally, this chapter provides a narrative review of the uses and determinants of social media in health communication.

3.2 Social media

3.2.1 Overview of social media

Social media platforms are computer mediated interactive technologies that are involved in facilitating the creation and sharing of information, ideas and others expressions through virtual network communities (Obar and Wildman, 2015). Although diverse in their interface and usage, social media platforms share some common features (Obar and Wildman, 2015):

- Social media are interactive Web 2.0 Internet-based applications
- Users generate contents (also known as UGCs that include text posts, comments, digital photos or videos, and data generated through all online interactions)
- Individuals and groups using the social media platforms create user service-specific profiles and identities for the social media website or app

- Social media facilitate the development of social networks online by connecting a user's profile and interests with other individuals or groups sharing similar profiles or interests

Traditionally, individuals and organisations, sharing a topic of interest, have been the source of information (written or audio-visual) for the end users on the World Wide Web (Internet). Web 2.0 applications influenced the way this interaction happened in changing the end user from a ‘consumer’ into a combination of ‘producer’ and ‘consumer’ (or a ‘prosumer’)(Ritzer and Jurgenson, 2010). Applications were designed to enable users to create, interact, collaborate and share content whilst accessing information (Obar and Wildman, 2015). Much more than an technological advancement, Web 2.0 represented an ideological frameshift which fashioned a platform for creating and publishing content, and where content can be modified by all users continuously in a participatory and collaborative fashion (Kaplan and Haenlein, 2010). Through the formation of networks of closely linked communities, social media created the introduced substantial and pervasive changes to communication between organisations, communities, and individuals (Kietzmann et al., 2011).

Users access social media on desktop and laptop computing devices, or through applications (apps) that offer social media functionality to their mobile devices (smartphones and tablets). Social media differs from traditional printed (newspapers and magazine) and electronic (Television, Radio and the Internet) media in respect of quality, reach, frequency, interactivity, usability, immediacy, and performance (Agichtein et al., 2008). Social media offer a dialogic transmission system (many sources to many receivers) that is in contrast to monologue based transmission systems associated with the traditional media (one source to many receivers) (McMullan, 2011).

3.2.2 Popular types of social media

Although challenging to define, thirteen types of social media usage are generally recognised by the experts that include blogs, business networks, collaborative projects, enterprise social networks, forums, microblogs, photo sharing, products/services review, social bookmarking, social gaming, social networks, video sharing, and virtual worlds (Aichner and Jacob, 2015). Although the description of the various types of social media is beyond the scope of this discussion, it would suffice to say that the most popular social media platforms include Facebook, Twitter, YouTube, Instagram, Snapchat and WhatsApp. This research focusses on the use of major social media platforms in health communication, with an emphasis on eye health.

Facebook

Founded in 2004 in California, US, Facebook remain the most popular social networking site with an estimated 2.5 billion users globally (Nadkarni and Hofmann, 2012; *Social media usage worldwide*, 2019). Through the creation of personal profiles, Facebook facilitates interaction and network creation allowing participants to join common-interest groups and buy or sell items or services on online marketplaces (*About Facebook*, n.d.).

Twitter

Founded in 2006, Twitter is an American microblogging and social networking service that allows users to post and interact with short messages known also known as "tweets" (*About Twitter*, n.d.). Although previously restricted to messages of 140 characters, the limit was doubled to 280 characters in 2017 (Rosen, 2017). Twitter is one of the leading social networks worldwide with 152 million daily active users worldwide (*Twitter*, 2020).

YouTube

A subsidiary of Google, YouTube is an American video-sharing platform headquartered in San Bruno, California. It was launched in 2005 and was acquired by Google in 2006. YouTube allows users to upload and view user generated and corporate videos that include short original video clips, TV show clips, music videos, short films and trailers, documentary films, audio recordings, live streams, video blogging, promotional and educational videos (*About YouTube*, n.d.). As of May 2019 approximately 1.68 billion use YouTube worldwide, and 2 billion users log on to YouTube services on a monthly basis (*YouTube*, 2019). 500 hours of video is uploaded on to YouTube services every minute (2019 estimates). The most common reason for viewing is entertainment followed by music (25 % and 20% of all viewing respectively as per 2018 estimates) (*YouTube*, 2019).

Instagram

First released in 2010, Instagram is an American photo and video-sharing social networking service owned by Facebook that allows users to upload photos and videos for public or membership sharing (*Instagram. About us*, n.d.). Instagram also allows users to browse other users' content by tags and locations, and view trending content. Worldwide, 804 million people use Instagram (2019 estimates), 500 million use Instagram on a daily basis (2017 estimates) and approximately 1 billion on a monthly basis (2018 estimate) (*Instagram*, 2019). Globally, 2020 estimates indicate that the United States leads on Instagram usage with an estimated 120 million followers followed by India (80 million).

WhatsApp

WhatsApp Messenger or simply WhatsApp was founded in 2009 at Mountain View, California and was later acquired by Facebook in 2014 . It is a freeware and allows cross-platform messaging and Voice over IP (VoIP) service. WhatsApp allows users to send text messages and voice messages, make voice and video calls, and share images, documents, user locations, and other media (*WhatsApp Features*, 2020). Although primarily accessed from mobile devices, WhatsApp allows accessibility from a desktop as long as the user's mobile device remains connected to the Internet while they use the desktop app. Standalone version for business users that was released in 2018 (Sulleyman, 2018). In 2019, it was estimated that some 500 million people worldwide use WhatsApp on a daily basis and it is the most popular global mobile messenger app with an estimated 1.6 billion active monthly users (*WhatsApp*, 2019). India has the highest number of WhatsApp users, estimated to be 340 million, followed by Brazil (99 million) and the United States (68.1 million) (*WhatsApp*, 2019). WhatsApp also remains the most frequently accessed messenger platform in the United Kingdom and Germany (*WhatsApp*, 2019).

Snapchat

First released in 2011, Snapchat is an American multimedia messaging application. Uniquely, Snapchat messages and pictures are only available for a short time before becoming inaccessible. Worldwide, 2019 estimates indicate that Snapchat is accessed by 293 million users and 218 million use it on a daily basis (*Snapchat*, 2020). The United States is the leading user of Snapchat (101.25 million in 2020) followed by India (22.95 million). There is a preponderance of women (61%) and the age group is more evenly distributed than is the case for other social media platforms.

3.2.3 Social media usage in the global context

Recent estimates suggest that amongst 4.54 billion registered internet users, approximately 3.8 billion actively use social media, and 3.75 billion access social media on their mobile social media platforms (*Social media usage worldwide*, 2019). Over the past decade, the number of social network users rose from 0.97 billion (2010 estimate) to 2.96 billion (2020 estimate) with average worldwide penetration of almost 49 % (*Social media usage worldwide*, 2019). The country with the highest social network penetration is UAE with 99 % penetration. 2018 estimates indicate that China has the highest number of social network users (673.5 millions or 47% of the whole population) followed by India (326.1 million (24 %)) and the United States (243.6 million (75%)). Amongst all social media platforms, January 2020 estimates indicate that Facebook remains the platform of choice for 2.5 billion users globally, followed by YouTube (2 billion) and WhatsApp (1.6 billion) (*Social media usage worldwide*, 2019). Twitter has approximately 340 million users. When considering global active usage penetration (February 2019 estimates), Facebook has the highest penetrance (64 %), followed by WhatsApp (45%) whereas Twitter penetrates 21% of the population. WhatsApp, the social media of interest in this research has shown an exponential increase in its monthly usage that had climbed from 200 million in 2013 to 1500 million in 2017 (*Social media usage worldwide*, 2019). Some 500 million reported use WhatsApp on a daily basis (2019 estimates). 2019 estimates indicate that users use social media primarily for sending emails, mobile messages and text messages closely followed by watching videos on the YouTube and search queries on Google (*Social media usage worldwide*, 2019). In the year 2018, users from the Philippines tend to spent approximately 4 hours on social media daily followed by Brazil 3.45 hours) and Columbia (3.36 hours).

3.2.4 Social media usage in the Indian context

In 2019, it was estimated that there were 687.6 million internet users in India, of whom 629.2 million access the internet on mobile devices (*Social media usage in India*, 2019). 400 million Indians identify themselves as social media users and almost all access social media on a mobile platform (*Social media usage in India*, 2019). 2018 estimates indicate that the most popular smartphone activity is visiting a social network, followed by watching videos, using the online search engines, looking for product information and playing online games. An increasing proportion of the population now access social networking sites (22% in 2017 vs 27% in 2020) and projections suggest increases in the next few years (31% in 2023) (*Social media usage in India*, 2019). Approximately 351.4 million use social networking sites (2019 estimates) and the number is expected to rise to 447.9 million in 2023. On an average, Indians spend 2.25 hours on social media (2018 estimates) and collectively social network sites are estimated to have a penetration of 29 % of the total population (2020 estimates).

Facebook is the commonest social media platform used in India and has an estimated 260 million users, the highest in the world, almost double that of United States (180 million), the second highest user (*Social media usage in India*, 2019). Facebook has the largest share of social media usage with almost 86.6% market share (2018 estimate) and has an estimated penetration of 23% (2019 estimate). YouTube remains the second most common social media platform, closely followed by WhatsApp. YouTube has a penetration of almost 30 % of the population.

The popularity of WhatsApp, the platform used in this study, has grown significantly in India over the last few years. WhatsApp usage has increased from 20 million users per month (2013 estimates) to 200 million in 2017 (*WhatsApp*, 2019). Almost 30 % of WhatsApp users report using it on a daily basis and estimates suggest that its penetration level is 28% of the population. Significantly, 39.1% of WhatsApp users in the rural communities, spends between one and two hours on a daily basis (2018 estimates) thereby making it a popular social media in these communities.

3.3. Health communication

3.3.1 Defining health communication

Health communication can be defined as “the study and use of communication strategies to inform and influence decisions and actions to improve health” (*Health Communication Basics | Gateway to Health Communication | CDC*, 2020). Introduced in 2011, the US National Library of Medicine MeSH (Medical Subject Headings) thesaurus defines health communication as “the transfer of information from experts in the medical and public health fields to patients and the public” and “the study and use of communication strategies to inform and influence individual and community decisions that enhance health” (*Health Communication - MeSH - NCBI*, n.d.). Health communication relates to all of the processes of communication that are evident in the diverse healthcare contexts. Moving considerably away from a linear and didactic “doctor – patient” or “governmental health agency – public” communication, health communication now incorporates a wide range of verbal, printed, audio visual and virtual mediums to achieve its intended purpose. Suitably devised behaviour-based health communication can significantly and positively impact on health-related attitudes, beliefs and behaviours, thus rendering it an important tool in public health campaigns and communicable disease prevention programmes (*What is health communication?*, 2020). In an effort to standardise and validate health communication across health sectors and geographical regions, some principles have been widely accepted as attributes of effective health communication that are listed below (Table 3.1).

Accuracy:	the content is valid and without errors of fact, interpretation, or judgment.
Availability:	the content (whether targeted message or other information) is delivered or placed where the audience can access it.
Balance:	where appropriate, the content presents the benefits and risks of potential actions or recognizes different and valid perspectives on the issue.
Consistency:	the content remains internally consistent over time and also is consistent with information from other sources.
Cultural competence:	the design, implementation, and evaluation process that accounts for special issues for select population groups and also educational levels and disability.
Evidence base:	relevant scientific evidence that has undergone comprehensive review and rigorous analysis to formulate practice guidelines, performance measure, review criteria, and technology assessments.
Reach:	the content gets to or is available to the largest possible number of people in the target population.
Reliability:	the source of the content is credible, and the content itself is kept up to date.
Repetition:	the delivery of/access to the content is continued or repeated over time, both to reinforce the impact with a given audience and to reach new generations.
Timeliness:	the content is provided or available when the audience is most receptive to, or in need of, the specific information.
Understandability:	the reading or language level and format (including multimedia) are appropriate for the specific audience.

Table 3.1. Principle attributes of effective health communication (*What is health communication?*, 2020)**.**

3.3.2 Domains of health communication

Effective health communication is primarily based on the six areas of modelling knowledge, developing practice and ongoing international debate (Fig 3.1). These domains include health advocacy, health education, health literacy, risk communication, crisis communication, and social marketing. Acknowledging overlaps across the domains, the discussion below briefly outlines these concepts.

Health advocacy

H*ealth advocacy* is aimed at raising levels of understanding of an issue at the individual and community levels, whilst promoting health and access to quality health care and public health services (*Health advocacy*, 2020). This may be an effective strategy in gaining political commitment, policy and systems support, and social acceptance for a particular public health goal or programme, and may involve an amalgamation of individual-specific or social discourses, which may affect change. Health advocacy involves information gathering activities on existing public health practice, a close monitoring and scrutiny of the existing legislation and providing feedback on the impact of specific regulations on local groups and communities. This exercise may also help in reshaping health policy reforms. Health advocacy is often undertaken through mass mobilisation, multi-media, direct political lobbying, and community mobilisation. Certainly, all health professionals are expected to act as responsible advocates for public health at all societal levels. The changes that ensue, may happen within a governmental institution, patients' organisations, public health associations, in NGOs and the private sector (*Health advocacy*, 2020).

Health education

Health education "aims to influence a person's knowledge, attitudes and behaviours connected to health in a positive way" (*Health education*, 2020). This educates the population at large to take care about their own and other's health and is concerned about lifestyle and behavioural changes that can help with disease prevention. This may be achieved through a variety of educational programs and initiatives that focus on improving existing medical problems or preventative education (*Health education*, 2020).

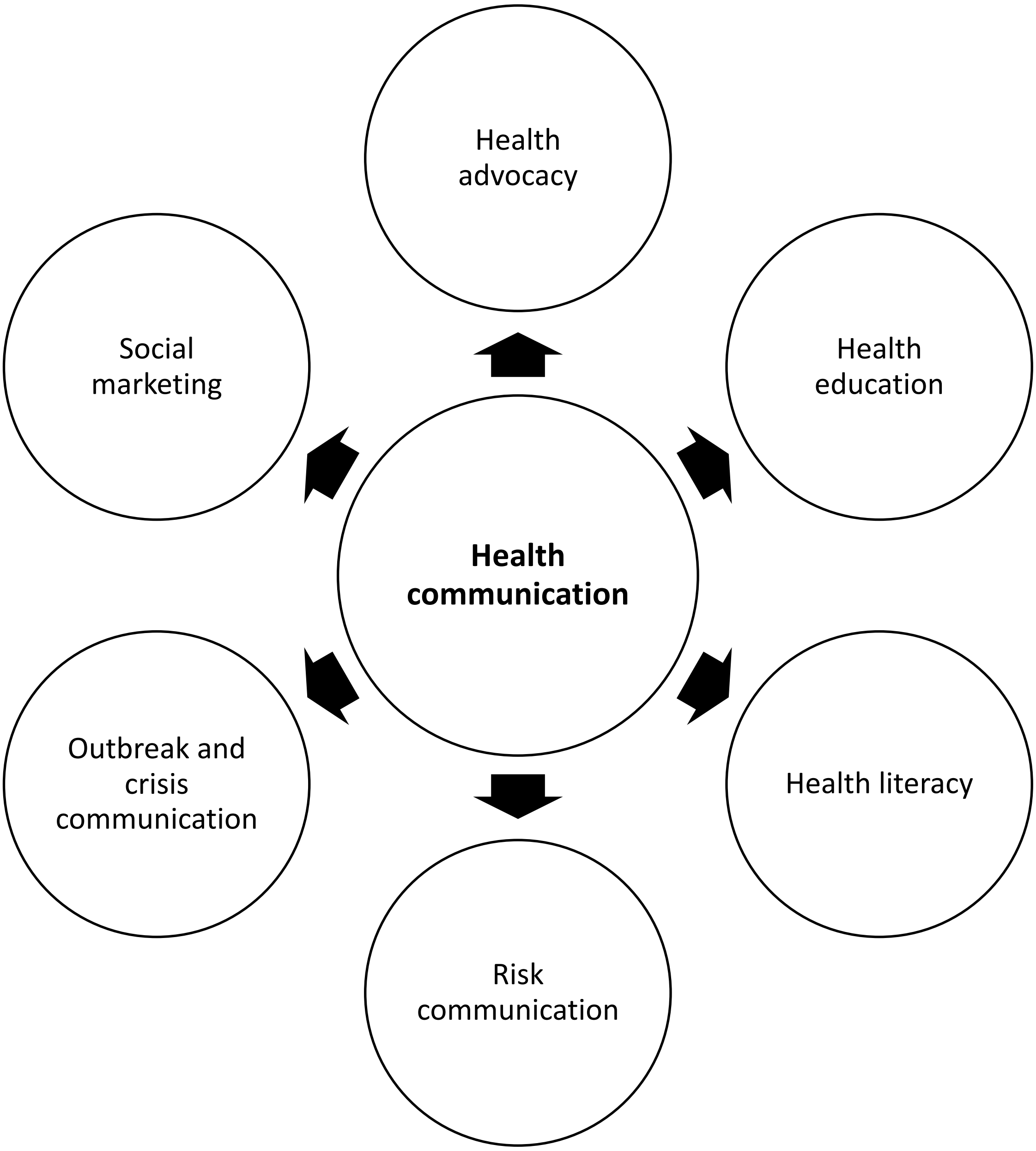

Figure 3.1. Domains of health communication

Health literacy

The World Health Organization (WHO) defines *health literacy* as "the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. Thus, health literacy means more than being able to read pamphlets and make appointments. By improving people's access to health information, and their capacity to use it effectively, health literacy is critical to empowerment" (*WHO* |

Health Literacy, 2020). Similarly, the National Health Service (NHS) states: "Health literacy is about people having enough knowledge, understanding, skills and confidence to use health information, to be active partners in their care, and to navigate health and social care systems" (*NHS The Health Literacy Place | Home*, 2020). Literacy is an important predeterminant in increasing an individual's capacity, to access and effectively use health-related information, however, an individual can be literate whilst simultaneously having limited health literacy (*Health literacy*, 2020). Health literacy may be achieved through a collective and concerted action from a number of stakeholders that include governmental agencies, civil society, media (including social media), community leadership and research focussed academic institutions (*WHO | Health Literacy*, 2020).

Risk communication

Risk communication is involved in all stages of risk management and mitigation and is aimed at creating public understanding of environmental and health-related risks by engaging communities in discussions about their outcomes and approaches to deal with them (*Risk communication*, 2020). It is a sustained process of communication with a diverse audience that highlights the likely outcomes of health and behavioural attitudes. This may be focussed on a specific health topic (for e.g. perceptions towards immunisations or a certain disease outbreak) or the consequence of certain behavioural traits (for e.g. risks associated with sexual behaviour or smoking).

Outbreak and crisis communication

An effective *outbreak communication* is aimed at achieving the goal of bringing quickly an outbreak under control, with as little social disruption as possible (*Outbreak communication*, 2020; *Crisis communication*, 2020). A number of strategies may be incorporated in an outbreak communication program that includes engaging community and building trust with the at risk population by using transparent, timely, easy-to-understand information that openly acknowledge uncertainty, and disseminate using multiple platforms, methods and channels (World Health Organization, 2017). Integrally blended with traditional media, the WHO specifically recommends the use of social media for public, engagement, facilitation of peer-to-peer communication and information sharing processes, to create and maintain situational awareness, to monitor and respond to misinformation and rumours, to manage public responses, reactions and concerns and to facilitate locally driven efforts (World Health Organization, 2017).

Social marketing

Health related *social marketing* implies the application of marketing methods to social non-for-profit causes and programmes and has been associated with promotion of knowledge or positive behaviours with a concomitant reduction of risky ones (*Social marketing*, 2020). It aims at improving people's health and quality of life in their contextual social, political and economic environment and requires, amongst all, a familiarity with the target audience, relevance and importance of the problem in focus and their capability to address the problem and their potential to promote change.

3.3.3 The health communication focus of this study

This study aims to explore prevailing knowledge about eye diseases amongst deprived communities and changes rendered by the WhatsApp based health communication channel. Despite a considerable amount of overlap amongst the stated health communication domains, this study focussed on aspects of eye care related health education, health literacy, and health advocacy. *Health education* was achieved by providing simplified and easy to understand information on common eye problems, preventative aspects of eye care, and available eye care services, to the members of the deprived community. *Health literacy* was attained by empowering deprived community members with necessary resources, to develop knowledge and adequate understanding to improve their own eye health and confidence to access eye care services. Finally, *health advocacy* was accomplished by scrutinising existing government policies, synthesising collective opinion involving healthcare providers, community health advocates and deprived community members on the past, present and future of health communication in eye care; thereby, raising levels of understanding effectively on eye care at the individual and community level, whilst promoting health and access to quality eye care.

3.4 Social media in health communication

Traditionally, radio, television and printed media (newspapers, magazine articles) have been used as preferred communication channels by healthcare providers for achieving a behaviour change in the target population (Finkelstein et al., 2012). The traditional *vertical* system of sharing information from sources of scientific authority, which were passed down to the public through local authorities (municipal corporation, village heads, etc) and clinicians, risks being made obsolete by emerging technologies that facilitate rapid *horizontal* information sharing (O-Adewuyi, 2016). A new form of communication platform has been established through social media by transforming monologue into a dialogue and social media based online forums allow patients to air questions and grievances, make suggestions and provide mutual support (McMullan, 2011).

The access and appeal of social media in the developing world has increased exponentially with the availability of affordable mobile technology, and cheaper data usage costs. Social media based information can be accessed conveniently through widely available mobile technologies, and offers significant potential for two-way communication between the healthcare providers with a wider audience, including those from the disadvantaged groups (O-Adewuyi, 2016).

The overall influence of social media has been to educate and empower by the transfer of information from the healthcare provider to the target population (Whitehead and Seaton, 2016a). Social media is perceived to have a greater potential to influence members of the public and decision-makers over traditional mediums (Côté and Darling, 2018). Social media has been used in identifying information needs, monitoring public response to health issues and communicating appropriate health messages to targeted communities. Social media have also been used in health education, disease surveillance, tracking and monitoring of disease outbreaks and providing cost-effective communication in real time (Fung et al., 2015; O-Adewuyi, 2016). Through the engagement of scientists and clinicians, and by promoting exchange of ideas virtually, social media has also created the potential to reach the broader scientific community (Choo et al., 2015; Collins et al., 2016; Côté and Darling, 2018; Cevik et al., 2019).

Despite its significant potential in health communication, research into social media in healthcare has been restricted to major platforms like Facebook, Twitter and YouTube (Moorhead et al., 2013; Weng Marc Lim, 2016). Twitter, remains the most popular social media tool used for science communication in health care (Cevik, 2019). However, importantly, the role of social media remains largely underutilised in eye health. Furthermore, no research has been undertaken on WhatsApp in health communication, which being inexpensively and widely available in the Indian subcontinent, offers the potential in communicating information on good eyecare on the face of high disease burden.

The subsequent sections discuss the research undertaken to date in the use of social media in health communication. It highlights common themes of social media usage and the multifactorial determinants that underpins and influences end-user engagement with social media based health communication channels.

3.4.1 Previous research into the uses of social media usage in communication

Social media platforms have been used for various purposes that range from disseminating health information to the general public to collecting user opinions and attitudes of using social media in healthcare communication. Fig 3.2 provides a schematic diagram of main themes of social media usage in health communication and the overarching flow of information between the healthcare providers and the end users. The subsequent sections review previous research on the various uses of social media in the context of health communication, an attempt has been made to construct key themes of social media usage in health communication.

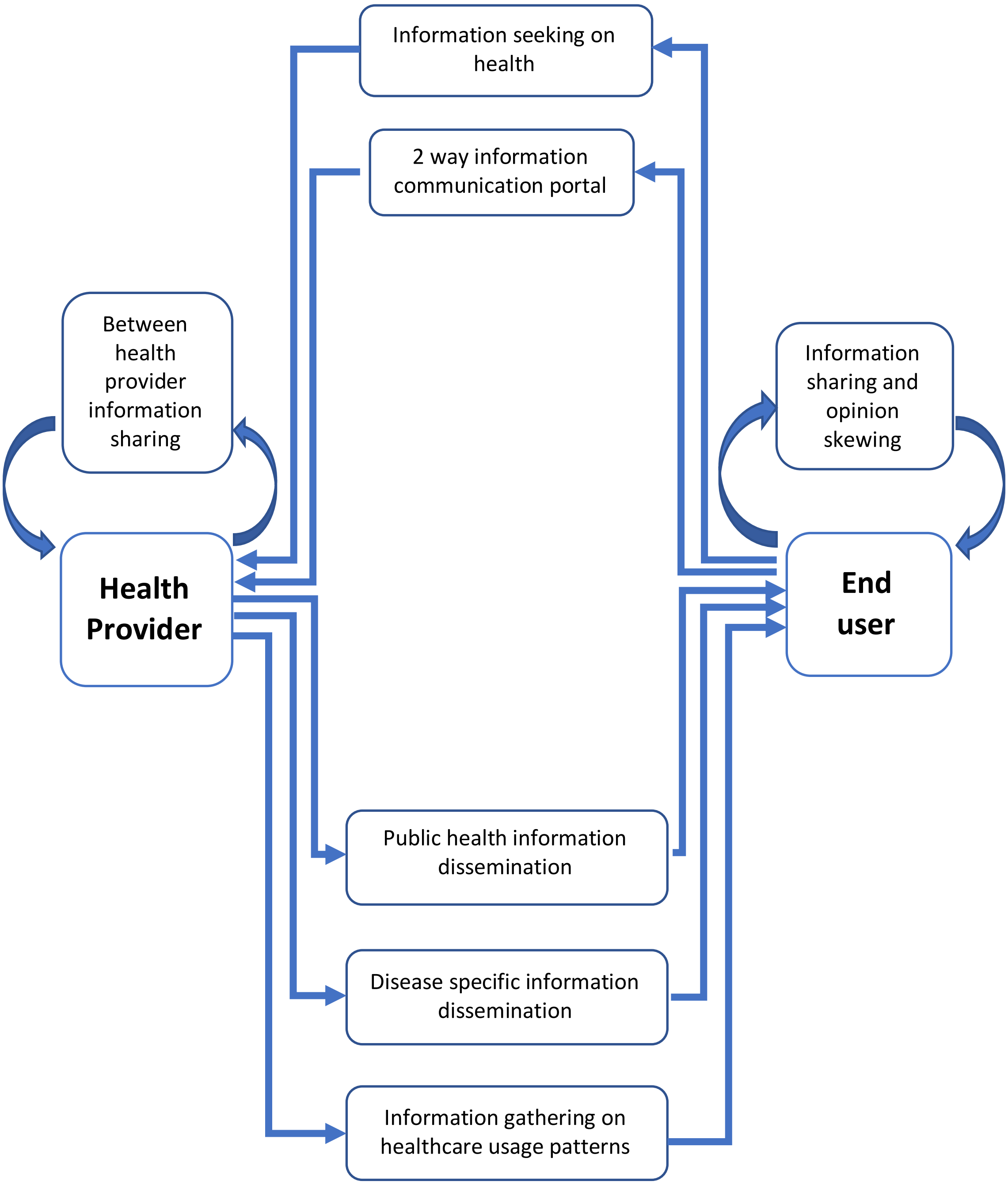

Figure 3.2. Domains of social media uses in health communication (Arrows indicate information flow pathways)

3.4.1.1 Social media usage by health providers

A large body of research has explored healthcare provider's approach towards health communication using social media. Primarily, healthcare providers have utilised social media in the context of disseminating information on either specific diseases or on public health matters, whilst others have analysed social media data to understand patterns of user engagement. Finally, a subgroup of studies have also explored communication between healthcare professionals using social media.

Social media as a public health information dissemination portal

One of the potential uses of social media in health communication relates to its ability in disseminating timely and accurate information, originating from healthcare providers and learned societies on public health issues, to the population at large. This is particularly evident during health crises like pandemics.

However, early studies have shown a degree of apathy from health organisations in engaging with social media. In an US study that evaluated the role of tobacco control programs (TCP) using Facebook and Twitter to engage with smoking cessation, it was evident that the reach of TCP social media sites was low and most TCPs were not promoting existing cessation services or capitalising on social media's interactive potential (Duke et al., 2014). Similarly, in a study of US poison centres, only slightly more than half of all centres were actively engaging with their Facebook portal of communication (Vo and Smollin, 2015). Recent studies however indicate a more proactive stance taken by health providers. For example, with the recent coronavirus disease (COVID-19) pandemic, Facebook was extensively used by the health authorities across Singapore (Ministry of Health, MOH), US (Centre for Disease Control and Prevention, CDC) and UK (Public Health England, PHE) for the dissemination of information on disease prevention and safety measures whilst providing regular situation updates (Sesagiri Raamkumar et al., 2020). Similarly, Facebook had been extensively used for disease communication in the Zika virus outbreak (Sharma et al., 2017; Vijaykumar et al., 2017). Twitter remained the major portal of communication in Ebola virus outbreak and Bird Flu pandemics (Househ, 2016; Vos and Buckner, 2016).

On other public health issues, social media has been used to disseminate information on poison control centres (Vo and Smollin, 2015), and for health promotion and public engagement (Park et al., 2016). In the study of US Poison control centres, Facebook remained the portal of choice for posting information related to self-promotion, public education, childhood safety, addictive drugs, environmental poisonings, and general overdoses (Vo and Smollin, 2015). Similarly, Twitter was favoured by a number of learned healthcare organisations including American Heart Association, American Cancer Society and American Diabetes Association in health promotion and public engagement (Park et al., 2016).

Social media has also been used in disseminating appropriate health information to a targeted audience and recruit participants, either for research purposes or into health programs. In New York city, Facebook was used to recruit gay couples from African American and Latino ethnicity, traditionally considered as a hard to reach population, to participate in an HIV prevention intervention program (Martinez et al., 2014). Similarly, Facebook was used as a recruitment portal for directing participants to a survey estimating local variation in HPV vaccine uptake among young men and women in Minnesota, US (Nelson et al., 2014).

Despite this use, questions have been raised as to the nature of the information being shared and to their accuracy of content and impartiality (Park et al., 2016). Additionally, social media outlets have been cited as a source of misinformation. In a study of Facebook in the Zika virus pandemic in US, misleading posts were far more widespread than those promoting accurate, relevant public health information (Sharma et al., 2017). In a Twitter analysis of Bird Flu pandemic, the researchers found that a significant share of messages contained correct information, but, few had information that would help individuals respond to the crisis appropriately (Vos and Buckner, 2016). Importantly, healthcare organisations have not always been in the forefront of information dissemination. During the Ebola virus outbreak, analysis of a month of Twitter data (September – October 2014) suggested that the news media outlets were the main influencers of the Twitter feeds and that the healthcare organisations had lagged behind (Househ, 2016). This notion was supported by a systematic review of health related disaster communication that confirmed that social media is yet to become routine practice in many governmental public health agencies (Eckert et al., 2018). The authors of this international review strongly recommended the need for incorporating social media into the daily operations of governmental agencies and implementing partners to build familiarity and effective use.

Social media as a disease specific interventional tool and an information dissemination portal

Health providers have used the potential of social media platforms to reach targeted audiences pertaining to some specific health conditions. In this context, social media has been used primarily in two major ways – increasing disease specific awareness and as a specifically designed healthcare interventional tool. Early studies indicate health providers to be somewhat slow to engage with the potential of social media platforms. Studies exploring the presence of dermatology-related content on Instagram and Tumblr, noted a lack of engagement from dermatology journals and organisations (Correnti et al., 2014; Karimkhani et al., 2014). On the other hand, in a study exploring urogynaecology information, an increase in useful information posted by health professionals on social media was observed that reflected an upsurge in engagement with social media (Alas et al., 2013). Over the past years, this trend has continued and an increasing number of health provider organisations have now engaged with social media in promoting heath.

In palliative care, a two-year retrospective analysis of Twitter posts surrounding awareness with end of life issues, the researchers observed an enhanced level of engagement with the topic and the existing care pathways (Liverpool Care Pathway) (Nwosu et al., 2015). Similarly, another study observed that Facebook was the chosen portal in awareness creation on hypertension across 187 groups with 8966 members (Al Mamun et al., 2015). Other activities included providing support to patients and caregivers, sharing disease experiences and life stories, service promotion, fund-raising, networking and conducting online research. Social media has been used in human immunodeficiency virus (HIV) prevention and treatment efforts. A systematic review of social media use in HIV revealed its usage across multiple purposes including disseminating health information, conducting health promotion, sharing experiences, providing social support, and promoting medication adherence (Taggart et al., 2015). Twitter based information originating from living donors and transplant professionals, hospitals, and organisations, were noted be useful in communicating living solid organ donation to the public (Ruck et al., 2019)

Others have used social media as an interventional tool, primarily for research purposes. A Facebook based pharmacy medicines information service addressed the medicines information needs of consumers, whilst promoting awareness about the correct and safe use of medicines in Australia (Benetoli et al., 2015). In Sri Lanka, Mo-Buzz, a mobile-based system that integrated three components – digitised surveillance, dynamic disease mapping and digitised dengue education – on a common platform, was developed to capture surveillance data and provide dengue related education (Lwin et al., 2016). Another randomised control trial explored the role of social media, as an add-on versus education and monitoring alone, to increase social support for physical activity (Cavallo et al., 2012). The authors did not demonstrate any measurable difference between the groups. More recently, through a twitter based information portal on skin cancer and its prevention, Gough et al observed that messages reached more than 23% of the population (Gough et al., 2017). A pre- and post-intervention Web-based survey suggested that the campaign to have contributed promisingly in improving knowledge and attitudes toward skin cancer among the population.

Health promotion campaigns form an unique area for social media based interventions. Childhood vaccinations have always been a highly debated issue and usual communication channels may not be enough in persuading favourable outcomes. A randomised controlled trial of social media based intervention to pregnant women (versus routine care) resulted in positive outcomes on vaccination uptake (Glanz et al., 2017). The intervened group had increased vaccination uptake and less number of unvaccinated days as compared to the group receiving routine care. Social media has also found an important role in diabetes awareness and its management as was evident in recent evidence based review (Gabarron et al., 2018). Social media based diabetic interventions resulted in better clinical outcomes but the overall effect on health-related quality of life measures, diabetes knowledge and empowerment was not clear as studies reported differing outcomes

Social media as an information gathering tool for healthcare providers

Social media has been used by healthcare organisations to gather information on end user engagement characteristics. Advantages attributed to social media relates to it being inexpensive, cost effective, discrete and having the potential to reach the 'difficult to reach' and 'stigmatised' population. A number of studies have evaluated the use of social media as an information gathering tool in global health crises, issues surrounding vaccination coverage, specific disease conditions, health promotional matters and mental health issues (Table 3.2). Furthermore, social media analysis had been conducted within healthcare providers and their interaction with shared communities. Such social network analysis is expected to provide techniques and vocabulary for understanding online interaction, as well as insights into who comprises and sustains a network and whether this results in the formation of an online network community. Information from this endeavour may be subsequently incorporated in making further advancements to social media campaigns.

- Monitoring global health crisis and outbreak like situations
- Monitoring vaccination uptake
- Exploring the population needs in mental health issues
- Exploring information sharing processes in health conditions, and restructuring of healthcare delivery services
- Monitoring and surveillance of health promotion strategies
- Understanding communication practices within healthcare organisations

Table 3.2. Information gathering by healthcare provider using social media

Social media network analysis has been shown to be useful in monitoring global health crisis and outbreak like situations. Twitter data was analysed in the H1N1 (swine flu) pandemic (Chew and Eysenbach, 2010). The authors concluded that social media may play a role as a potential 'infodemiology' tool for public health research and that Tweets can be used for real-time content analysis and knowledge translation research, allowing health authorities to respond to public concerns. During the Ebola virus pandemic, Tweets were examined through time series analysis with geologic visualisation to observe information dissemination and content that allowed temporal assessments of social media usage (Odlum and Yoon, 2015). Interestingly, the authors noted a rise in tweeting before the first cases were clinically diagnosed. Similarly, Twitter was analysed to obtain information on the Zika virus outbreak in South America with a particular focus on temporal variations in the analytic triad of locations, actors, and concepts (Stefanidis et al., 2017). In another study Twitter data was analysed to understand the magnitude of public interest during the Ebola virus epidemic (Househ, 2016). In a study of Twitter account analyses during this flu epidemic, the authors concluded that health campaigns should focus on recruiting influential Twitter accounts encouraging them to retweet or mention 'flu' was highly effective in disseminating flu-related information (Yun et al., 2016). During the HIV epidemic, Twitter data was analysed in a Brazilian study to inform communication campaigns promoting HIV testing and reducing HIV/ AIDS related discrimination towards key populations (Nielsen et al., 2017). In another study of tweet analysis pertaining to global major health issues (malaria, human immunodeficiency virus, tuberculosis, non-communicable diseases and neglected tropical diseases), prevention, control, and treatment were identified as the most prevalent themes, followed by advocacy, epidemiology and social impact (Fung et al., 2017). This information, the authors suggested, was instrumental in reflecting the perspectives and priorities of advocates, funders, policymakers, and practitioners of global health on these high-burden diseases.

More recently, the coronavirus (COVID -19) pandemic provoked an even closer examination of the patterns of social media usage amongst members of the public. An infoveillance study examined English language based Twitter data usage pattern during the COVID 19 pandemic (Abd-Alrazaq et al., 2020). Analyses of 160929 tweets indicated that four main themes existed in these tweets; viral origin; its sources; its impact on people, countries, and the economy; and, ways of mitigating the risk of infection. This study demonstrated that the crisis response activities amongst social media users were increasing getting simultaneous and intertwined with that happening in policy and practice. The authors postulated that social media increasingly provided an opportunity to directly communicate health information to the public. Another study, using Chinese social media platform Weibo, found a positive correlation between the number of Weibo posts and the number of Covid-19 reported cases in Wuhan (Li et al., 2020).

Vaccination uptake patterns remain another major topic of interest amongst healthcare organisations as this may allow necessary strategic adjustments to optimise coverage. Twitter trends on human papilloma virus vaccination, the commonest sexually transmitted disease in US, were analysed (Massey et al., 2016). The authors concluded that such trend analyses can aid health organisations and health-focused Twitter users in creating a meaningful exchange of ideas and in having an impact on vaccine uptake. Similarly, a recent Twitter analyses from Australia, indicated a positive correlation with HPV vaccine coverage in Australia (Dyda et al., 2019). The authors concluded that such analysis may be useful in providing timely and localised reports of the information access and sharing by the target population, and may be utilised to inform directed vaccine promotion interventions.

Social media has been an important tool in understanding the needs of the population with mental health issues that are often being underreported and underdiagnosed. Park et al developed Emotion Diary, a Facebook based web application, to successfully evaluate depressive symptoms whilst providing useful tips and facts to users (Park et al., 2013). In China, social media platforms like Weibo have been used to examine language markers of suicide risk and emotional distress in an effort to pick up early distress signals (Cheng et al., 2017). Another study gathered Twitter and Tumblr based information on communication between sufferers of eating disorders (Branley and Covey, 2017).

Social media analysis has been helpful in understanding information sharing processes in health conditions, and subsequent restructuring of healthcare delivery services. Cardiac arrest and resuscitation is a time sensitive condition where initial treatment often relies on public knowledge and response. Twitter analysis of data, confirms that it is used to both seek and share a wide variety of information about cardiac arrest and resuscitation and that resuscitation related messages are retweeted (Bosley et al., 2013). Given the large volume of tweets, the authors of this study proposed that using certain key search terms, relevant content may be identified and that such analyses may serve as a window into public interest and communication in health in real time. Twitter, combined with an analytical software tool, was found to be a reliable method for capturing real-time food consumption and diet-related behaviour of young adults (Hingle et al., 2013). Furthermore, data visualization using a GMap algorithmic mapping software provided a method to identify relationships between dietary and behavioural factors. Twitter evaluation was helpful to collect fast, cost-effective, and customizable data to understand sleep issues in American adults (McIver et al., 2015). In another recent study exploring patient's experiences with dermatological surgery (Mohs surgery) on Instagram and Twitter, the authors noted key themes that included, spreading awareness of skin cancer/encouraging others to protect their skin (on Instagram) and treatment updates (on Twitter) (Kamath et al., 2019). The authors concluded that social media platforms offers outlets for patients to educate others on important dermatological issues, by sharing their own personal experiences. Another recent study involving Twitter analysis of physiotherapy-related discussion reported that the reach may not be as broad as intended and that health care providers ought to implement strategies to engage with a broader audience with online messages (Sabus et al., 2019).

Healthcare organisations may beneficially explore social media in health promotion strategies for monitoring and surveillance purpose that may result in strategic alterations. Novel insights were generated in one study exploring the content and sentiment analysis of tobacco-related Twitter posts with a particular focus on new and emerging products like hookah and electronic cigarettes (Myslín et al., 2013). The authors observed that machine classification of tobacco-related posts showed a promising edge over strictly keyword-based approaches, yielding an improved signal-to-noise ratio in Twitter data. This methodological advantage may pave the way for automated tobacco surveillance applications.

Finally, some researchers have analysed social data to understand communication practices within healthcare organisations. For example, Facebook has been used to obtain rating information on hospitals in US allowing evaluation with other hospital through comparison matrices (Glover et al., 2015). In another form of interaction between shared communities of healthcare providers and patients and caregiver, social network analysis have proven beneficial. In a Canadian social network analysis study examining interaction patterns within communities (healthcare providers and end users) via Twitter, the authors reported the community as one component, with a set of core participants prominent in the network due to their connections with others (Gruzd and Haythornthwaite, 2013). Further analysis showed that social media health content providers were the most influential group.

Social media usage for professional communication amongst health care providers

With its permeating presence, social media can be envisaged to be used in professional communication between healthcare professionals. In a systematic review of 33 studies (mainly surveys and interviews) exploring communication usage of social networking sites amongst the healthcare professionals, the researchers concluded that these platforms facilitated efficient communication, interactions, connections, professional networks, education, and training (Chan and Leung, 2018). Social media was used to support clinical service delivery, making referrals, and sharing information across the front line staff. The authors identified that limitations existed in the form of technical knowledge, professionalism, and risks associated with breach of data. Social media networks have been used for peer to peer support by general practitioners in Australia and New Zealand to post clinical queries and seek support from fellow practitioners (Albarqouni et al., 2019). Social media has also been instrumental in the dissemination of best practice guidelines within healthcare organisations. In a study of information dissemination about nursing best practices in hypoglycaemia management to other healthcare professionals in a multi-centre set up, the researchers observed a significant reach of social media to enable widespread information dissemination (Sousa et al., 2018). Myocardial infarction (heart attack) is a time sensitive medical emergency where the duration of time from the event happening and specific intervention (percutaneous coronary intervention) being provided is related to outcome. In an US based interventional study, intra-hospital social media communication systems were used to transfer the ECG (electrocardiogram) to cardiologists beforehand about patients being admitted with infarction at a different hospital (Yu et al., 2019). When compared to the non-interventional group, the group where communication was facilitated had better outcomes, as the cardiologists could activate the necessary procedures sooner.

Summary

Social media has been extensively used in providing health communication originating from health providers. Most studies have demonstrated a positive association of social media based information dissemination strategies in attaining a desired outcome and provide insights into ways that the users engaged with this novel form of communication. Nevertheless, a considerable heterogeneity exists in the choice of the study population and research methodology adopted, thereby making generalisation difficult. This literature review identifies some major themes in social media usage by healthcare providers that includes information dissemination for public health and specific health issues. Moreover, social media has been effectively used to gathering information in an effort to comprehend user engagement patterns, and such understanding has been instrumental in redesigning information dissemination strategies for a better reach. Other uses of social media includes usage for professional communication and research and scholarship dissemination.

3.4.1.2 End user use / attitude / beliefs and expectations of social media in health care communication

Whilst social media has provided a portal for transmission of information from the providers to the users, it has been used by the end users for a variety of reasons including seeking health information online, sharing opinions and opening up a dialogue with the healthcare provider.

Social media as a heath information seeking tool

A number of studies have explored the usage of social media by end users in seek health information.

In an early survey exploring information seeking behaviours of adults on the Internet and social media about type 2 diabetes, participants frequently visited and discussed health information on popular online social networking sites (Shaw and Johnson, 2011). Another study explored the role of social media in understanding information sought by the general public and their hopes, concerns, and attitudes towards gene therapy (Robillard et al., 2013). A content analysis of Q&A site “Yahoo! Answers” for the 5-year period between 2006 and 2010 was undertaken and it was observed that users sought a wide range of information on gene therapy, with requests for scientific information and ethical issues at the forefront of enquiry. The authors concluded social media as an important research resource in exploring attitudes toward biomedicine and as a platform for knowledge exchange and public engagement with gene therapy. An Italian cross-sectional exploratory survey explored knowledge, attitudes, and behaviour toward antibiotic use, and on the role of internet to provide necessary information (Zucco et al., 2018). Online use was higher among females, younger subjects, with a higher level of education, those who reported self-medication with antibiotics and those who needed additional information on side effects. In a similar study from Kuwait exploring eHealth literacy, females had higher eHealth literacy scores and YouTube remained most trusted social media portal for accessing health information (Alhuwail and Abdulsalam, 2019).

One particular area of interest in understanding consumer health seeking behaviour relates to the availability of cancer information in social media platforms. An early study from Japan showed that cancer patients (via Twitter) shared information about their underlying disease including treatment and this was then accessed by other members of the public for their own information needs (Tsuya et al., 2014). An US study analysed tweets on cancer seeking information and observed that the primary reason for engagement was inquiry, followed by sharing experiences (Park and Park, 2014). Social media was an important source of information for cancer patients and their relatives in another study (Braun et al., 2019).

Understanding social media usage gives helpful insights into certain special communities who may traditionally not be able to access health information otherwise or be hard to reach. In a study of 18 – 30 year old college students, participants showed a strong preference for online and social media based health information (Prybutok and Ryan, 2015). Another study of young adults seeking health information online on diabetes and mental health observed a strong engagement with social media for health related contents (Fergie et al., 2016). A study of American Korean immigrants, who have been culturally isolated for linguistic reasons, showed a strong engagement with social media for the health information needs on the topic of cancer (Park and Park, 2014). Assessing information seeking behaviour on the risk of colorectal cancer amongst ethnic minority groups (African American and Latinos aged 50 years and above), showed that social media was preferred source on health information as compared to their white counterparts (Lumpkins et al., 2017). More recently, in a UK based study on men who have sex with men, acceptability, potential uses and impacts of delivering sexual health information to MSM through social media was explored (Kesten et al., 2019). The authors observed that participants regarded positively receiving information when browsing social media as that allowed them time to absorb information. Social media was observed to be popular for seeking health information on sexually transmitted diseases for the sake of anonymity, rapid diagnoses and multiple opinions from health practitioners, however the possibility of misdiagnosis remained high (Nobles et al., 2019).

Other studies have focussed on the multifactorial reasons behind this public engagement with social media for seeking health information. Reasons may include the desire to remain better informed, curiosity, self-management of an underlying health condition, exploring alternative therapies, clarification and validation of information and dissatisfaction (lack of time, insufficient information or disagreement) with health professional delivered information (Alhuwail and Abdulsalam, 2019). Patient's online health information seeking behaviour subsequent to a medical consultation was explored in one study and the authors reported that a staggering 80% went online post visit (Li et al., 2014). The most common source of information being other's forum posts, the most common reason cited for going online was curiosity followed by dissatisfaction with the medical consultation. An increasing number of subjects were eHealth literate, had lower approval to healthcare providers in patient centred communication and experienced increased worry due to the visit. Moreover, eHealth literate patients made greater use of specialised medical information like online medical journal articles than less literate patients. In another study of first time mothers during the first 6 months of their postpartum period, social media was extensively accessed for peer support and information (Price et al., 2018). Peer support was greatly valued and mothers often used social media to make in-person social connections. Racial and ethnic preferences were noted in studies exploring health information and those from the immigrant background with limited linguistic adaptation (Park and Park, 2014;

Lumpkins et al., 2017). In a recent review of direct to consumer prescription medication advertisement (DTCA) practices amongst college students, the authors observed that reading social media DTCA print content on Twitter was positively correlated with obtaining a prescription medication (Fogel and Zhuk, 2019). In a recent review of the existing literature on health seeking behaviour on social media, the authors observed that the need for information varied with the health condition being explored (Zhao and Zhang, 2017). Additionally, patients with chronic conditions and their caregivers were observed more likely to seek peer advice online, shared personal experiences and sought emotional support.

Social media use in information sharing and opinion skewing

Despite the enhanced engagement by the public on social media in seeking health information, end user’s perceptions have been influential in guiding them and social media has been implicated in skewing opinion, either favourably or against a prevalent thought or idea. Consequently, social media mediated opinion formulation and propagation may affect the ways through which end users trust healthcare information. In this section, studies that have predominantly explored end-user’s information sharing behaviour to their fellow users, and towards healthcare providers, are discussed.

A number of studies have observed the sharing of positive sentiments on social media outlets. An European study exploring the use of social media networking sites by parents of very low birth weight infants, observed that parents desired to engage online not only with other parents but also with medical staff (Gabbert et al., 2013). Social media has been used by families affected by rarer conditions and is well suited to discussion, support and advocacy for health-related conditions and can be especially important in connecting affected families (Wittmeier et al., 2014). In a study involving patients and carers of pulmonary fibrosis, a rare but debilitating lung disease, patients engaged with social media to satisfy their needs to better understand the condition and to support others facing similar challenges (Albright et al., 2016). On a similar positive note, active participation in social media platform like WeChat has been correlated with HIV testing in gay population in China (Cao et al., 2017). In a content analysis of Facebook pages hosted by parents of children with cancer, the authors observed that experiential similarity allowed highly specialised health-related information to be exchanged along with emotional support through comparison, empathy, encouragement, and hope (Gage-Bouchard et al., 2017).

Positive sentiments shared online on social media may be augmented by targeted health promotion campaigners. In a study examining the influence and penetration of a selfie image of skin cancer shared on Facebook, the authors noted an exponential increase in related search online (Noar et al., 2018). Postulating from this sharing experience, the authors concluded that detecting these events in near real time, may allow public health practitioners to engage and potentially elevate positive effects. Similarly, In a Michigan based study, opinions and attitudes has been collected from Facebook comments and posts on users unaware of controversial projects (biobank) (Platt et al., 2017). The authors of this study concluded that Facebook ad campaigns can improve engagement by pushing out relevant content and creating dynamic, responsive, visible forums for discussion.

On the other hand, a few other studies have examined the influence of negative perception. Affiliation with a pharmaceutical company may negatively influence the perception amongst those who are accessing the information. In a study of social media sites posted by healthcare organisations on allergy medications, declared affiliation to a pharmaceutical company generated mistrust and negative publicity amongst end users (DeAndrea and Vendemia, 2016). Furthermore, such end users were less likely to share the information through their social media connections. Social media can cascade negative sentiment as was observed in one Australian study of Tweets about human papilloma virus (Dunn et al., 2015). The authors observed that exposure to negative tweets resulted in retweeting of negative opinion compared to those who weren't exposed. Social media has been implicated in forming skewed attitude towards dieting and striving for inappropriate thinness. This was explored in an online survey of 1001 15 – 29 year old Australians (Carrotte et al., 2015). The authors demonstrated that at least 38 percent of the study population, predominantly teenage girls, were involved in accessing information about diet, detox and weight loss.

Social media use in two - way communication tool between end users and healthcare providers

One of the unique attributes of social media, unlike its traditional counterparts, relates to its ability to support and facilitate two way communication between the provider and the recipient. Nevertheless, early studies observed an hesitancy of the part of the end user to get involved in this dialogue and the flow of information was predominantly unidirectional. Ramanadhan et al performed a content analyses of social media presence and patterns of usage of community based organisations engaged in health promotion in Massachusetts, US (Ramanadhan et al., 2013). The authors observed that 42% of organisations used at least one of the channels of interest and that organisation promotion was the most common theme for content. The authors reported limited interaction and engagement with audience members which led the authors to conclude that much of social media use was unidirectional with a flow of information from the organisation to the audience. Simultaneously, in a telephone survey of users who use social media to seek health related information, the authors observed that individuals were more likely to consume information than contribute to the dialog (Thackeray et al., 2013). The authors concluded that the inherent value of “social” in social media was not being captured with online health information seeking.

On the other hand, the importance of dialogue was firmly established in a Dutch cross sectional study, where the authors observed that 1 in 4 persons wanted to communicate with their physician via social media channels and this was anticipated to rise further (Van de Belt et al., 2013). Recent studies have supported a two way engagement over monologue. Russell et al (2016) reported on their experiences in the development and evaluation of a Facebook based research advisory community, connecting a diverse group of parents of special needs children with researchers at a tertiary centre (Russell et al., 2016). This community aimed at working together and exchange knowledge in order to improve research and the lives of children and their families. This shared community facilitated exchange of information between the healthcare providers (evidence based health information) and the end users (sharing and understanding of issues that were most relevant to them). In another study, Rabarison (2017) explored Twitter chats and found it effective in facilitating two way communication between public health entities and their target audiences (Rabarison et al., 2017).

Summary

This literature review identifies ways users engage with health communication using social media. Primarily, end-users have used social media in obtaining health related information, the nature and purpose of which has varied according to user needs. Social media has also been used in sharing health information and experiences and had been observed as an effective opinion skewing instrument, either positively or negatively. Social media has also been used by some in engaging with health providers through a two way communication tool thereby facilitating horizontal information sharing. However, these studies have varied significantly in their context, research questions, and methodological approaches thereby making it difficult to generalise findings.

3.4.2 Social media use in eye health communication

Very little research has been undertaken in the field of social media usage in eye health. Mostly, this has been in the form of content analysis on the quality of information disseminated on eye health issues like retinopathy of prematurity (Şahin et al., 2019), cataract surgery (Bae and Baxter, 2018), glaucoma (McGregor et al., 2014) and blepharospasm (Ehrlich et al., 2012) and have been excluded from further discussion. Amongst the handful of studies using social media in health communication on eye care, one has evaluated technology utilisation and patient preferences, two others have examined social media as an epidemiological surveillance tool, whilst one other has used social media as an interventional tool.

In a study of patients attending an urban tertiary eye care centre, digital technology use and engagement with social media platforms were evaluated through a questionnaire (Aleo et al., 2014). Specific research questions focussed on ownership of technology, levels of comfort, frequency of use, and preferences for receiving health reminders. Computer ownership was high (80%) and younger age was significantly associated with technology ownership, comfort level, and frequency of use. However, only 3% of the participants preferred using social networking to receive health reminders, the vast majority opting for text message and e-mail notifications.

Social media has been used as epidemiological tool in two studies. In one study of conjunctivitis, social media posts (from Twitter, and from online forums and blogs) were analysed by machine learning methods and compared with clinical records from a large tertiary hospital (Deiner et al., 2018). Social media posts identified as conjunctivitis (infectious or seasonal) correlated well with clinically confirmed cases. Moreover, allergic conjunctivitis showed a distinctively seasonal pattern with a mean occurrence time later in the spring. The authors concluded that social media posts broadly track the seasonal occurrence of conjunctivitis, and may supplement routine epidemiologic monitoring. Broadly, these findings are in agreement with an earlier study, where weekly analysis of Twitter data on allergic conjunctivitis symptoms and antihistaminic usage correlated with total pollen counts (Gesualdo et al., 2015). The authors suggested using Twitter in the surveillance of allergic eye diseases.

Only one study has explored the potential of social media as an interventional tool. Sanguansak et al (2017) explored the feasibility and efficacy of a two-way social media messaging to deliver reminders and educational information about postop care to cataract patients (Sanguansak et al., 2017). Patients undergoing cataract surgeries were divided in two groups (message group and the standard control group). Messages were delivered via mobile social media platform using standardised content that included nine messages on hand and face hygiene, medication and postop visit adherence, and links to patient education videos about postop care. Patients were encouraged to respond to messages as desired. Outcome measures considered included adherence to medication and postop visits, clinical outcomes, and patients' subjective assessments of two-way messaging. Medication adherence in the early post-op stages and adherence to scheduled clinic visits were higher in the message group. No difference in medication adherence was noted at the end of the study period with no difference in clinical outcomes. Patients expressed satisfaction with messaging.

It is apparent from the discussion above that there is a serious dearth of research into social media engagement in eye diseases, Moreover, none so far has explored the role WhatsApp as an intervention in health communication. This background sets the need to evaluate WhatsApp and other social media based information dissemination strategies in eye health and forms the core principle of this research.

3.4.3 Determinants influencing end user engagement with social media in healthcare communication

Whilst it is important to understand the precise pathways through which information may flow between the healthcare providers and the community of users (end users), it is reasonable to explore the sociocultural, demographical and attitudinal factors influencing and shaping communication channels. Understanding these aspects supports the unravelling and shaping of the issues behind user engagement with social media in health communication. A body of research exists and can be broadly divided in two groups; factors which pertain to the health providers and those particularly focussing on the end users. Nevertheless, such determinants should not be examined in isolation, but in the context of the communication flow in entirety as this allows a deeper insight into the processes involved.

3.4.3.1 Health provider or host determinants

From a health provider's perspective, research has been undertaken to explore factors facilitating user engagement with health information content provided by healthcare organisations. Broadly, they can be grouped under factors that influence the healthcare providers themselves to engage with social media and those that relate to content matter of health communication.

3.4.3.1.1 Healthcare provider's engagement, usage and perception of social media

Some studies have attempted to examine the aptitude of health professionals and their beliefs of social media as a significant tool in disseminating health information. Overall, the attitude of healthcare providers towards social media based health communication strategies has been somewhat mixed; some expressing scepticism whilst others feeling positive about its potential.

One of the early studies, explored the use of technology by clinicians to access social media (Cooper et al., 2012). Of the 1750 participants surveyed, technology use during the previous 6 months ranged from using a portable device (80.6%) to access the internet to 12.9% writing a blog. The most consistent predictors of use were young males, and having teaching hospital privileges. In a study of Baltimore academics, Keller et al observed that a small minority were actually engaged in this space professionally, whilst most were either disinterested or actively opposed to professional engagement (Keller et al., 2014). In a Dutch study, motives, barriers and expectations of using social media were explored amongst a group of health care professionals in obstetrics and gynaecology (Antheunis et al., 2013). The authors observed that that social media was used by professionals primarily for communication with their colleagues, networking and marketing reasons. Although professionals expected increased social media usage in future, their current barriers with social media engagement related to concerns about inefficiency (related to extra burden of time and resources), lack of skills, issues surrounding legality and privacy concerns. Issues pertaining to privacy, remained a major concern amongst staff members of large Canadian healthcare team, resulting in a low engagement with social media (Lofters et al., 2016). Healthcare organisations usually have large managerial teams that work alongside healthcare professionals in delivering clinical care and their understanding and attitude towards social media may also have a bearing on the overall engagement of clinical staff with social media. A cross sectional study explored the perception of healthcare managerial staff's towards social media usage in health communication (Bermúdez-Tamayo et al., 2013). The authors observed that social networks were used most often by larger hospitals and public hospitals (than by private ones). Furthermore, respondents with a negative perception of social media were worried about the possibility of abuse by healthcare professionals, whereas those with a positive perception believed that in the potential of social media in improving communication within and outside the hospital premises.

3.4.3.1.2 Content of health communication disseminated through social media

One of the important considerations in bilateral engagement with social media relates to the factors that determine the content of health matter being disseminated.

These factors relate to readability, accuracy, trustworthiness and relevancy of health information that is being provided for further evaluation. Strategies that focus on understanding and rectifying the shortcomings are expected to reach out to a wider population. A brief discussion ensues on a number of studies that have attempted to explore this aspect of health communication.

Content matter and style of engagement

The content of the actual health matter being disseminated remains an important factor in end user engagement and is determined by its' relevancy, audio-visual content, discourse style and message framing properties.

The topic of interest (relevancy) posted online by healthcare organisation is an important determinant in user engagement. In a study examining Centers for Disease Control and Prevention (CDC) Facebook posts during the Ebola outbreak (2014), it was observed that despite less Ebola related posts being published by CDC than non-Ebola posts, audience engagement was significantly higher with Ebola related communication (Strekalova, 2016). Similar were findings from another study which observed that serious discrepancies existed between topics that were of interest and concern to the general public, and what public health authorities provided during the Zika outbreak (Gui et al., 2018).

Audio-visual content matter and its effect on user engagement was explored in a few studies. In a study exploring engagement with Facebook platforms on diabetes, interesting observations were noted (Rus and Cameron, 2016). Messages with images emerged as a strong predictor, being liked and shared more frequently than those didn't. Diabetes consequence information and a positive identity were associated with higher sharing as compared to negative affect, requirement for social support. In an Australian study exploring Facebook post features with higher user engagement with public health organisations, video posts attracted the greatest amount of user engagement (Kite et al., 2016). Posts depicting positive emotional appeal or providing factual information attracted higher levels of user engagement, while marketing (sponsorships and the use of persons of authority), discouraged user engagement, with the exception of posts by a celebrity or sportsperson. Similarly, in an US study exploring the engagement with cancer risks on a Facebook page (National Cancer Institute), images and links were the top two most frequent types of content for both risk-related and non-risk posts (Strekalova, 2016; Strekalova and Krieger, 2017). However, risk-related messages were more amplified through comments, shares, and likes. Unlike the previous study, videos were not more effective in attracting audience engagement over images.

The impact and influence of message framing was explored in another study exploring user engagement with smoking cessations posts on Tobacco Free Florida's Facebook page (Strekalova and Damiani, 2018). The researchers observed that message framing (dominant-submissive or affiliate-disaffiliate) and a call for engagement was associated with enhanced engagement patterns.

The method of information discourse may also be important in engaging end users. In an experimental study, feasibility, expertise claims, and user-generated ratings about anonymous HIV testing, were explored to understand readers' assessments of advice (Walther et al., 2018). End users were more influenced with online content that were both systematic and experiential (heuristic). Moreover, with conflicting information, consensus user-generated ratings were more influential over self-promoted expertise.

Trustworthiness and marketing motives

Not all information available on the social media platforms serve the stated purpose of spreading awareness on health conditions, and may have inherent marketing themes. In a comprehensive analysis of health information available on Facebook, Hale et al found that marketing and promotion was the most common theme followed by information and awareness. Also, marketing and promotion engaged the end users more than those with support information (Hale et al., 2014). In another study, social media (Facebook) was the chosen platform for online marketing amongst a group of orthodontic practitioners (Nelson et al., 2015).

Similarly, trustworthiness of online content and the organisation behind is expected to influence user engagement. A study examining the content of tweets undertaken by health professionals and found that around only half of them contained tweets that were supported by medical evidence (Lee et al., 2014). During the flu outbreak, Twitter analysis revealed that influential accounts (media or healthcare organisation) were more trusted and highly effective in disseminating flu-related information, as compared to other influential individual accounts (Yun et al., 2016). Trustworthiness of the information provider remains a major driver for members of the public to engage online (Hether et al., 2014; Song et al., 2016)

3.4.3.2 End user characteristics

The complex processes involved in this engagement with social media platforms for health communication, is also underpinned by a number of intricate inherent end user characteristics. It is however worthwhile to recognise that, despite an extensive body of research, a clear pattern does not emerge and much remains a matter of speculation. The following discussion intends to summarise current research that has focussed on end user factors in engaging with social media for health related communication.

3.4.3.2.1 Patient’s motives, barriers and preferences

Engagement with social media, as would be anticipated, is also shaped by end user preferences and has been specifically explored in some studies. In a study exploring patient’s motives, barriers and perceptions, the authors observed that patients primarily engaged with social media for increasing knowledge, exchanging advice and social support (Antheunis et al., 2013). However patients remained concerned with the privacy and reliability of such online information. A study of first time mothers supported the value of peer support and the role of social media in making in-person social connections (Price et al., 2018). Motives for engagement may include curiosity, a desire to remain well informed, medical self-management, exploring therapeutic alternative, clarification of healthcare provided information and dissatisfaction with health professional (Li et al., 2014; Alhuwail and Abdulsalam, 2019). In another study, patients with chronic conditions were more likely to seek and share experience online, whilst seeking emotional support (Zhao and Zhang, 2017). Lu et al (2017) performed a stakeholder’s analysis (patients, caregivers and specialists) on understanding social media engagement in lung cancer, diabetes and breast cancer (Lu et al., 2017). Whilst, patients remained concerned about lung cancer symptoms, medications related issues in diabetes and examination for breast cancer, caregivers were concerns about medications in treating lung cancer, procedural topics with breast cancer and complications. Patients were more likely to express their emotions in this study. In another study of caregivers of paediatric cancer patients, preference for social media based cancer-related information arose as the information was instantaneous, targeted to specific caregiver concerns, and tailored to the caregiver’s information needs (Gage-Bouchard et al., 2019). Other studies have also shown a preferential usage of social media by adolescents for oral health information (El Tantawi et al., 2019) and dating apps by MSM communities (Kesten et al., 2019).

On the other hand, some studies have explicitly, showed a disinclination towards this form of engagement. In a study examining the use and preference for electronic communication channels among physical activity researchers and practitioners, most preferred non-social media channels (Jake-Schoffman et al., 2018). Similarly, in an eye clinic, setting only 3 % of patients preferred social media has a medium of health related communication (Aleo et al., 2014).

3.4.3.2.2 Age, gender, place of residence, sociocultural and ethnic factors

Some studies have descriptively analysed the population demographical characteristics of the end users engaging with social media health communication portals. However a clear cut sociodemographic pattern of user engagement is not forthcoming. These findings are primarily shaped by the context where the research was undertaken.

Age

Age has been observed to be an independent determinant in engagement with social media but the relationship is not clear. In one of the earlier studies, Chou et al, explored the sociodemographic and health-related factors associated with current adult social media users of healthcare information in the United States (Chou et al., 2009). The authors reported that 69% had access to internet amongst which 5% participated in an online support group, 7% reported blogging, and 23% used a social networking site. Younger age was the only predictor of blogging and social networking site participation. Younger age, poorer subjective health, and a personal cancer experience predicted support group participation. Social media use was independent of education, race/ethnicity, or health care access. Unlike findings from this study, other researchers observed that participants to be generally older, predominantly white population who had lower writing level than the reading level of the population (Sadah et al., 2015). More recently, in a large study on social media trends in cancer related health information (National Cancer Institute's Health Information National Trends Survey), younger population were observed to be at higher odds of using social media for health communication (Huo et al., 2019)

Some studies have specifically focussed on adolescents and young adults as traditionally, it is anticipated that this group will blend well with general social media usage. In a study of 428 Latino adolescents and youths, the researchers observed that 97 percent of the youths had at least one social media account (89 % had Facebook and the mean number of accounts was three) (Vyas et al., 2012). English speaking Latino youths were more likely to own a phone and remain highly engaged with social media. Social media was also the chosen portal amongst Saudi adolescents for receiving oral health information (El Tantawi et al., 2019).

End user expectations may vary with age with younger audiences demanding more autonomy over privacy. Consequently, not all adolescents and young adults were keen on engaging with social media mediated health discussion. In a content analyses of semi-structured interview of Dutch teenagers, the authors observed that most teenage patients did not disclose their personal health information on social media and did not use social media to come into contact with others with similar conditions (van der Velden and El Emam, 2013). Similarly, in a more recent cross sectional survey of adolescents and young adults attending a primary care clinic, only 51.5% shared health information online (about mood, wellness and acute medical conditions) and those with self-reported poor health were more likely to share health information than other groups (Hausmann et al., 2017). Participants were mostly concerned about privacy and only 25% perceived social media to provide them with useful health information, most did not want to use social media and preferred texting.

Gender

It has been anticipated that social media usage may vary by gender. However, there is very little evidence to support this notion. In an Australian study examining the correlates of online health seeking behaviour, reporting poor health and the presence of two chronic health conditions were positively associated in women (Nikoloudakis et al., 2018). However, no gender difference were found on other parameters that were positively associated with online health seeking (young age, social media use, non-smoking status and university education). For new-borns delivered premature, much effort goes in understanding maternal needs and support is directed accordingly, but little is known about paternal concerns. In a study that exclusively examined social media usage by fathers to address their concerns, quite like the mothers, various social media platforms were used to discuss concerns and obtain information, companionship, and emotional supports (Kim et al., 2016).

Other studies have explored social media usage in specialist communities including the LGBT (Lesbian, Gay, Bisexual and Transgender) and MSM (Men seeking Men) people. In a survey of 2274 members of LGBT community examining health information needs, Park et al (2018) observed that age, sexual orientation, number of Internet access points, and use of smartphones predicted levels of social media involvement (Park et al., 2018). Email was the preferred channel for health communication irrespective of their social media usage. Those with high engagement with social media showed preference towards social networking sites and the Internet for health communication needs, whilst non users were inclined towards healthcare professionals as their primary source of information. Nevertheless, traditional mediums were equally acceptable independent of social media usage. Similarly, sexual health information delivery through social media and dating apps was considered acceptable by a group of MSM people, although concerns were raised about judgements and discrimination on the online medium (Kesten et al., 2019). The MSM community preferred information that was positively engaging, less clinical, focused on building social norms and delivered by trusted organisations.

Place of residence

Residence, either in an urban or rural setting, may independently influence end user engagement with digital technology and social media. Access to digital media was assessed by one study in the urban setting. In this US based study, 257 caregivers of predominantly African - American children attending two urban paediatric primary care centres were surveyed on access to digital technology (Demartini et al., 2013). Eighty percent of respondents reported accessing Internet at home, 71% had a smartphone, 91% used e-mail, 78% Facebook, and 27% had Twitter accounts. A large proportion (70%) of respondents reported their intention to digital health care information approved by their child's medical provider. Residence in the rural community was explored in another. This cross sectional study examined access to and use of digital technology among rural African Americans, Caucasians, and Hispanics (Powe, 2015). Digital technology was accessed by a few and the community preferred health information from friends and family, and other traditional mediums like printed matter, over information provided through digital platforms.

Sociocultural and ethnic factors

Some studies have explored the sociocultural and ethnic determinants of user engagement with social media in health communication, but the relationship remains unclear and no clear pattern emerge. In one of the early studies, exploring the use of social media in communicating child health information amongst low income predominantly Hispanic parents, a lack of time and credibility was cited as the main barriers (Stroever et al., 2011). On the other hand, another study of patients attending a community health centre, the Hispanic population were observed to be more keen on social media networks as compared their white counterparts (Hanson et al., 2014). In a study performed across various locations that included the US, Korea and Hong Kong on trusting social media as a source of information, Koreans and Hongkongers exhibited more trust in experience-based health information sources (blogs, online support group, social networking sites) whilst Americans preferred expertise-based information sources (CDC, etc) (Song et al., 2016). Although, trust in expertise based information sources was universal, however, searching on behalf of someone and information sharing preferences varied by culture. In a US based study of Korean immigrant community isolated by social and linguistic barriers, participants expressed preference in social media platforms for inquiring health conditions and sharing experiences (Park and Park, 2014). In another study of Americans aged 50 years and over towards colorectal cancer risk, African Americans and Latinos were slightly more likely to use social network sites to seek information compared to their White counterparts (Lumpkins et al., 2017). Whites, on the other hand, were more likely to use the Internet to seek health information and be informed by a physician about the risks. However, the National Cancer Institute's Health Information National Trends Survey found no racial/ethnic disparities in the use of social media for health communication (Huo et al., 2019).

3.4.3.2.3 Health literacy and perception towards healthcare provider

Health literacy

The relationship of health literacy amongst end users and their engagement with social media based health communication dissemination is complex, and digital literacy may not equate with active participation with social media. One study in the US observed that, enhanced participation on social media was positively associated with subjects who were eHealth literates, and, made greater use of specialised medical information like online medical journal articles (Li et al., 2014). In another US study, exploring the characteristics of orthopaedic patients attending a major centre, found that those who engaging with social media were likely to be younger and researched their condition prior to their appointment (Curry et al., 2014). In a recent study involving 1350 residents in New York State, a cross sectional telephone survey was undertaken to examine the relationship of health literacy With digital technology usage for health information (Manganello et al., 2017). The authors observed that self-reported health literacy did not predict digital technology use. However, subjects with low self-reported health literacy were less likely to use search engines, more likely to get health information from social networking sites and use health-related phone apps. Moreover, those with lower self-reported health literacy reported greater difficulty in finding their required health information, preferred text messages and radio to receive health information.

Perception towards a healthcare provider and health issue in consideration

Perception towards a healthcare provider or a health condition may influence engagement in health communication. Dissatisfaction with the current providers have been an important influential factor behind accessing social media base online health information (Li et al., 2014; Alhuwail and Abdulsalam, 2019). In another study, the influence of stories on human papilloma vaccination (HPV) circulating on the social media channels was explored in parents with adolescents eligible for HPV vaccination (Margolis et al., 2019). The authors observed that stories of harms more often came from social and traditional media, but stories of preventable diseases more often came from conversations. Parents exposed to stories about harms were less likely to have initiated the process, and more likely to have delayed or refused HPV vaccination. Processes influencing this perception may be different to what is conceived by the healthcare provider as was noted in one study. In evaluating credibility of cancer related information, caregivers of paediatric cancer survivors, ascertained this by assessing the user who posted the information, how frequent such information was shared and external corroboration (Gage-Bouchard et al., 2019).

3.4.3.3 Conclusions

Despite an extensive volume of research being performed exploring the determinants of user engagement with social media based health communication, it has been difficult to identify consistent themes and patterns. Rather, and quite confusingly through contradictory observations, research has made it somewhat difficult to comprehend what truly determines an effective user participation on social media for health related communication. In fact, what is acceptable to some, remains less preferred for some. Consistent with ethnographic research, the reasons behind this heterogeneity may be multifactorial that includes amongst many, varying contextual settings where these studies were conducted, variability in asking research questions and inconsistencies in the choice of outcome measures. Therefore, generalisation of findings from these variable body of research is rendered difficult. Nevertheless, an assessment of the possible factors through this review, has highlighted the complex and multifactorial determinants that may either independently, or in conjunction with other elements, influence end user participation in social media based health communication channels. Information gathered thus is expected to be incorporated in designing this study.

3.5 Chapter overview

Through this extensive review of current literature on the use of social media in health communication, it is apparent that information flows through complex channels in a bi-directional fashion between healthcare providers and end-users and across a range of domains (or themes). Furthermore, a detailed analyses of factors or determinants of user engagement with social media based health communication remains complex and confusing with no consistent pattern emerging. This may be related to study heterogeneity including varying contextual settings where these studies were conducted and variability in ascertaining research outcomes.

CHAPTER 4. Research Methodology

4.1 Introduction

The research methodology chapter sets the framework for conducting research and relates the types of methods and tools which will be adopted to help in answering the research questions. The initial step in undertaking any research project is the formulation of a research question (Bryman, 2007). The following section details the philosophical paradigms of social science research, research approaches, methods commonly undertaken and the choice between quantitative and qualitative research. The chapter then describes the choice and articulation of research questions, the rationale for a case study approach, study methodology, the approaches adopted, and the rationale. Subsequently, the chapter then moves on to describing data analyses , particularly thematic analyses of qualitative data and its stages. Finally, the methods ensuring research quality and ethical considerations are discussed.

4.2 Research philosophy (paradigms)

In common with many other disciplines, social science research is informed by broad philosophical outlooks, often referred to as research philosophies or paradigms. These influence the researcher's choice of the most appropriate approach to be undertaken to find answers to the proposed research questions. Every study is informed by specific worldviews or perspectives held by the researcher (Creswell and Creswell, 2018). A worldview is defined as "a basic set of beliefs that guide action" (Guba, 1990 p17). These 'worldviews' are also referred to as research 'paradigms' (Lincoln et al., 2017), which may be regarded as a broad framework comprising of perceptions, beliefs and understandings of theories and practices to undertake a research (Cohen et al., 2017). Paradigms are belief systems formed by ontological, epistemological and broadly conceived methodological assumptions (Guba et al., 1994). A research paradigm is a way of examining ad understanding and explaining social phenomena (Saunders et al., 2015). For the researcher, the choice of a paradigm establishes an approach to perceiving the world and determines how the data obtained is interpreted.

4.2.1. The ‘positivist’ paradigm

Also referred as the ‘scientific’ or the ‘hard science’ paradigm, the aim of positivist research is to prove or disprove a hypothesis (LeCompte and Schensul, 1999; Mack, 2010; Creswell and Ceswell, 2018). Stemming out from the belief that reality can be observed through senses, in positivistic research, the inquirer views a reality objectively (Mack, 2010). Positivist research is normally associated with a quantitative research approach. Underpinning this philosophy is the belief that reality is observable and comprehensible and that findings from a representative sample can be generalised to the whole population (LeCompte and Schensul, 1999; Mack, 2010). Positivists assume a well-defined conceptual and social detachment on the part of the investigator and this approach is considered to render the research ‘objectivity’ (LeCompte and Schensul, 1999; King and Horrocks, 2010). Researchers and participants refrain from being influenced by their own preconceptions and biases and from manipulating the research setting (LeCompte and Schensul, 1999; King and Horrocks, 2010). As it is presumed that personal values and preferences influence outcome, the methods adopted in positivist research are regarded as neutral and value free (LeCompte and Schensul, 1999). The scientist is an objective observer and everything possible needs to be done to avoid contamination of the research being conducted (LeCompte and Schensul, 1999).

From an ontological perspective, positivists believe in realism – that there is an detectable objective reality that is understood through natural laws and mechanisms (Guba et al., 1994; Anderson, 2013). They share a belief that there is tangible social reality that exists independent of those developing the reality (Guba and Lincoln, 2005) and that this is external to the investigator (Mack, 2010). From an epistemological perspective, positivists believe that knowledge is created from a theory or hypothesis (Mack, 2010). Only observable phenomena can provide credible facts and data this approach focuses on the phenomenon of causation (Saunders et al., 2015). The researcher and the object are independent of each other and the investigator can investigate without impacting or being affected (Guba et al., 1994; Guba and Lincoln, 2005; Anderson, 2013).

The research methodology adopted is experimental and manipulative, the questions asked are in a propositional manner and empirically tested for confirmation (Guba et al., 1994; Anderson, 2013). The research approach is quantitative, the variables are identified prior to undertaking the research and empirical tests confirm or refute the proposition (Guba and Lincoln, 2005).

4.2.2. The ‘interpretivist’ paradigm

Also known as the ‘phenomenological’ or ‘constructivist’ paradigm, this is a much preferred approach in philosophy, sociology and allied disciplines (LeCompte and Schensul, 1999). Arising from a theoretical perspective that proposes that the social realm cannot be studied with the scientific method of investigation applied to the natural world, interpretivists seek understanding by interpreting perceptions (Denzin and Lincoln, 2017). Regarded as a ‘contrasting epistemology to positivism’, it is ‘anti-positivist in nature (Mack, 2010). Interpretive research is aimed at ‘social construction of reality’ (LeCompte and Schensul, 1999) and the researcher aims to rely on individual’s beliefs of the situation being investigated (Creswell and Ceswell, 2018). In contrast to the positivist approach where findings are ‘true’ and may be ‘confirmed’ , interpretivists feel that ‘social constructions of individuals and groups are not more or less ‘true’ in an absolute sense, but simply more or less informed and/or sophisticated’ (LeCompte and Schensul, 1999). In this approach, constructs are not established, rather they change during communication or in time and these variations can cause different perceptions of realty and alternative forms of action (LeCompte and Schensul, 1999).

To interpretivists, culture is cognitive and affective and is ‘constructed’ as individuals communicate together in shared actions (LeCompte and Schensul, 1999). Interpretative meanings are ‘situated’; they are positioned in or influenced by societal, political and cultural background and by demographic considerations like ethnicity, age, gender and various other contextual attributes of people who embrace them as they influence their thinking, beliefs and presentation (LeCompte and Schensul, 1999). Therefore, the socio-political status of each participant has to be understood by the researcher before accepting their perspectives in the ‘web of meaning’ (LeCompte and Schensul, 1999). Instead of sharing ‘one story’ interpretivists utilise complicated accounts of poly-vocal texts and narratives as told by individual participants to build up a conclusion (LeCompte and Schensul, 1999).

One other key characteristic that differentiates interpretivists from positivists is their inherent participatory nature as meanings are only developed through communication – the investigator observes social dialogue and communication along with the process of developing constructs, thoughts and meaning of opinions as it happens (LeCompte and Schensul, 1999; Creswell and Ceswell, 2018). In this approach, the researcher is usually involved in asking more general questions and open ended questions so that the participants can relate to the research question and respond appropriately (LeCompte and Schensul, 1999; Creswell and Ceswell, 2018). Here, investigators and participants share equal positions and in effect, the researcher is part of the procedure. The findings thus obtained get developed and redeveloped as the investigations proceed; instead of starting from a theory, interpretivists create a theory (LeCompte and Schensul, 1999; Creswell and Ceswell, 2018).

Ontologically, interpretivists are relativists as this is socially constructed, subjective and that may change (Saunders et al., 2015). There are many realities as ‘realities exist in the form of multiple mental constructions, socially and experimentally based, local and specific, dependent for their form and content on the persons who hold them (Guba, 1990; Guba et al., 1994). These realities can be examined and established through communication and meaningful activities. The aim is to discover how individuals understand their social worlds in the natural setting through daily events, interactions and writings, while communicating with people around them (Anderson, 2013). Epistemologically, the approach is subjectivist where the researcher and object are merged into one being and results are developed based on communication between the two (Guba, 1990). The investigator relies on focussing on the details of a situation and the reality behind these details (Saunders et al., 2015). The inquirer and the participant are connected and the findings are shaped and developed with study progression and the conventional difference between ontology and epistemology disappears (Guba et al., 1994)

4.3 Research approaches – deductive and inductive

Research approaches may be described as ‘the plans and procedures for research that span the steps from assumptions to detailed methods of data collection, analysis and interpretation (Creswell and Ceswell, 2018). There are two primary approaches deductive and inductive (Saunders et al., 2015).

Deductive research is concerned with testing a hypothesis and exploring the causal relationships between variables using a highly structured methodology that in particular takes study reliability and validity into account (Saunders et al., 2015). Inherent in this approach is the assumption that the researchers and the research process are independent of each other and that facts derived must be quantitatively measured and generalised (Saunders et al., 2015). The five stages that underpin deductive research have been proposed as (Robson and McCartan, 2015):

1. Formulating a hypothesis from theory developed
2. Expressing the hypothesis in operational terms that proposes a relationship between two distinct concepts of variables
3. Testing the operational hypothesis
4. Examining the outcome of this enquiry
5. Modifying the theory (if necessary) in the light of this new knowledge

Inductive research, on the other hand, is involved in detailed understanding of what is actually happening in a specific context, organisation, process or an event (Saunders et al., 2015). In contrast to deductive research, inductive research necessitates the researcher to make empirical observations and collect data first and subsequently analyse data for patterns to derive at a theory. As the researcher is part of the research process, bias and preconceptions may be influential in dictating outcomes (Saunders et al., 2015).

4.4 Approaches to research in social science – quantitative, qualitative and the mixed methodology

Several research methods have been used in social science research that can be either quantitative, qualitative or mixed methods in approach.

Quantitative methods are often associated with the positivist research paradigm and involve techniques that emphasise measuring and counting, such as large scale surveys or experiments (Rubin and Rubin, 2012). Quantitative methods use 'standardised measures so that varying perspectives and experiences of people can be fitted into a limited number of predetermined response categories to which number are assigned' (Patton, 2002). Generally, quantitative research 'leads us to regard the world as made up of observable, measurable facts" (Glesne and Peshkin, 1992).

Qualitative research, on the other hand, uses an interpretative approach (Patton, 2002) and aims at illuminating, understanding and extrapolating data (Hoepfl, 1997; Golafshani, 2003). Qualitative research seeks to understand phenomena in context-specific 'real world' settings, that is not manipulated by the researcher (Patton, 2002). This approach is broadly defined as any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification (Corbin and Strauss, 2015). Instead, this type of research results in findings that arrive through real world settings where the phenomena of interest unfold naturally (Patton, 2002). Qualitative methods consist of systematically collecting, organising and interpreting textual material derived from conversation (interview) or observation (Malterud, 2001). The 'data tend to be continuous rather than discrete, and the emphasis is on description and explanation more than on measurement and prediction (Taylor and Trujillo, 2001). The researcher aims at developing explanations and examining the qualities of the communication phenomena (Malterud, 2001).

The third approach, a combination of both qualitative and quantitative methods, is used where an integration of qualitative and quantitative data is required or in situations where one method does not fully answer the research questions (Bryman, 2007; Teddlie and Tashakkori, 2009; Creswell and Ceswell, 2018). In this approach, quantitative data (performance tests, questionnaires, etc) is collected along with qualitative data (interviews, open ended questions, focus groups, observations or content analysis). The quantitative data undergoes formal statistical analysis resulting in a numerical representation. On the other hand, qualitative data gathered in this process, is analysed differently using qualitative data analyses methods. Therefore, In this mixed approach, the researchers are able to use all resources and collect comprehensive data that would have been otherwise, not possible for analyses using either a quantitative or qualitative method alone. This approach may result in a broader understanding of research topic. Additionally, this combined approach may add to the validity of the research process and render findings more generalisable.

4.5 Case studies in social science research

Case study design has been successfully used in social research and is concerned with the intensive examination of the complexity of a phenomenon in the setting of an organisation or a community (Bryman, 2016). Yin defines a case study as an empirical inquiry that investigates a contemporary phenomenon within its real life context, especially when the boundaries between phenomenon and context are not clearly evident (Yin, 2017). Yin argues that a case study research is useful when a 'how or why' question is being asked about a contemporary set of events over which the investigator has little or no control (Yin, 2017). Case studies support deeper and more detailed investigation of the type of research question that is normally necessary to answer 'how and why' questions (Rowley, 2002). In particular, single case studies are useful when little previous research has been conducted on a topic (Rowley, 2002).

4.6 Interviews for data collection in qualitative research

Various methods of data collection exist in qualitative research including face-to-face interviews, focus interviews (asking participants about a specific event or situation), focus group interviews (group interviews where several subjects discuss specific issues in groups), oral history interviews (participants recall and reflect on historical events) and life history interviews (exploring the biography of each participant) (Bryman, 2016). Interviews provide a rich insight into perspectives of participant's world and their points of view, beliefs, emotions and experience in real life situations that might otherwise not be captured (Hove and Anda, 2005). Such interviews have the potential to reveal the meanings ‘behind’ interviewee’s perceptions that cannot be directly measured or quantified (Patton, 2002).

4.7 Study Methodology

This research adopted a qualitative case study approach designed to generate rich insights. The following sections detail the rationale, the methodological stages in this research, the process of selecting and interviewing participants, the interview schedule and the process of conducting and recording of the interviews.

4.7.1 Rationale for adopting a qualitative methods approach for this study

This study aimed to explore the uses of, and challenges with, the use of social media (WhatsApp) as a vehicle for healthcare (eye health) communication. Deprived community members, neoliterate women facilitators, healthcare providers and community health advocates, came from a diverse range of backgrounds and held differing levels of confidence in taking part in the research process. It was anticipated that the members of the deprived community would be illiterate, socioeconomically isolated, research naïve and be nervous of the research process. Consequently, it was envisaged that understanding the opinions, beliefs and perspectives of all participants (healthcare providers, community health advocates and the members of the deprived community) is best achieved through a ‘situated’ interpretivist approach, as this would allow the researcher to explore the rich context and reality behind these findings whilst being part of the research process. Therefore, by adopting a less formal ‘friendlier’ approach, it was thought that the participants would trust the investigator, form a stronger relationship and more openly ‘unfold’ their own viewpoints. As the aim of this study was to explore and gain insights into the diversity of perspectives on WhatsApp usage in health communication, such an informal approach would have been more effective than a more ‘rigid’ and ‘formal’ positivist approach in delivering outcomes. Qualitative data was collected from open ended face to face semi-structured interviews and focus groups. Inherent to this interpretivist approach, a qualitative research analysis was undertaken to systematically collate and interrogate the rich data to derive at meaningful themes in an effort to explain the phenomenon of interest.

4.7.2 Research strategy - The ‘case study’ approach

In social research, case study design has been successfully used for an intensive examination of a complex phenomenon in the context of an organisation or a community. This study aimed to critically examine the complex phenomena of behavioural change associated with the WhatsApp mediated information dissemination platform, in a real life context. Additionally, the study sought to explore and understand key stakeholder perspectives on benefits and barriers in the establishment of a new form of communication. To understand these complex processes a case study based approach appeared much appealing. The ‘case setting’ comprised of the healthcare provider, community health advocates and the deprived community as the key stakeholders in their natural real world settings, and the processes of WhatsApp based information sharing on eyecare. It was envisaged that this approach was necessary to answer the ‘how and why’ questions posed by this research; the ‘how’ referring to the observed phenomenon of behavioural change post WhatsApp adoption, whilst the ’why’ attempting to explain the change.

4.7.3 Context of the study

This study was conducted in the village of Chowbaga and the metropolitan city of Kolkata, the capital of the eastern Indian state of West Bengal (Fig 4.1, 4.2 and 4.3). Nested in Ward 108 (Borough 12) of the Kolkata Metropolitan Development Authority (KMDA), the village of Chowbaga is situated in the eastern fringe of Kolkata Fig . As per the 2011 census, ward 108 had a total population of 64,777, of which 33,428 (52%) were males. Population under the age of 6 years was 7,204 with 46,487 individuals (80.74% of the population over 6 years) considered as literate (*District Census Handbook - West Bengal*, 2014). Kolkata (previously known as Calcutta) is the principal commercial, cultural, and educational centre of Eastern India. The Indian census of 2011 ranks it as the seventh most populous city in India with a population of 4.5 million whereas the Kolkata metropolitan area has a population of 14.1 million making it the third most populous metropolitan area in India (*Urban Agglomerations/Cities having population 1 million and above*, 2011; *Kolkata Metropolitan Development Authority*, n.d.). It has a population density of 24,306 / square km (*Bengal Facts and Figures - Egiye Bangla*, 2019). Recent estimates indicate the Kolkata metropolitan authority has a gross domestic product between $60 to $150 billion making it the third most economically active area in India (n.d.; Hawksworth et al., 2009; Parilla et al., 2015).

Figure 4.1. Political map of the province of West Bengal

Figure 4.2. Metropolitan map of Kolkata

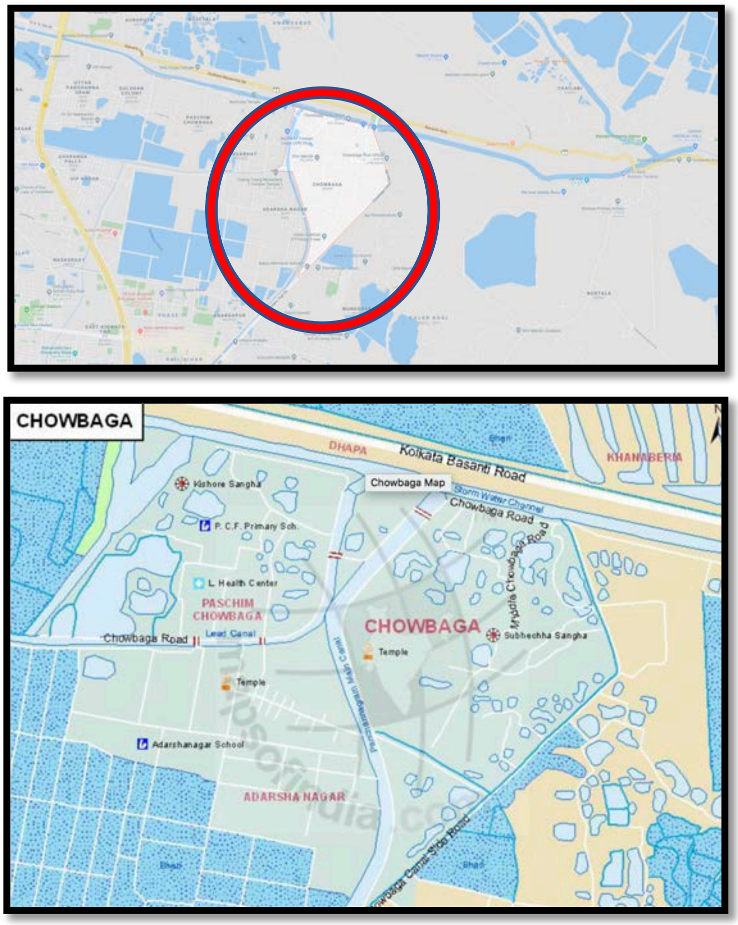

Figure 4.3. Area map of the location of study

Deprived community

The deprived community members belonged to a locality within the Chowbaga village, were below the poverty level (BPL) in their gross family earnings and were resident mostly in rented dwellings that were thatched or tile roofed houses or semi-permanent makeshift settlements. Education was low and unemployment was high. The male members of the community were mostly employed in low pay temporary jobs, particularly in the construction sector which made them characteristically mobile. Although electricity was available at homes, drinking water was sourced from outside the house, overcrowding was common and the toilet was shared. Vehicle ownership was low and was mainly restricted to owning bicycles. Public transportation links and the road infrastructure were considerably underdeveloped. Smart phone ownership was low and access to information on any health topic was through television, radio and wall-posters. There was a high burden of eye diseases in this deprived community. This was mainly in the form of unaddressed refractive errors, untreated cataracts, infections and injury. Although, there was a village medical unit providing basic medical care, the nearest specialist eye unit was based in the city of Kolkata, almost 5 miles away (more than an hour of bus journey). The tertiary eye hospital in consideration for this study (Susrut Eye Hospitals) was located almost 8 miles away (almost 1.5 hours on a bus journey).

Surya Kiran School (Kalyan Bharti Trust)

All members of the deprived community were recruited from the neighbourhood of a charitable school (Surya Kiran school) where their children attended. Situated in Chowbaga municipality ward, Surya Kiran School is an evening school dedicated for the needs of underprivileged children (*Suryakiran School*, n.d.). Surya Kiran school is funded and maintained by Kalyan Bharti trust, an NGO established as a public charitable foundation to promote and provide higher education in the country. Established in 2006, the school reflect the motto of Kalyan Bharti trust in promoting the cause of education in economically backward sections of the society. In addition to free education, children are provided with all essential items required for schooling and free nutrition.

The eye healthcare provider (Susrut Eye Hospital)

Susrut Eye Hospitals (shortly Susrut) is a tertiary provider of comprehensive eye care to the city of Kolkata and beyond (*Susrut Eye Foundation and Research Centre*, n.d.). Headquartered in Kolkata as a not for profit organisation, it has seven other satellite branches in different geographical locations delivering a varying level of eye care. Recent estimates (June 2019) indicate that Susrut attends to the needs of around 1000 patients per day in the outpatient department and 100 patients are managed on an average as inpatients (*Susrut Eye Foundation and Research Centre*, n.d.). Alongside the provision of hospital based clinical care, Susrut is involved in a variety of community based eye care projects that is available to individuals belonging to any socio-economic background. This involves organising free for all eye examination clinics in the community that includes vision screening, spectacle dispensing and referral to hospital for further investigations and surgery (*Susrut Eye Foundation and Research Centre*, n.d.). Working under the directives of the National Programme for Control of Blindness, Government of India (*National Programme for Control of Blindness, Ministry of Health & Family Welfare, Government of India*, n.d.; Vemparala and Gupta, 2017), many of these projects are delivered by Susrut through its close association with partner organisations like Vision2020 (‘VISION2020,’ n.d.), SightSavers India (*Sightsavers India*, n.d.), Orbis (Putty, 2019), Koshika Foundation (*Koshika Foundation - Building block of life*, n.d.) and HelpAge India (*HelpAge India*, n.d.).

Venue of conducting the study

Members of the deprived community were interviewed at the Surya Kiran School, where the educational sessions and the assessment session were also conducted. The healthcare providers were interviewed at the premises of the Susrut Eye Hospital during working hours. The community health advocates were interviewed at a time and venue that varied according to the individual needs of the participants.

4.7.4 Selection of participants

As with any qualitative study, choosing the number and type of participants was an integral and important part of research planning. Unlike random selection of participants in quantitative studies, the qualitative methodology of this study allowed participants to be carefully chosen through purposeful sampling (Patton, 2002;

Rubin and Rubin, 2012). The emphasis was on quality and usefulness of data whilst keeping the participant numbers balanced.

This study sought to explore a diversity of opinion from a wide range of users as this was considered relevant in understanding the possible uses and challenges of WhatsApp in healthcare communication. It was intended to capture the perspectives of health care providers and the deprived community separately. ***Healthcare providers*** comprised of a diverse range of professionals who were based at the tertiary hospital (Susrut Eye Hospital) and involved in the delivery of eye care. The ***deprived community members*** belonged to a group of socioeconomically challenged populace resident at the fringe of the city, all of whom were considered to be below the poverty line. Deprived community members, were identified from the parents whose children attended the Surya Kiran school, the list being provided by the school authorities. Additionally, this study was keen on understanding the views and opinions of the ordinary people representative of the general population, who were not affiliated to the healthcare providers, did not possess specialist knowledge on the topic of research and who did not belong to the deprived community. These ***community health advocates*** represented the views of the general population on issues surrounding eye health and formed the third group of participants to be interviewed. Potential participants were shortlisted and approached for further formal face to face interview.

In an effort to enrich the quality of research, and to understand the diversity of opinions and perspectives, a variety of professionals within each major group (healthcare providers, community health advocates and deprived community) were chosen. It was envisaged that ten participants, each from the healthcare provider and community advocate groups, was a reasonable number to attain to gain a broad perspective of views and opinions. For the deprived community group, the aim was to recruit up to 30 willing participants who would be representative of the whole community. The healthcare providers group included higher managerial staff, doctors, nurses, optometrists, pharmacists and allied healthcare professionals. The list of potential participants were provided by the Susrut Eye Hospitals for the purpose of this research. For the community health advocates group, the aim was to include participants from a wide range of professions that included academics, journalists, teachers, social workers, government officials and those who had experience in working with deprived communities. These participants were identified through the researchers prior acquaintances and recommendations from the community health advocates themselves.

Persons interviewed

Ten members from the healthcare provider group (Susrut Eye Hospitals) participated in providing their opinions and perspectives through semi- structured interviews (Appendix A). This group comprised of the Chief Executive Officer (CEO), Chief Operating Officer (COO), two Consultant Ophthalmologists, two Specialist Nurses, one Optician, a Specialist Pharmacist and two Senior Managers (Table 4.1). This process was staggered over a month as it was difficult to get the opinion of all participants in one setting because of individual time commitments. Ten community health advocates participated in this study; this group comprised of an University academic, two high school headteachers, a social worker, two head of local non-governmental social care organisations (NGOs), a journalist, a financial advisor, a government official and a community doctor (Table 4.1). Their opinions and perspectives were explored through semi-structured interviews (Appendix B). The timings and venue of interviews varied according to the individual needs of the participants. Overall, 35 parents whose children attended the Surya Kiran School, initially consented in taking part in this study but subsequently, 5 parents dropped out citing work related commitments. The final study population comprised of 30 women (Table 4.1). Basic demographic data on the deprived community members were obtained through a data capture sheet (Appendix C) and post study, opinions were explored through a focus group interview (Appendix D).

Through pre-arranged sessions with the potential participants from all the three groups, the researcher explained in simple and local language about the study's aims and objectives, the duration of the study and required commitment. For the participants from the deprived community, one-to-one sessions were also undertaken by the researcher to ensure that the participants had fully comprehended the study. Once the researcher felt happy about the participant's understanding and willingness to take part, written and verbal consent were obtained (More details on Ethical Considerations section 4.11).

Participant Code	Participant Group	Occupational Role
HCP 1	Healthcare Provider	CEO, Chief Executive Officer
HCP 2	Healthcare Provider	COO, Chief Operating Officer
HCP 3	Healthcare Provider	Consultant Ophthalmologist
HCP 4	Healthcare Provider	Consultant Ophthalmologist
HCP 5	Healthcare Provider	Specialist Nurse
HCP 6	Healthcare Provider	Specialist Nurse
HCP 7	Healthcare Provider	Optician
HCP 8	Healthcare Provider	Specialist Pharmacist
HCP 9	Healthcare Provider	Senior Manager
HCP 10	Healthcare Provider	Senior Manager
CA 1	Community Health Advocate	University academic
CA 2	Community Health Advocate	Headteacher
CA 3	Community Health Advocate	Headteacher
CA 4	Community Health Advocate	Social Worker
CA 5	Community Health Advocate	Head of NGO
CA 6	Community Health Advocate	Head of NGO
CA 7	Community Health Advocate	Journalist
CA 8	Community Health Advocate	Financial advisor
CA 9	Community Health Advocate	Government official
CA 10	Community Health Advocate	Community doctor
CSP 1	Community Study Participant	Local resident, homemaker
CSP 2	Community Study Participant	Local resident, homemaker
CSP 3	Community Study Participant	Local resident, homemaker
CSP 4	Community Study Participant	Local resident, homemaker
CSP 5	Community Study Participant	Local resident, homemaker
CSP 6	Community Study Participant	Local resident, homemaker
CSP 7	Community Study Participant	Local resident, homemaker
CSP 8	Community Study Participant	Local resident, homemaker
CSP 9	Community Study Participant	Local resident, homemaker
CSP 10	Community Study Participant	Local resident, homemaker
CSP 11	Community Study Participant	Local resident, homemaker
CSP 12	Community Study Participant	Local resident, homemaker
CSP 13	Community Study Participant	Local resident, homemaker
CSP 14	Community Study Participant	Local resident, homemaker
CSP 15	Community Study Participant	Local resident, homemaker
CSP 16	Community Study Participant	Local resident, homemaker
CSP 17	Community Study Participant	Local resident, homemaker
CSP 18	Community Study Participant	Local resident, homemaker
CSP 19	Community Study Participant	Local resident, homemaker
CSP 20	Community Study Participant	Local resident, homemaker
CSP 21	Community Study Participant	Local resident, homemaker
CSP 22	Community Study Participant	Local resident, homemaker
CSP 23	Community Study Participant	Local resident, homemaker
CSP 24	Community Study Participant	Local resident, homemaker
CSP 25	Community Study Participant	Local resident, homemaker
CSP 26	Community Study Participant	Local resident, employed
CSP 27	Community Study Participant	Local resident, employed
CSP 28	Community Study Participant	Local resident, employed
CSP 29	Community Study Participant	Local resident, employed
CSP 30	Community Study Participant	Local resident, employed

Table 4.1. Coding of the study participants

4.7.5 Neo-literate women facilitators

WhatsApp use was facilitated by the creation of a select group of local women trained in the use of information usage on WhatsApp to disseminate healthcare information related to eye health (neo-literate women). Chosen from the local community, these women were well-placed to understand the needs and challenges facing the community, and, were selected for their approachability. Three individuals belonging to the neighbourhood of the study population were identified to play the role of neo-literate women but one dropped off citing personal inconveniences. These two women were educated up to higher secondary level (A level), were in their mid-twenties and were willing to be trained in the basics of eye care by the provider institution Susrut Eye Hospitals. As neither had any background in health sciences, focussed training was organised on an individual basis by Susrut Eye Hospitals, with the researcher providing them with the necessary non–medical support, including the provision of smart phones for the use of this study. The neo-literate women advocates were specifically trained by the Susrut Eye Hospitals in the WhatsApp based delivery of specialised medical content to the target audience in prearranged educational sessions (Section 4.7.11) . Altogether 5 educational sessions were organised by Susrut Eye Hospitals, mediated by the neo-literate health advocates and facilitated as a two way communication by the researcher. The neoliterate women remained in close contact with the deprived community, Susrut Eye Hospitals and the researcher all throughout the study.

4.7.6 The case for face to face semi-structured interviews

This study involved exploring the opinion, beliefs and perspectives of the participants in considerable detail to gather rich insights within the real life context. Semi-structured face to face interview using *a priori* questionnaire was chosen as the method of choice for collecting research data. Semi structured interviews offered the flexibility to holistically capture the participant's views and perspectives about the usages and challenges of WhatsApp as an effective healthcare communication tool. This flexible approach without predetermining participant thoughts, allowed the interviewer to remain on the topic whilst exploring laterally for relevant and emergent topics (Hove and Anda, 2005).

Healthcare providers and community health advocates were interviewed once at the outset of this study but the participants from the deprived community were interviewed twice; at the outset and finally at the time assessment of learning outcomes and behavioural and attitudinal changes post WhatsApp intervention. An ‘interview schedule’ was designed flexibly to optimise capturing detailed qualitative data with due consideration to flow of conversation whilst remaining focused on the subject of interest (Appendices A, B and C). The interview schedule was carefully designed to help with the interview process which was designed to obtain relevant information and insights in an orderly and logical fashion whilst keeping the flow of conversation uninterrupted (Cohen and Crabtree, 2006). Although written in English, the language was kept deliberately simple so as to be easily comprehensible to the interviewees, many of whom had limited English language skills, but questions were also translated into Bengali, the native language of the deprived community (Bryman, 2016). Ambiguity and theoretical terms were minimised as much as possible to avoid participant confusion (Bryman, 2016) and to maximise their level of participation and the usefulness of their responses. There was also scope for the interviewer to marginally deviate from the interview question sequence when the opportunity arose for encouraging further elaboration in response to a specific question (Cohen and Crabtree, 2006; Bryman, 2016). The number of questions asked, the way in which they were asked, and their order were adapted as the interviews progressed taking into account interviewee’s responses (Bryman, 2016).

The interview schedule was broadly based under three to four sections. For the healthcare providers and community health advocates, the first section asked about their demographical data including social media usage (quantitative data) whilst the second section explored their understanding of eye health promotion in India using social media (qualitative data). The final sections explored their opinions about the type of information that was to be shared with the deprived population (qualitative data). For the healthcare providers, there was an additional section that explored communication between the healthcare providers and the deprived community (qualitative data). For the deprived community, demographic data (quantitative data) on health information resources were collected initially. The learning outcome assessments and behavioural / attitudinal changes (qualitative data) was collected from focus group interviews on members from the deprived community and intended to explore the now ‘new’ knowledge and perspectives of the members of the community about healthcare communication through WhatsApp technology. Consequently, the interview schedule for this final assessment of learning outcome encompassed a different set of questions (Appendix D).

4.7.7 Pilot interviews

The interview schedule was piloted on three participants (who were subsequently excluded from the final research analysis), and finer adjustments were rendered for subsequent use in the study. This pilot study was considered necessary to improve the overall interview process and probe further areas that were considered relevant and interesting to the proposed research questions.

4.7.8 Conducting interviews

The intention of this study was to conduct face-to-face interviews of participants in three major groups. For the sake of consistency and repeatability of data, it was intended that the researcher herself interviewed all participants. It was anticipated that the majority of the participants, including medical professionals, would be naïve to research principles and be somewhat apprehensive of the processes involved. Before commencement of the interview, the potential participant was introduced to the researcher, the study subject in consideration, the academic institution supporting this (Manchester Metropolitan University) and the processes involved. Participants were given sufficient time to ask questions and allay anxieties and were informed about the voluntary nature of their participation and that they were free to terminate the interview process at their will at any time they considered necessary. Additionally, the issues of confidentiality and data protection was also highlighted. Written and verbal consent was obtained and the whole interview process was recorded on a voice recorder for the purposes of transcription. That this recording was only for research purposes was made clear to the participants at the outset.

It was the intention of this study that the researcher / interviewer would be non-judgemental and sensitive whilst facilitating the interview process (Hove and Anda, 2005). The interviewer expressed a genuine interest in the interview process by careful attentive listening, maintaining eye contact and asking follow up questions

(Hove and Anda, 2005). The use of leading questions was avoided as much as possible as the same may lead to biased responses (Lewis, 2009). Participants were encouraged to talk freely and introduce more ideas, comments and opinions. Where ambiguity existed or the answer provided was not clear, questions were repeated to ensure that the respondent understood them.

Providers of healthcare information on eye health were the first group to be interviewed. As it was anticipated that most healthcare providers would have spare time in their workplace setting, the interviews were conducted in a designated section of the tertiary eye hospital (Susrut Eye Hospitals). It was also perceived to be logistically convenient for the participants to attend the interview sessions whilst carrying on with their busy schedule. This approach was also anticipated in enhanced participant engagement, thereby adding to the comprehensiveness and quality of the data being collected. On the other hand, the community health advocates were anticipated to have varying availability and hence the interviews were timed flexibly to best suit their needs. Such interviews happened at their work place or at a venue of mutual convenience within or outside of normal office hours. For the participants from the deprived community, a completely different approach was undertaken. All interested participants were requested to attend the school premises of Surya Kiran School for the purpose of the first interview, the educational sessions and the final interview to assess learning outcomes. The reason behind choosing this venue related to their familiarity with this school premises (as their children attended there on a regular basis). By allaying study related apprehension and increasing the comfort of unfolding in relaxed surroundings, this approach anticipated to enhance participant engagement and enrich the quality of data from a traditionally shy community.

4.7.9 Recording of interviews

Recording the interview process is an essential component of good research and it is integral to the accuracy and objectivity of the information gathered in the study (descriptive validity). Audio interviews have been associated with increased richness of detail and more accurate information whilst loosing little relevant information (Hove and Anda, 2005). Audio transcripts are important in coding the information and quoting exact and specific examples (Hove and Anda, 2005). On the other hand, serious limitations of this way of recording information relates to technical issues like battery failures, muffled and interrupted recordings and the possibility of loss of data on transfer to a computer or even repeat recording on existing recorded data. Moreover, the most important shortcoming of audio recording relates to the tedious nature of transcribing the recorded data. It is estimated that one hour of tape recorded data takes around eight hours to transcribe and results in a significant increase in work load on the researcher (Hove and Anda, 2005). Consequently, a mixed approach was undertaken whereby a mixture of 'ticked', 'pencilled' (by the researcher) and 'audio data' was recorded for each participant. A Phillips Digital Audio recorder was used for the recording of interviews in this study.

4.7.10 The rationale for choice of WhatsApp

WhatsApp, is a freeware that allows cross-platform messaging and Voice over IP (VoIP) services. WhatsApp allows users to send text messages and voice messages, make voice and video calls, and share images, documents, user locations, and other media (*WhatsApp Features*, 2020). Although primarily accessed from mobile devices, WhatsApp allows accessibility from a desktop as long as the user's mobile device remains connected to the Internet while they use the desktop app. The popularity of WhatsApp has grown significantly in India over the last few years. India has the highest number of WhatsApp users, estimated to be 340 million, (*WhatsApp*, 2019). Almost 30 % of WhatsApp users report using it on a daily basis and estimates suggest that its penetration level is 28% of the population. Significantly, 39.1% of WhatsApp users in the rural communities, spends between one and two hours on a daily basis (2018 estimates) thereby making it a popular social media in these communities. Certainly, its audio-visual message carrying capabilities and it's ability to support textual, telephonic and video consultations, makes it a suitable platform of choice for healthcare provider providing eye care information. From the deprived community perspective, widespread availability (deeper penetrance into these communities than other social media platforms) and free accessibility on mobile devices provides an attractive option. This formed the rationale of choosing WhatsApp over other social media platforms for disseminating eye care information.

4.7.11 Educational sessions for dissemination of eye health information through WhatsApp

The aim of the study was to explore the nature of behaviour change in the deprived community resulting from the adoption of WhatsApp as the healthcare communication portal on eye care. WhatsApp based eye care information was shared by the healthcare providers to the deprived community in educational sessions and this process was facilitated by neo-literate women advocates. The information flow in these educational sessions are described in the schematic diagram (Fig 4.4).

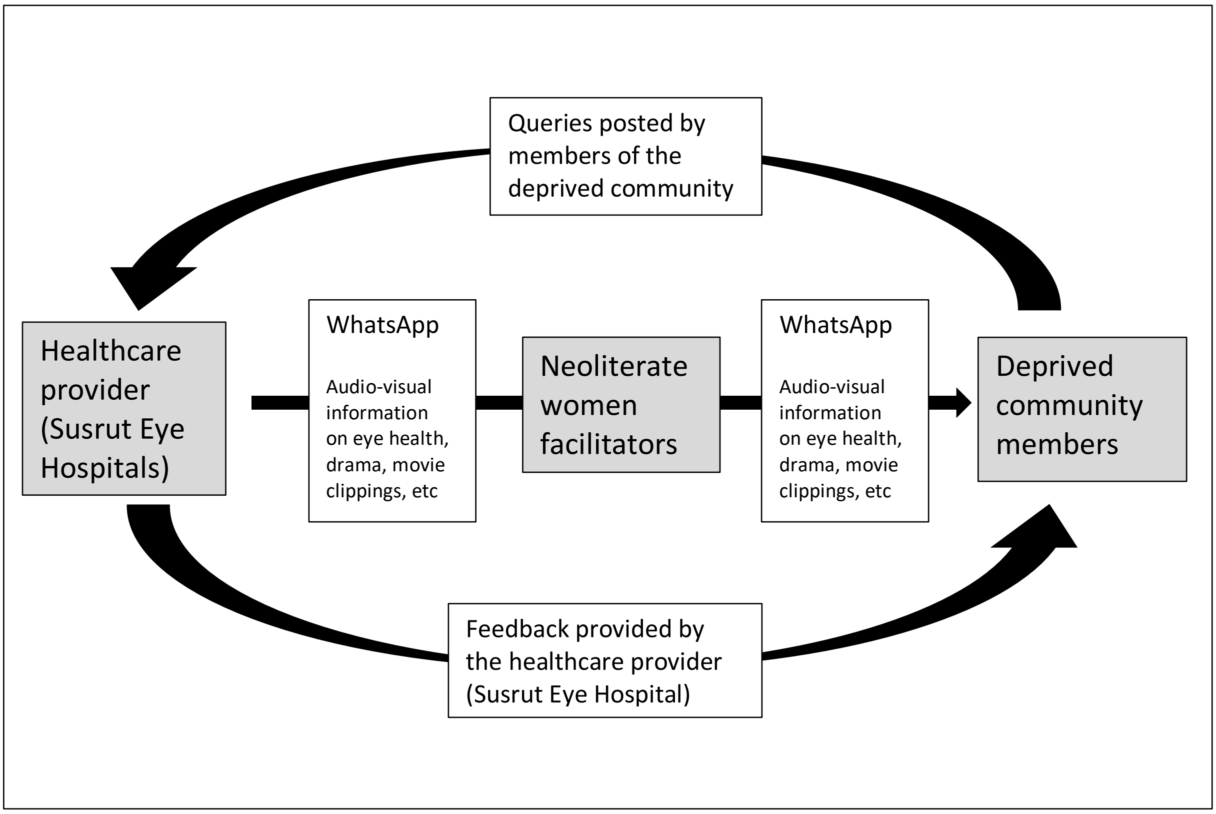

Figure 4.4. Schematic diagram of flow of information in the individual educational sessions

These educational sessions allowed the researcher to interact with the members of the deprived community in an effort to gain valuable insights into their perspectives and also address their queries (qualitative data). In order to achieve this, native language-based, easy to understand, relevant, and tailormade eye health related audio-visual information was prepared by the healthcare provider (prepared by doctors at the Susrut Eye Hospitals). Information provided in these educational sessions included routine preventative eye care, common eye diseases, eye donation, and suggestions regarding pathways for eye related emergencies. This was achieved through a variety of learning materials including pictures, videos, audio clips and remote based direct interactive communication that was shared across the WhatsApp platform. Quite commonly, storytelling was used as a pedagogic method to get the message across to the informal adult learners belonging to the deprived community. For example, one such story related to a conversation between two members of the deprived community (voiced up by the healthcare providers) discussing the benefits of routine eye check in children. Storytelling is a well-established pedagogic method in adult learning (Caminotti and Gray, 2012). The researcher also ensured that the audio visual educational material for information dissemination was tailor-made to suit the needs and understanding of the deprived community. The language used was colloquial Bengali but occasional medical terms were narrated in English. Words and narration were deliberately kept simple and were carefully tailored to ensure that they were accessible to learners.

This educational material was subsequently disseminated to the deprived community through multiple community based educational sessions. These sessions involved attendance of the neo-literate health advocates from Susrut Eye Hospitals and the members of the deprived community in a chosen venue (Surya Kiran School). The sessions were conducted in the afternoons as it was expected that this would allow most members to be free for a short while whilst their children were in school. A very large class room was made available for this purpose. The neo-literate advocates had access to four smartphones which were used for the purpose of delivery of educational material. Participants usually sat in groups around the neo-literate advocates to allow them to access the multimedia content. As per the study protocol, the chosen platform for information delivery was WhatsApp. On an average, each session lasted for 30 minutes which included a playback of a variable length audio-visual document covering all aspects of eye health. Participants were actively encouraged to ask questions and any queries generated were fed back to the provider in real time through the same social media platform.

Altogether, five educational sessions were conducted between Susrut Eye Hospitals and the members of the deprived community over a period of five months. Each session was attended by the same 30 members of the deprived community (Table 4.2).

First session: involved a brief introduction to the project, the team involved, an outline of forthcoming educational sessions and an introduction to the concept of good eye care and consequences of blindness and eye diseases. This session commenced with a story of an individual who met with an accident as a consequence of an explosion involving a cooking stove. The story narrates how proper and affordable treatment of the affected eye was made possible through the availability of a state health insurance plan.

Second session: Through a narrative drama, this session introduced the benefits of regular eye check-ups – where available and for whom, at what age and for any special groups, when and how often such checks would be necessary, and where further information can be found. This session specifically highlighted the need for eye checks in certain age groups and familial, social or occupational circumstances where there is an enhanced exposure to hazards. It also emphasised the existence of governmental free-to-access eye care health check-up clinics that may be particularly relevant to the participants.

Third session: Through a narrative audio drama, this session aimed to introduce the audience to the importance of good eye health in children, the type of hazards that can affect eye-health in children, common and prevalent childhood eye diseases, early warning signs of impending eye problems in children, the precautions that need to be taken by the parents to prevent such calamities from happening, with specific reference to socio-cultural prejudices. This session talked about the steps that need to be taken to promote good routine eye care and mitigate against preventable eye diseases. It signposted the audience as to where to seek help locally, and specifically talked about the role of good antenatal and perinatal care including new-born eye screening checks for early detection of eye problems.

Fourth session: Again through a narrative audio drama, this session introduced the audience to common eye disorders that affects adults, their triggers and specific home and occupational related eye-health hazards, and the contribution of other coexisting common medical conditions like diabetes and hypertension. The session also highlighted the role of good nutrition, a clean environment and a healthy life style as important adjuncts to good preventative eye care. This session also covered: the early warning signs of eye diseases and how to detect them; how an early medical input can prevent disease progression and vision loss; and, signposted the participants to locally available affordable healthcare and where to seek further information, both routine and in a crisis.

Fifth session: The final session covered the importance of posthumous eye donation through drama and a short video. This session sought to dispel the cultural and social negativity towards eye donation that is considered as the biggest barrier to eye donation in India. It signposted the participants to further information about eye donation.

Table 4.2. Educational session content

4.7.12 Assessment session

Post completion of the five educational sessions, participants were invited to attend an assessment session. This intended on exploring the change in eye health behaviour as a result of the implementation of information dissemination through WhatsApp. This was achieved through a focus group interview and was conducted over an hour where the participants were encouraged to ask questions (Fig 4.5). The researcher was involved in asking a number of questions aimed at understanding the impact of this information. Specifically, questions were asked about the benefits of this strategy, whether this helped in making the deprived community understand the need of good eye care and where to seek help when required. Finally, challenges anticipated in the implementation of this strategy was also explored. The objective of this research stage was to understand the learning processes associated with accessing WhatsApp, information gathered and benefits realised, the extent of word of mouth in assimilating this new advice and their future use intentions. Changes intended by the community that resulted from their interactions with the app and their perceptions of the challenges associated with its use were also explored in this session. This stage of the research formed the basis for the framework of the behavioural change associated with the adoption of WhatsApp and provided a conceptual framework of the types of challenges associated with its adoption for eye health.

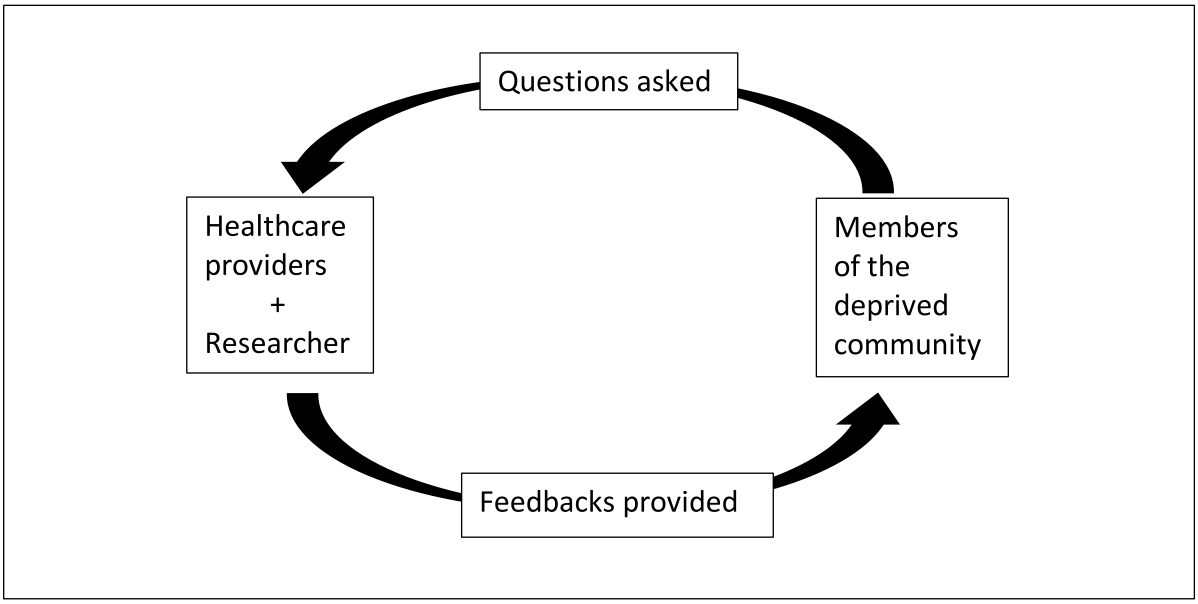

Figure 4.5. Assessment session

4.8 Data analysis

This section details the theoretical basis of analysing qualitative data and also provides the rationale for adopting a style for this style. Qualitative data analysis is associated with working with the data, organising and breaking them into manageable units, subsequently, coding and synthesising them whilst searching for patterns (Bogdan and Biklen, 2007). Broadly speaking, qualitative analyses involves one of the three main methods; content, thematic and theoretical (Braun and Clarke, 2006). In content analysis, commonly used to analyse communication, categories are developed, and the data set is systematically evaluated for contents that associate with those predefined categories and statistical analysis follows (Hambrick et al., 2010). The technique is achieved by any qualitative and sense-making effort that interrogates a volume of qualitative material in an effort to identify core consistencies and meanings (Patton, 2002). In thematic analysis, the primary focus rest on units of data (words, phrases, sentences or paragraphs) that relates to a meaningful concept, and a 'particular code' is then generated (Patton, 2002). Subsequently, these codes are extracted and carefully scrutinised for emerging themes that would undergo further refinement and finally, would result in the generation of a collative and meaningful report (Patton, 2002). On the other hand, theoretical analysis, involves testing theories that emerge against existing literature, or, from conducting data analysis (Patton, 2002). As this research explored a diverse range of opinions on the use of WhatsApp in healthcare communication in an interpretative perspective, an approach based on thematic analysis of qualitative data was considered more suitable in understanding key themes. This choice of analytical method also received support from the previously undertaken systematic review of the current literature.

Analyses of preliminary data from the pilot interviews allowed a priori fine tuning of the interview questions before the initiation of the final stages of the study. Analysis of pilot interviews was based on the same rationale for the subsequent stages of the study and was driven the interviewer's interest in answering the research questions before the final interviews. It also allowed the researcher to start the process of analysis early on in an effort to continue refining and improving data collection approaches. Additionally, this preliminary analysis was also instrumental in hinting at themes representing the 'core meaning' of interviewee's perspectives in the context of phenomenon under investigation. Finally, these interviews prepared the researcher to appropriately undertake a thematic analysis that is also the most widely used qualitative analysis of method (Braun and Clarke, 2006).

The remainder of the section describes the theoretical process of thematic analysis in the context of social research and its application to this study.

4.8.1 Thematic analysis – Theoretical basis and the rationale for choice in this study

Widely used in social research, thematic analysis is often regarded as the foundational method in qualitative analysis that provides core skills that may come useful in conducting many other forms of qualitative analysis (Braun and Clarke, 2006). Braun and Clarke further describe thematic analysis as “a method for identifying, analysing and reporting patterns (themes) within data. It minimally organises and describes your data set in (rich) detail” (Braun and Clarke, 2006 p.79). As it shares generic skills across qualitative analysis, it may be considered not as a specific method, but as a tool to use across different methods (Boyatzis, 1998). However, thematic analysis may be considered a method in its own right as has been argued by some (Braun and Clarke, 2006). Thematic analysis is essentially independent of pre-existing theory and epistemology, and can be applied across a range of theoretical and epistemological approaches that makes it a powerful but flexible tool (Braun and Clarke, 2006). Through its theoretical freedom, thematic analysis can potentially provide a rich and detailed, yet complex, account of data. Often identified as a realist/experiential method for being based on interviewee’s perspectives, experiences, reality and meanings (Aronson, 1995; Roulston, 2001), thematic analysis can also be viewed as a constructionist method, which examines the ways in which events, realities, meanings, experiences and so on are the effects of a range of discourses operating within society (Braun and Clarke, 2006). On the other hand, thematic analysis can also be a ‘contextualist’ method, that sits between essentialism and constructionism, that acknowledge ways individuals make sense of their experience, and, in turn, is influenced by the broader social context, while retaining focus on the material and other limits of ‘reality’. Therefore, “thematic analysis can be a method that works both to reflect reality and to unpick or unravel the surface of reality” (Braun and Clarke, 2006).

However, in an effort to increase transparency, there is a strong argument for stating the theoretical position of a thematic analysis in a given research setting at the outset, to comprehend the assumptions about the nature of the data collected and they truly represent in terms of 'the world' or 'reality'.

In thematic analysis, it would be anticipated that the process would ultimately results in generation of themes through the process of coding but what counts as a theme? According to Braun and Clarke, " a theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set" (Braun and Clarke, 2006). Given the qualitative nature of analysis, there are no stringent rules as to what constitutes themes in terms of actual prevalence across the data set and researcher judgement is necessary to determine what a theme is and there is an argument in favour of 'flexibility' over 'rigidity'. It is also important to comprehend that the 'keyness' of a theme is not necessarily reliant on quantifiable measures, rather on the assumption that something important in relation to the overall research question has been captured. Braun and Clarke argue that there is no right or wrong method for determining prevalence of a theme and the implicit flexibility of thematic analysis allows theme determination (and prevalence) in a number of ways: it is important that the researcher is consistent all throughout the analysis (Braun and Clarke, 2006).

In thematic analysis, patterns or themes may be identified in one of two primary ways: an inductive or 'bottom up' approach (Frith and Gleeson, 2004), or in a theoretical or deductive or 'top down' approach (Hayes, 1997; Boyatzis, 1998). The inductive approach is strongly driven by data but not guided by the researcher's theoretical interest in the area or topic and themes identified may bear little relation to the specific questions asked of the participants (Braun and Clarke, 2006). In other words, this approach involves coding data without trying to fit it into a pre-existing coding frame, or the researcher's analytic preconceptions. On the other hand, a 'theoretical' thematic analysis is driven by the researcher's theoretical or analytic interest in the area, and consequentially analyst driven . Unsurprisingly, this approach is associated with less richer description of the overall data with more detailed analysis of some of its aspects (Braun and Clarke, 2006).

For this study an inductive approach was undertaken. Understanding of the existing literature about the uses of social media in healthcare communication and experience from conducting the pilot interviews were fundamental in developing an understanding of expected themes from these interviews. However, as the researcher was keen on understanding the broad range of factors behind the uses and challenges of WhatsApp based communication, an inductive approach appeared more appealing as that would have allowed new themes to emerge providing further insight.

4.8.2 Conducting the analysis

Acknowledging that there are many different approaches in conducting thematic analysis, this study followed the six phase guidance developed by Braun and Clarke that remains widely cited for this type of social research (Table 4.3) (Braun and Clarke, 2006). It was perceived that this step-by-step guidance would be helpful for the researcher to analyse the rich data in considerable detail. The following section describes the phases of thematic analysis in the context of this study. These phases encompass 'familiarising with the data' (Section 4.8.3), "generating initial codes' (Section 4.8.4),'searching for themes' (Section 4.8.5), 'reviewing themes' (Section 4.8.6), 'defining and naming themes' (Section 4.8.7) and 'producing the report' (Section 4.8.8). It has to be noted here that this analysis is not a 'linear' one in moving from one phase to the next one, rather a 'recursive' one, where movement is back and forth as needed, throughout the phases, thereby allowing considerable flexibility (Braun and Clarke, 2006). In this study, these guidelines were used not as rigid rules but applied flexibly to fit the research questions and data (Patton, 2002). Thematic analysis commenced in phase one, and did not stop until the end of the process, with the researcher moving back and forth throughout the phases and across the empirical data (Braun and Clarke, 2006).

Steps	Phase	Description of the process
1	Familiarizing yourself with your data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas
2	Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code
3	Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme
4	Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis
5	Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme
6	Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis

Table 4.3. Braun and Clarke's (2006) phases of thematic analysis (Braun and Clarke, 2006)

4.8.3 Familiarisation with data

This is the first phase in thematic analysis whereby acquired 'data is transcribed (when necessary), read and re-read whilst noting down initial ideas' (Braun and Clarke, 2006). Often regarded as the key stage of data analysis, verbal data is transformed into a written form as "an interpretative act, where meanings are created, rather than simply a mechanical act of putting spoken sounds on paper" (Lapadat and Lindsay, 1999). The process of transcribing may be tedious and boring, but it also allows the researcher to deeply familiarise themselves with the data. Various methodologies exist for transcribing spoken text to their written versions, however, as a basic prerequisite, transcribing requires a rigorous and thorough process of capturing "orthographic transcript - a 'verbatim' account of all verbal (and sometimes nonverbal) utterances" (Braun and Clarke, 2006). Importantly, the transcript should retain the information needed (from the verbal account), and is a 'true; representation of the original nature suited for the purpose of analysis (Edwards and Lampert, 1993; Poland, 2002). A detailed review of the data allows the researcher to develop a deeper understanding of the data, where notes are taken and ideas are marked for further coding purposes (Braun and Clarke, 2006).

Familiarity with the existing published literatures, informed the researcher of the issues related the use of social media in healthcare communication. This allowed the researcher to anticipate some ideas about what to expect from these interviews. As the researcher was personally involved in conducting the interviews, a deep familiarity of the perspectives, commenced at the early stages of data collection process. The verbal data was then translated to English and manually transcribed by the researcher and this process, although painstakingly slow, allowed the researcher to understand the data in a deeper context. Nevertheless, this ensured that the data transcribed was contextual, rich and true to its content. Interviews were transcribed on more than one occasion, carefully looking for any missing data whilst maintaining the accuracy of the transcript. Although the process was time consuming to start with, subsequently, it became relatively faster due to the experience gained in the process. Transcription followed a standard style for all respondents. Simultaneously, during the process of transcription, the researcher continued to make notes and to record her ideas and inferences, whilst going back and forth to the source data. Fig 4.6 provides an extract from an individual transcript from this study.

Please give your opinion of using WhatsApp in disseminating health information

“WhatsApp is such a versatile platform … it is so simple to use and so easily navigable … this would be beneficial for members of the deprived community as it is user friendly … it allows delivery of all kind of multimedia materials that we would like to promote in eye health …these videos can be sent as small files too and be downloaded fast in lower network speeds for later offline viewing … at a time of convenience … anywhere … also, allowing a two way communication, telephonic and multimedia, to happen in real time for all queries … to be answered at a later time by a member of our team … WhatsApp would be a highly workable platform” (Participant HCP1)

Figure 4.6. Data extract from a transcript

4.8.4 Generating initial codes

This stage involves coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code (Braun and Clarke, 2006). After the data has been meticulously reviewed, an initial list of ideas are generated about what is interesting about the primary data set, which is then used in the production of initial codes. Codes refer to the “most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon” (Boyatzis, 1998). It is that “feature of the data (semantic content or latent) that appears interesting to the analyst” (Braun and Clarke, 2006). This is the process of organising data into meaningful groups and depends on whether the themes are ‘data-driven’ or ‘theory-driven’ - in the former, the coding will depend on the data, but in the latter, data is coded around specific questions in mind (Braun and Clarke, 2006). Codes could be generated for the whole data set or a subsection, manually or using specialised software programmes like NVivo (Woods et al., 2016; Elliott, 2018; Raskind et al., 2019). Coded data must differ from themes that are broader and where interpretative analysis of data occurs in relation to the phenomenon being examined (Boyatzis, 1998).

This study involved interviewing subjects with a varied range of linguistic skills (literate with refined use of language versus illiterate and colloquial use of local language) from diverse backgrounds and levels of education. Moreover, their sociocultural context and dialects differed, and hence it was anticipated that a software based coding system might not be sufficiently flexible to capture the richness of the data. Hence the researcher manually coded the translated and transcribed data. During this process, she wrote notes on the texts whilst highlighting and colour coding to indicate potential patterns, used ‘post-its’ to identify data segments and matched them with data extracts. Furthermore, she coded all extracts from the individual data set and collated the extracts within the code for the wider data set. This involved copying and pasting the data from individual transcripts into different files organised under different codes. Table 4.4 provides an example of how coding worked for this study.

Data extract	**Coded for**
“… no one comes here and we are not provided with any specific information about eye health … in our locality, we see no information visibly displayed …”.	Lack of eye care related information
“…we do not have access to newspapers … our access to television is also restricted as my in-laws have their own programs to watch too … we squeeze ourselves into one room and the children also study there, therefore the television has to be switched off too … we are very busy and spend almost all our time attending to the chores of the household … my husband works elsewhere and I have to look after my old and disabled in-laws .. where is the time for anything else?”	Lack of eye care related information Lack of free time Lack of privacy Lack of money Sociocultural restraints

Table 4.4. Data extract with codes applied

4.8.5 Searching for themes

Once data is collected and coded, this phase involves collating codes into potential themes and gathering all data relevant to each potential theme (Braun and Clarke, 2006). The focus in this stage is to grouping and collating coded extracts within the identified themes, where relationships between codes and between themes (main overarching themes and sub-themes within them) are identified. Some initial codes may become primary themes, some may remain as a sub theme whilst others may disappear altogether and be discarded. Yet there may be a group of themes which are important and relevant but may not fit into any set category and may be categorised as miscellaneous. Finally, the coded extract results in the generation of candidate themes and sub themes and await further refinement, separation or removal in the next stages (Braun and Clarke, 2006).

The researcher, at this stage continued to examine the extracted data and used various aids like colour coding and mind maps, until some key themes and subthemes emerged. Prior examination of the existing body of research was helpful in providing some guidance.

4.8.6 Reviewing themes

In this fourth phase of thematic analysis, candidate themes generated earlier undergo further refinement resulting in strengthening, merging or redundancy of some of the candidate themes. Data within themes must cohere together meaningfully, while between themes, there should be a clear and identifiable distinction (Patton, 2002; Braun and Clarke, 2006). This process may be achieved through two levels – the first level involves reviewing at the level of the coded data extracts to ensure that a coherent pattern emergences; the second step involves considering whether the candidate thematic map ‘accurately’ reflects the meanings evident in the data set as a whole (Braun and Clarke, 2006). This is essentially to ensure that themes work within the data set and to code any data within themes that has been missed in the earlier coding stage. If the map does not fit, further revisions and refinement are necessary. For this study, the researcher kept going back and forth in these stages of creating the thematic map as is illustrated an example in Fig 4.7.

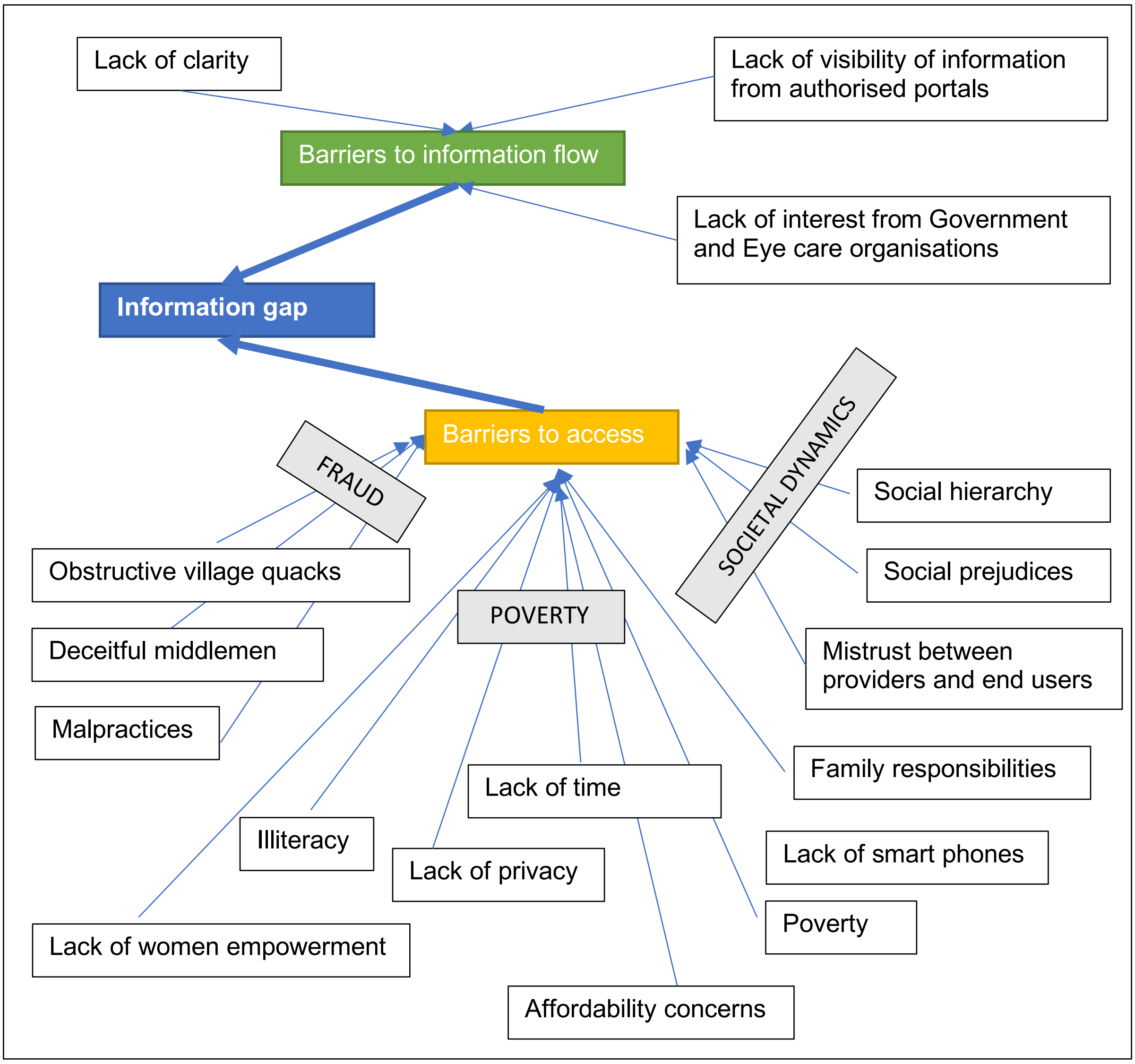

Figure 4.7. Example of creation of thematic map from coding and collation of candidate themes for this research (adapted from Braun and Clarke, 2006)

4.8.7 Defining and naming themes

With the generation of a satisfactory thematic map, the themes hence generated are 'defined and refined' further, identifying the essence of what that theme stands for (Braun and Clarke, 2006). In this stage, collated extracts are organised coherently and consistently with an accompanying narrative and that data extracts are not simply paraphrased, but identify what is of interest about them and why (Braun and Clarke, 2006). The themes narrate a 'story' but there is a need to fit this into the broader overall 'story' that is being told about the data in relation to the research question whilst ensuring little overlap between themes. Refinement may result in subthemes that gives structure to a large and complex theme (Braun and

Clarke, 2006). The main themes and subthemes identified in this study are detailed below (Table 4.5)

- **Thematic analysis of barriers in accessing eye care information, views on social media and WhatsApp based health communication**
  - **Information gap in eye health and barriers to access information**
    - Perspectives of health care providers
    - Perspectives of community health advocates
    - Perspectives of the deprived community
  - **Health promotion in eye health using social media**
    - Views on the benefits of social media
    - Views on ease of use and accessibility of social media
    - Views on credibility, authenticity and trustworthiness of social media content
    - Views on financial implications of a social media based eye health intervention
    - Views on data privacy and security on social media
    - Views on the choice of social media platform
  - **Information dissemination by WhatsApp**
    - Information topics distributed through WhatsApp
- **Thematic analysis of learning outcomes assessments**
  - Overall benefits of WhatsApp based health communication on eye care
  - Benefits of WhatsApp in increasing awareness of eye problems in the deprived community
  - Challenges anticipated by the deprived community in implementation of WhatsApp in health communication on eye care

Table 4.5. Main themes identified in this study

4.8.8 Producing the report

The final stage of thematic analysis involves the process of final refinement of themes; incorporation of selected extracts that relates back to the research question and literature and the synthesis of a scholarly report that tells the complicated story of collected data in a way which convinces the reader of the merit and validity of the analysis (Braun and Clarke, 2006). It is of utmost importance that the report provides “a concise, coherent, logical, non-repetitive and interesting account of the story the data tell within and across themes” (Braun and Clarke, 2006). This should provide sufficient evidence that enough data extracts exists to support a theme (through the choice of vivid examples or extracts that capture the essence of the point being demonstrated without unnecessary complexity)(Braun and Clarke, 2006). Furthermore, the extracts needs to be embedded within an analytic narrative that tells a compelling story about the data and make arguments in relations to the research question (Braun and Clarke, 2006).

4.9 Research quality

Unlike quantitative research, qualitative research is embedded in a interpretivist approach whose purpose is to understand the phenomenon of interest in a specific context or setting (Golafshani, 2003). However, it is imperative that both qualitative and quantitative researchers test and establish the credibility of their studies. Unlike the former, where the researcher is disassociated from the research process and impartiality is maintained, qualitative research encourages the researcher to be deeply involved in the research process. Thus, whilst quantitative research supports credibility through instrument construction, in qualitative research, “the researcher is the instrument" (Patton, 2002). Consequently, research validity and reliability in quantitative research infer to a research that is credible, whereas, the credibility of a qualitative research depends on the ability and effort of the researcher (Golafshani, 2003). In qualitative research, validation is achieved through perspectives established using the views of people who conduct, participate in, or read and review a study (Creswell and Miller, 2000). Therefore, unlike quantitative studies that consider reliability and validity separately, qualitative research considers them together using terminology that encompasses both, such as credibility, transferability, and trustworthiness (Golafshani, 2003). This section discusses the issues of validity and reliability in the context of this study.

4.9.1. Validity of research

Bryman argues that the main criterion in judging qualitative research is its validity (Bryman, 2016). Creswell and Miller (2000) define validity as “how accurately the account represents participants’ realities of the social phenomenon and is credible to them” (Creswell and Miller, 2000). In qualitative research, the concept of validity is not a single, fixed or universal concept but “rather a contingent construct, inescapably grounded in the processes and intentions of particular research methodologies and projects” (Winter, 2000). A confusing array of terms has been used to describe study validity in qualitative research, including authenticity, goodness, verisimilitude, adequacy, trustworthiness, plausibility, validity, validation, and credibility (Creswell and Miller, 2000).

Another important factor in assuring validity in qualitative research arises from the researchers own paradigm assumptions and world views; post-positivist, constructivist, and critical (Guba et al., 1994). In the post-positivist paradigm, the researcher assumes that quantitative research consists of rigorous methods and systematic forms of inquiry and actively establish validity using specific protocols (Creswell and Miller, 2000). In the constructivist (or interpretivist) paradigm, reality is perceived though pluralistic, interpretive, open-ended, and contextualised notions and the validity procedures reflect 'labels' distinct from quantitative approaches, such as trustworthiness (credibility, transferability, dependability, and confirmability), and authenticity (fairness, enlarges personal constructions, leads to improved understanding of constructions of others, stimulates action, and empowers action) (Creswell and Miller, 2000). The third paradigm, the critical perspective holds that "researchers should uncover the hidden assumptions about how narrative accounts are constructed, read, and interpreted" (Creswell and Miller, 2000). Historical situatedness of the inquiry, based on social, political, cultural, economic, ethnic, and gender antecedents of the studied situations, governs the narrative perspectives, and in this approach, validity is "called into question, its assumptions interrogated and challenged, and the researchers need to be reflexive and disclose what they bring to a narrative" (Creswell and Miller, 2000).

It has also been argued that validity is affected by the researcher's own perception of validity in the study (lens (viewpoint) used by researcher) and the paradigm assumption (Creswell and Miller, 2000). As an example of such a lens, "researchers determine how long to remain in the field, whether the data are saturated to establish good themes or categories, and how the analysis of the data evolves into a persuasive narrative" (Creswell and Miller, 2000). This is the process whereby the researchers return to their data repeatedly to ensure constructs, categories, explanations and interpretations make sense (Patton, 2002). Another example of a researcher's lens in ascertaining validity, arises from the notion that reality is socially constructed and driven by participants' perceptions. Here, researchers actively involve participants in assessing whether the interpretations accurately represent them (Creswell and Miller, 2000). Finally, another form of lens may arise from the credibility of an account by individuals external to the study (reviewers not affiliated with the project as well as various readers for whom the account is written) (Creswell and Miller, 2000).

Various methods have evolved in qualitative research to this effect that include member checking, triangulation, thick description, peer reviews, and external audits and researchers engage in one or more of these procedures and report results in their investigations (Creswell and Miller, 2000). Table 4.6 outlines a framework proposed by Creswell and Miller (2000), for tools that can be used for the differing perspectives (Creswell and Miller, 2000).

Paradigm assumption/Lens of researcher	**Postpositivist or Systematic Paradigm**	**Constructivist or Interpretivist paradigm**	**Critical Paradigm**
Lens of the Researcher	Triangulation	Disconfirming evidence	Researcher reflexibility
Lens of Study Participants	Member checking	Prolonged engagement in the field	Collaboration
Lens of people external to the study (reviewers, Readers)	The audit trail	Thick, rich description	Peer debriefing

Table 4.6. Validity Procedures Within the Qualitative Lens and Paradigm Assumptions. Adapted from Creswell and Miller (2000) (Creswell and Miller, 2000).

Triangulation

Arising from navigation in sea to determine the ships bearing from different distal points, triangulation is a validity procedure where “researchers search for convergence among multiple and different sources of information to form themes or categories in a study” (Creswell and Miller, 2000). This mixed methods approach involves comparing results from two or more methods of data collection (like interviews and observation) or two or more data sources (interviews with members of different interest groups) (Mays and Pope, 2000). Four types of triangulation methods have been identified: one that happens across data sources (i.e. participants), or across multiple theories, or various data collection methods (i.e., interview, observations, documents), or among different investigators (Denzin, 2017). Researchers systematically sort the data using their perspective and judgement to find common themes or categories by eliminating overlapping areas and provide corroborating evidence collected through multiple methods to locate major and minor themes (Creswell and Miller, 2000). Theoretically, validity is ensured by reliance on multiple forms of evidence rather than a single incident or data point in the study, however, critics question this because it assumes that methodological weaknesses in one source will be counter-balanced by strengths in another, and that it is always possible to resolve different accounts (Mays and Pope, 2000). In fact, it has been argued that triangulation may be better regarded as a method of ensuring comprehensiveness of data that encourages a more reflexive analysis than as a pure test of validity (Mays and Pope, 2000).

Disconfirming evidence

In this process that is closely associated with triangulation, the researcher firstly establish a preliminary theme or category and then uses his / her perspective to evaluate the data that is either consistent or disagreement with these themes (Creswell and Miller, 2000). This method allows the researcher to rely on her own perspectives to examine all of the multiple perspectives on a theme or category; in practice, this may be difficult as researchers have the inclination towards identifying confirming rather than disconfirming evidence (Creswell and Miller, 2000). Although less systematic than other methods, as measure of validity, this search for disconfirming evidence lends support the credibility of the report.

Researcher reflexivity

This validity procedure in qualitative research allows the researcher to explicitly express and self-disclose personal beliefs, values, and biases that may influence their inquiry, early in the research process, thereby allowing the readers to understand their positions, and to consider researcher bias, as the study proceeds (Creswell and Miller, 2000). Situated within the critical paradigm , this method allows validity by allowing reflection on the social, cultural, and historical forces that shape their interpretation and may be achieved by the researcher through various methods including the creation of a separate section on the "role of the researcher," or provision of an epilogue (Creswell and Miller, 2000).

Member checking

Described as a crucial technique for establishing credibility, in this method, validity is assessed by shifting the focus from the researcher to the participants (Creswell and Miller, 2000). This involves the researcher taking back the data, along with the interpretations, to the participants to ensure and corroborate an accurate representation of their account. This may be achieved by several methods that include convening focus groups (where participants review and comment on this data) or by separately reviewing the raw (transcribed) data whilst commenting on its accuracy. Throughout the process, the researcher focusses on the feedback from participants as to whether themes and categories make sense, have enough supportive evidence, are realistic and accurate and incorporates these comments into the final report (Creswell and Miller, 2000). This allows the participants to add credibility to the study by responding to the initial data and the final narrative.

Prolonged engagement in the field

Prolonged contact with the context (research site) has been considered as a validity instrument in ethnographic qualitative research. It is anticipated that repeated observations situated within the phenomenon and context of interest and its consequent benefits: trust building by establishing confidence and rapport, would allow the researcher to generate an accurate and valid narrative, hitherto not available from outside and in research of shorter duration (Creswell and Miller, 2000). It is conceived that prolonged exposure in the field over time 'solidifies' evidence as researchers can cross check and compare interview data with observational data (Creswell and Miller, 2000). Although not a systematic instrument of validity in the strictest sense, constructivists acknowledge that long stay allows pluralistic perspectives and allows better understanding of the context of participant views.

Collaboration

In this process, the participants engage and influence the research process as co-investigators or in less formal arrangements, allowing credible data to be generated from a close collaboration between them and the researcher (Creswell and Miller, 2000). This approach belongs to the critical paradigm perspective as this respects and supports participants in a study, and not further marginalise them, through several methods like developing the research questions, assisting with data collection and analysis, and be involved in writing the narrative account (Creswell and Miller, 2000).

The audit trail

This is a systematic process of establishing credibility by receiving formal input from individuals external to the project (auditors or readers) after formal review of the narrative account and the detailed processes (clear documentation of all research decisions and activities) involved in reaching to that conclusion (Creswell and Miller, 2000). The inherent rigor in the process; the research log of all activities; the data collection chronology and record of data analysis procedures, all contributed towards adding credibility to the study.

Thick, rich description

Thick rich description is another procedure to establish credibility to the report and involves providing deep, dense and detailed accounts to convince the reader of the experience of the events being described in a study (Creswell and Miller, 2000). Herein, credibility is established through the lens of the reader who “read a narrative account and are transported into a setting or situation” (Creswell and Miller, 2000). The researcher provides as much detail as possible that may involve describing an episode of interaction, experience, or action; placing individuals in particular situations; depicting a relationship or an interaction alive; or providing a detailed representation of people’s feeling (Denzin, 2017). This helps readers understand the account is credible and to make decisions about the applicability of findings to other settings or similar contexts (Creswell and Miller, 2000).

Peer review or debriefing

This process involves supporting the qualitative researcher through the review of the data and research process by someone who is familiar with the research or the phenomenon being explored (Creswell and Miller, 2000). From the perspective of the critical paradigm, this approach establishes validity and credibility by allowing close collaboration between the external reviewer and the researcher.

4.9.2 Research reliability

Reliability relates to the replicability of the study and is focussed on understanding whether an application of a particular research technique, yields similar results when being applied repeatedly to the same object (Lewis, 2009; Bryman, 2016). In quantitative research the concept of reliability relates to "the consistency of the analytical procedures, including accounting for personal and research method biases that may have influenced the findings" (Noble and Smith, 2015). On the other hand, Lincoln and Guba (1985) provides a more contextual version of reliability in qualitative research that is centred around consistency and neutrality (or confirmability) (Lincoln and Guba, 1985). *Consistency* "relates to the 'trustworthiness' by which the methods have been undertaken and is dependent on the researcher maintaining a 'decision-trail'; that is, the researcher's decisions are clear and transparent" (Lincoln and Guba, 1985). This is to ensure that eventually, a different researcher should be able to arrive at a similar or comparable conclusion. On the other hand, *neutrality (or confirmability)* is achieved when validity (truth value), consistency and generalisability (applicability) has been addressed, and focusses on the complex issue of prolonged researcher engagement in the research process and its participants; this ensures that the researchers' philosophical position, experiences and perspectives that influences the choice of a particular research methodology, are fully accounted for and separated from participants' accounts (Lincoln and Guba, 1985).

4.10 Ensuring research quality in this study

To ensure that this study was of high quality, a mixture of approaches were used that served the purpose. However such approaches were not rigidly applied but flexibly rendered at the discretion of the researcher, so that the overall aim of a high quality research output could be reached. Based on an interpretivist paradigm, this research sought to perceive reality through pluralistic, interpretive, open-ended, and contextualised notions, with validity being assessed through concepts of trustworthiness and authenticity. Research validity was established through researcher reflexivity, collaboration, prolonged engagement in the field, peer debriefing and the maintenance of an audit trail.

At the outset, the researcher explicitly declared her personal beliefs, values, and biases that may influence this study (Chapter 1, section 1.2), which will allow readers to understand her perspectives and bias, during the entire study process and with the reported outcomes (*researcher reflexivity*). The total duration of field work, the process of groundwork, interview preparation, and data collection happened over a period of six months. This may be considered as a *prolonged engagement in the field of social research* and was instrumental in adding validity to the study. This was also supplemented by the fact that the researcher belonged to the same wider geographical region as the participants, with a similar cultural background and could speak the native language. This, allowed the participants to establish rapport at ease and unfold vividly with their individual narratives.

Collaboration, another validation method*,* was achieved through the pilot interviews that allowed *a priori* fine tuning of the interview questions, guided by the feedback from the initial participants (who were not included in the final analysis) before initiation of the final stages of this study. It allowed the researcher to start the process of analysis early on in an effort to continue refining and improving data collection approaches, and was instrumental in hinting at themes representing the ‘core meaning’ of interviewee perspectives and to appropriately undertake a thematic analysis as the qualitative analysis method of choice.

An *audit trail* was maintained, whereby all notes and documentations were kept allowing a log of all research decisions and activities, the time frames involved, data collection chronology, data recording procedures, and the processes in writing of the final thesis. The validity of this study was also enhanced by the provision of a *thick, rich description,* that provided detailed extracts of participant’s perspectives, allowing the reader to be transported into the setting to explore the phenomenon of interest. Finally, *peer debriefing* was used as an important validity tool, whereby the researcher and her supervisor, met on numerous occasions, face to face and remotely, conceiving, exploring and discussing every aspect of the research process, to ensure that the researcher remained true to research process in its entirety.

Reliability of this study was ensured through a number of steps that included the implementation of a number of validity tools, extensive documentation of the research process including an explicitly detailed methodology, keeping a research log of all events, recorded interview recordings and transcripts, and detailed plans for analysis. The researcher explicitly detailed her involvement from the outset, the processes and rationale behind participant choice and selections, the type of interviews undertaken and the data recorded. The researcher detailed the rationale behind the choice of data analysis method and that she did not rely on a software based program. Furthermore, she familiarised with data herself to generate codes and understand prevailing themes, prior to the production of the final report. Precisely explaining her rationale and documenting the step-by-step accounts, coupled with in-depth explanation of her rationales, the researcher sought to enable other researchers to arrive at similar conclusions if they were using a similar research technique.

4.11 Ethical considerations

As this research involved working with human subjects, it was envisaged at the outset that a comprehensive ethical approval would be necessary. Fritz (2008) outlines the overarching ethical principles in qualitative research as detailed below (Fritz, 2008):

All researchers are responsible for ensuring that participants:

- Are well-informed about the purpose of the research they are being asked to participate in
- Understand the risks they may face as a result of being part of the research
- Understand the benefits that might accrue to them as a result of participating
- Feel free to make an independent decision without fear of negative consequences

This study involved submission of the ethics application to the EthOS (Online Ethics Application System, Manchester Metropolitan University, the final approval was obtained in August 2019 (Appendix H).

The researcher ensured that the participants were well informed about the purpose of the study (Participant Information Sheet, Appendix E) that described the study in depth. Details included the rationale behind the study, the researcher's academic affiliations and the research team involved, potential advantages and risks in taking part, the audio-visual nature of the data collected and stored, the voluntary nature of their participation, the confidentiality and security arrangements in place and the non-commercial nature of the study. Healthcare providers and community health advocates were provided with the participant information sheet one week in advance and allowed to reflect on the same. The participants from the deprived community were approached differently as it was anticipated that, they would have difficulties in comprehending printed material. Instead, the researcher explained the study in a plain and simple manner in their native language, whilst simultaneously encouraging them to ask questions. This ensured that every participant had the opportunity to consider their options before providing an *informed consent* to be part of the study (verbal, finger print or signed). The healthcare providers and the community health advocates provided written consent whilst verbal consent was obtained from the participants from the deprived community (secondary to issues surrounding literacy) (Appendix F and G). At the commencement of the interview, the participants were reconfirmed for their consent and their permission in recording and storing interviews through audio and visual mediums, emphasising their right to withdraw at any time and were assured about the confidential treatment of their responses (Fritz, 2008; King and Horrocks, 2010). Informed consent forms were then signed in pairs; one for the researcher and the other for the participants to keep. Once each interview was conducted, all empirical data collected was secured in a password protected folder that was only accessible to the researcher.

4.12 Chapter overview

This chapter provides a broad theoretical overview of the philosophical concepts that underpin quantitative and qualitative research, approaches needed and methodology applied. It provides a detailed overview of the study methodology in a step-by-step manner explaining all necessary processes. This includes the rationale of adopting a qualitative research approach for this study using a case study, the study context, participant selection processes, the interview plan for semi structured and focus group interviews. It also provides a detailed discussion on approach to qualitative data analysis using thematic analysis and methods employed to ensure research quality. Finally, it outlines the ethical considerations.

CHAPTER 5. Findings and analyses

5.1 Introduction

This chapter discusses the main findings of this study. It commences with a descriptive analysis of the participants, and their perspectives on the various topics of health communication on eye care using social media as explored through questionnaire survey. The subsequent section describes in detail the findings from the thematic analyses of participant's opinions, beliefs and perspectives, as explored in the semi structured interviews.

5.2 Descriptive analyses

The following sections provide a demographic overview of the participants involved in this study (healthcare provider, community health advocates and members of the deprived community), and their perspectives as surveyed through the questionnaire (Appendix A, B and C)

5.2.1 Healthcare providers

The purpose of this study was to understand the issues of healthcare promotion in eye care from a multidimensional perspective. To explore from a healthcare provider's perspectives, ten members of staff working for Susrut Eye Foundation were identified and invited for the interview. These members were selectively chosen from a varied occupational background for evaluation of a diverse range of opinions and perspectives. The interviewees comprised of two specialist nurses, two doctors, one specialist pharmacist, one optician, two managers and two senior members of the executive body. All interviewees were fluently bilingual and could speak both English and Bengali. There was a slight male preponderance (6 males and 4 females). The average (median) age of the respondent was 41.3 years (40 years) and the age ranged from 26 years to 58 years.

Clinical staff accounted for almost sixty percent of the interviewees. The specialist nurses have been specially trained in the diagnosis and management of eye diseases that include working in outpatient and in-patient settings, assisting doctors in the operation theatres and supporting the team in remote and rural eye care camps. Nurses who participated in this study, had been employed at Susrut Hospitals for more than five years, and were well conversant with the policies and workings strategies of the hospital. Doctors who participated in this study, had received specialist training and have been highly experienced in the complex management of eye diseases. Both of them were associated with Susrut Hospitals for more than a decade as full time employees and were well versed with the hospital's policies and management strategies. They had also been professionally involved in the organisation and execution of community based eye camps held in remote rural locations. The optician was relatively new to this organisation but had had extensive experience of working across a range of healthcare institutions prior to joining Susrut Hospitals. Importantly, the optician had a background of coming from a remote community that allowed him to offer valuable insights into the issues being explored. The pharmacist had received specialist training in eye care pharmacy after having obtained a general degree in pharmacy. He had been involved with Susrut for the past five years prior to which he had first experience of working in the community setting.

Managerial and administrative staff consisted of two senior site managers, the Chief Executive Officer (CEO) of Susrut Eye Hospitals and the Chief Operating Officer (COO). Both managers had a decade long experience of working with Susrut Hospitals and were primarily involved in the day-to-day planning, directing and overseeing the delivery of eyecare. They worked independently but collaboratively to make the whole organisation work smoothly. They were involved in strategic planning that also included accessing and following national and international directives on delivery of eyecare. The CEO held the highest administrative position and was in charge of managing this institution, was involved in strategic planning and reported directly to the board of directors and trustees. However, her background in general medicine, allowed the CEO with the rare insight of understanding health issues from a medical outlook. The COO, on the other hand had a background in finance and acted as the second most senior administrative officer in the organisation, who reported directly to the CEO. He oversaw the overall day-to-day administrative and operational functions of the hospital.

5.2.1.1 Opinion of healthcare providers on eye health promotion

Healthcare providers unanimously agreed strongly on the importance of awareness increasing strategies as an effective interventional tool in disease prevention, particularly in eye diseases. They also agreed that increasing disease awareness may be specifically beneficial to individuals belonging to the disadvantaged background. Participants also agreed that social media has an important role to play in promoting information dissemination. There was unanimous agreement that healthcare promotion using a free to access technology was a relevant and cost effective strategy with wider benefits. Participants acknowledged that the current practice was significantly under-resourced. However, participants were sceptic whether such a strategy was achievable on a wider scale and whether such an approach would be considered as intrusive by the recipient population.

5.2.1.2 Perception of health providers on national and international strategies that promote eye care awareness

Most participants (six) were unsure as to the existence of organisations (either, national or international) that focussed on eye disease prevention by promoting dissemination of appropriate eyecare information. A handful, who were aware of such organisations, were unsure as to how these may influence their own practice. Only, the CEO, COO and the doctors were aware of such institutions and their *modus operandi* and their involvement with Susrut Hospitals. When specifically enquired about the national information dissemination strategy on eye health in its current form, most participants considered it to be beneficial and relevant to the needs of the population. Furthermore, they perceived the strategy to be achievable and cost effective in the long run. They also agreed that the current national strategy is under resourced. However, participants also expressed concerns about the intrusive nature of the strategy.

5.2.1.3 Opinion of healthcare providers on eye health promotion using social media

All respondents identified themselves having the use of a smart mobile phone and all had access to social media. However, their choice of social media platforms varied and is shown in Fig 5.1. Although Facebook, WhatsApp and YouTube was accessed by all, only a handful accessed others platforms like Twitter, Snapchat and Instagram that comprised of doctors and executive directors of the institution.

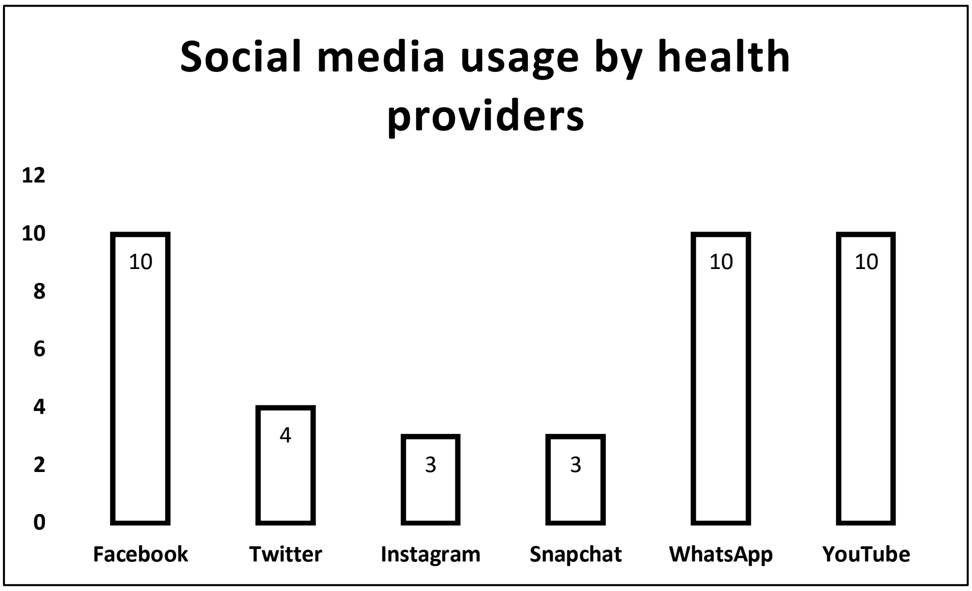

Figure 5.1. Social media usage by healthcare providers

When asked about the role of social media based video assisted information dissemination strategies, most participants were in favour of such an approach. Amongst social media platforms, WhatsApp was the preferred platform followed by Facebook and YouTube. There was an overwhelming agreement amongst participants about WhatsApp as a workable and versatile platform that had the capacity of two way communication between the providers and the target audience. However, most participants were unfamiliar with other social media platforms like Twitter, Instagram or Snapchat. Consequently, it was difficult to draw conclusion from a handful of respondents conversant with this technology.

When asked about the category of eye care information that could be delivered to the deprived community, participants unanimously agreed on addressing routine eye care and identifying signs and symptoms of commonly prevalent eye disease, both in children and in adults. Agreement was also unequivocal about other topics like posthumous eye donation, what to do in an emergency and where to access relevant information.

5.2.2 Community health advocates

In an attempt to understand the perspectives of the wider population, ten individuals were chosen from the local community and invited for the interview. These members were chosen from a diverse occupational background in an effort to explore opinions and beliefs from a varied perspective. The interviewees included two head teachers from local schools, one university academic, one social worker, one financial advisor, one community based medical practitioner, one journalist, one government official and two senior executives working for non-governmental organisations (NGO) (Fig 4.4). Community advocates were predominantly male (8 males versus 2 females) (Fig 5). Respondents in this group were slightly older than the healthcare providers with an average (median) age of the respondent as 53.8 years (55.5 years) and a range from 42 years to 63 years.

The head teachers were in charge of two large government supported secondary schools. Both schools had a significant proportion of students coming from a disadvantaged background. This experience, made the headteachers well aware of the specific needs of the deprived community. They also had experience in being involved with awareness campaigns involving other issues like ‘universal immunisation’ and ‘deworming’. They were also aware of various governmental and non-governmental directives in place to address common health issues pertaining to school aged children. The University academic had a background in information sciences and was employed by a large and highly reputable educational institution. His research involved information dissemination in deprived communities using low cost ICT based technology. The social worker has been engaged in awareness campaigns and extensive experience in field work. He was acutely aware of the nature of problems faced by the members of the deprived communities. The financial advisor was engaged with the financial implication of ill-health affecting his clients and was knowledgeable about the availability of healthcare related insurance policies. The medical practitioner, through his long presence in the local community, had an all-round overview of the health issues. He had been actively involved in various health promotion campaigns under the directives of the local and national government. He has also been a key opinion leader on healthcare promotion in the national and local press. The journalist participant had extensive experience in engaging with the deprived community on a variety of sociocultural issues. He has been instrumental in covering a number of such issues in the local press. The head of one of the NGO was associated with a wide range of community based social care programs spanning across diverse socioeconomic topics that included running a school for children with special needs and an old age retreat. The other NGO executive headed a charitable school that catered to the educational needs of the children from disadvantaged background. Both of them were highly involved in organising various awareness campaigns and community health camps.

5.2.2.1 Opinion of community health advocates on eye health promotion

Similar to healthcare providers, community advocates strongly agreed that increasing awareness was an effective disease prevention strategy that is also pertinent to eye diseases. Respondents agreed that by promoting information dissemination, social media have a role to play in increasing disease awareness and that this is highly relevant to communities from a underprivileged background. In agreement with the healthcare providers, community advocates opined that information dissemination through free-to-access digital technologies was an appropriate strategy, which could have beneficial effects. They also perceived the strategy to be cost effective on the long run. However, some interesting differences in opinions were also noted between the healthcare providers and the community advocates. Community health advocates perceived an eye health promotion strategy to be non – intrusive in nature and that it was highly achievable. They also opined that the strategy in its current form was constrained by lack of resources.

5.2.2.2 Perception of community health advocates on national and international strategies that promote eye care awareness

Similar to the healthcare providers, most community health advocate participants were unaware of the existence of health focussed organisations (national and international) working in this field of information dissemination in eye care. When asked about the current national strategy of information dissemination, most participants thought it to be relevant, achievable, cost effective and beneficial to the needs of the population. However, in contrast to health care providers, community advocates did not perceive the national strategy to be under-resourced or intrusive.

5.2.2.3 Opinion of community health advocates on eye health promotion using social media

All community health advocates reported that they had the use of a smart mobile phone and had access to social media. However, the choice of social media platforms varied and is shown in (Fig 5.2). Although Facebook, WhatsApp and YouTube remained the social media of choice with universal acceptance, none were conversant with Twitter, Snapchat and Instagram. All but one used social media for leisure and entertainment purposes (Fig 5.3). Social media was also used to access and share information with friends and families and for work and family related communication.

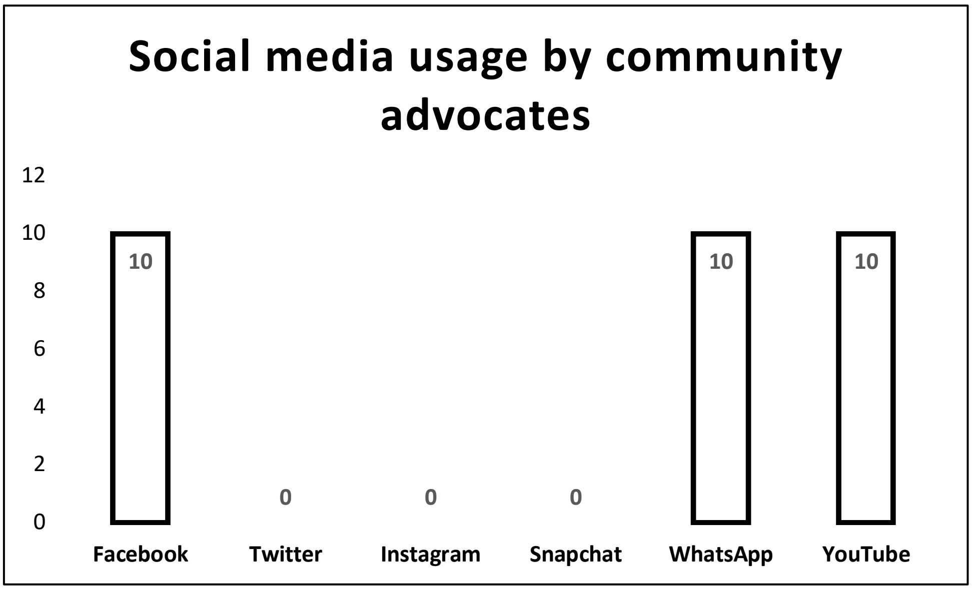

Figure 5.2. Social media usage by community advocates

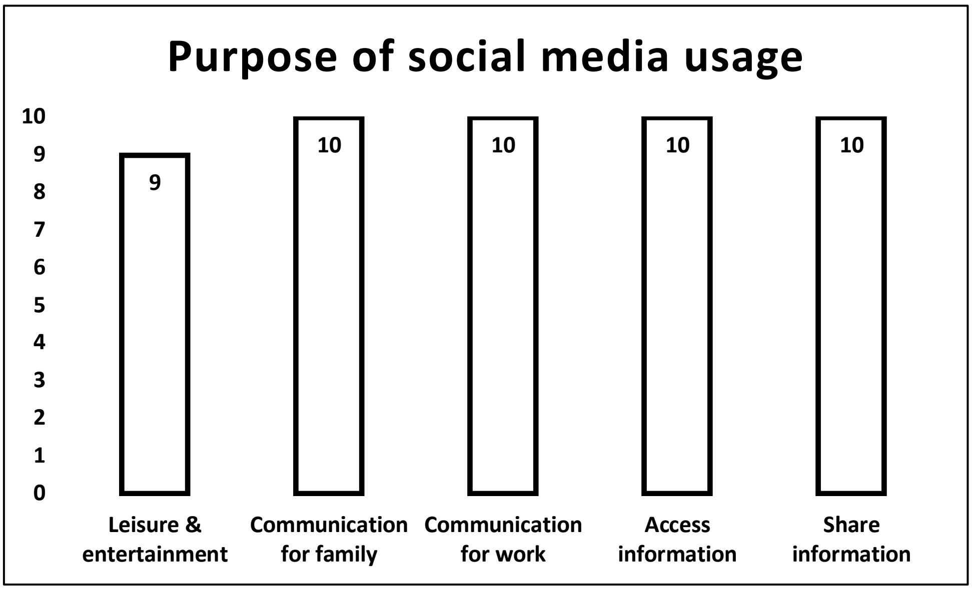

Figure 5.3. Purpose of social media usage by community advocates

Similar to health care providers, community advocates agreed unanimously on the positive role of social media based video assisted information dissemination strategies. WhatsApp remained the platform of choice followed by YouTube and Facebook. WhatsApp was considered to be a workable and versatile platform by all respondents as that facilitated two way communication. However, participants were unfamiliar with other social media platforms like Twitter, Instagram or Snapchat and were unable to comment on their advantages and disadvantages. When asked about the categories of information that should be included, strikingly similar to healthcare providers, community advocates agreed that addressing routine eye care and identifying signs and symptoms of commonly prevalent eye disease, along with posthumous eye donation, emergency eye care, and where to access relevant information.

5.2.3 Study population

The invitation was open to all parents attending Surya Kiran school. However, only women chose to participate, citing the unwillingness of their partners for work related commitments. Altogether, 30 women participated in this study. The average age of the participants was 27.6 years (median 27 years) and ranged between 20 and 48 years. Most respondents were married (93%), and practised Hinduism as their primary religion. As to their highest educational attainment, nine participants (30 %) reported having no formal education and only one respondent was educated at higher secondary (A Level) standards. The biggest group (40 %) of women however, reported themselves to be educated up to primary level (up to Year 5 equivalent) followed by 27% who had attended secondary school (up to GCSE).

Participants were specifically asked about their long term residency status. Eight women (27 %) identified themselves as locals; they were born in the locality and have stayed on since. Others, reported having migrated from other geographical locations, near and far, and for a variety of reason. Some identified that their migration was purely economic for better job prospects, access to superior resources, improved quality of life or for matrimonial or other cultural reasons. Participants were enquired as to their household size with particular reference to the number of children in each family. On average, respondents reported having 5 members in their household (median 5, range 2 – 7 members). Median number of children in the family was 2 (range 1 – 4 children).

A wide range of socioeconomic demographic variables were considered to be useful in portraying an accurate picture of the population being studied. These factors were considered important as they may be associated with adverse outcomes on eye health. Participants reported on their employment status, homeownership, the type of dwelling construction, number of rooms including kitchen and toilet in the house, availability of electricity and drinking water, type of cooking fuel and ownership of pet, vehicle, television and radio.

Altogether, 5 women (17 %) were in active employment and the rest were homemakers. Gross household income was reported to be between Rs 5000 – Rs 10000 per calendar month (£55 - £110 per calendar month) by 23 respondents (77 %). 7 respondents (23 %) reported earning less than Rs 5000 (£55) per calendar month and none earned more than Rs 10000 (£110) in a calendar month. Seventeen of the participants (57 %) reported their partners to be paid daily wages thereby increasing the uncertainty of their family income as compared to the thirteen (43%) who were paid monthly in their employment. All respondents confirmed having a BPL (Below Poverty Level) certificate issued by the Government of India to access special facilities and concessions available to people from a very disadvantaged background.

Although all participants reported residing in a home, only 5 (17 %) lived in a permanent dwelling that was owned outright. The remaining 25 participants (83 %) reported renting in thatched or tile roofed houses and semi-permanent makeshift settlements. In all cases, home comprised of only one room, although five respondents did have a separate kitchen. Although, all participants reported having electricity in their homes, drinking water was sourced from outside the house and the toilet was shared. The main cooking fuel was kerosene (17 participants) although cooking gas (LPG) was used by 6, and a variety of combination of fuel types were used by 7 participants. When considering vehicle ownership in the household, 3 participants owned a bicycle as their only vehicle and relied on public transportation for their travel needs. None owned a pet, but, all participants owned a television and a radio.

5.3 Thematic analysis of barriers in accessing eye care information, views on social media and WhatsApp based health communication

During the course of the interviews, a number of key themes became apparent (Table 5.1). As would be anticipated, these themes reflected the varied perspectives of the different groups of people interviewed. An attempt has been made to summarise the varied perspectives below.

- **Information gap in eye health and barriers to access information**
    - Perspectives of health care providers
    - Perspectives of community health advocates
    - Perspectives of the deprived community

- **Health promotion in eye health using social media**
    - Views on the benefits of social media
    - Views on ease of use and accessibility of social media
    - Views on credibility, authenticity and trustworthiness of social media content
    - Views on financial implications of a social media based eye health intervention
    - Views on data privacy and security on social media
    - Views on the choice of social media platform

- **Information dissemination by WhatsApp**
    - Information topics distributed through WhatsApp

Table 5.1. Thematic analysis of barriers in accessing eye care information, views on social media and WhatsApp based health communication

5.3.1 Information gap in eye health and barriers to access information

During the course of the interview, it became obvious that all participants agreed on the existence of an information gap in eye health and the reasons varied with the interviewees. There was a shared feeling that not enough good quality, relevant and topical information exists in eye health. Whatever minimal information exist, it was not available in an easy to access format and therefore remained beyond the understanding of most of the population. All participants strongly agreed on the role of increasing awareness about eye diseases as an effective interventional strategy that may be beneficial to individuals belonging to deprived background.

5.3.1.1 Perspectives of health care providers

The health providers felt that barriers in accessing information on eye care resulted from a lack of effective existing information dissemination strategy and the population characteristics of the deprived community (Fig 5.4).

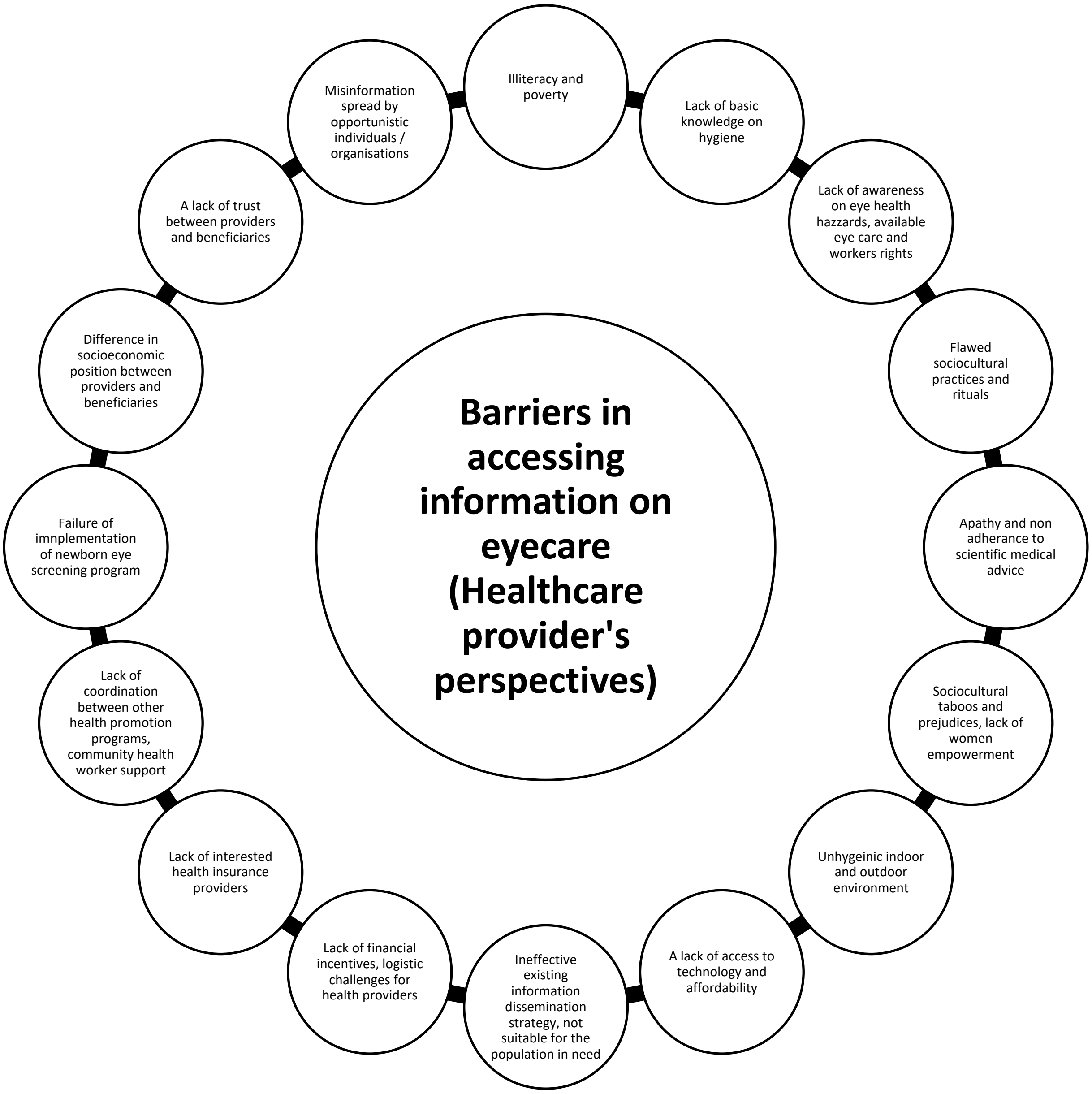

Figure 5.4. Information gap and barriers in accessing healthcare information on eye care (Healthcare provider perspectives)

It was highlighted that the deprived individuals were unable to access eye health related information as they lacked basic literacy and thus cannot access traditional sources of information like print media. Additionally, access to digital information is also limited as the community lacked access to technology like smart phones. Women and young parents were considered particularly vulnerable as their concerns might be overlooked for other pressing family needs. It was however stressed that although, the government has attempted to provide this information and had taken steps to improve overall health and hygiene, it has been beyond the capacity of the deprived community to accept because of intrinsic sociocultural and economic traits. A lack of basic knowledge and apathy to proper scientific medical advice leading to exploitation was also brought to attention.

> HCP 5: *"… most parents fail to understand the onset of eye disease and its progression until it is too late …….. typically, such parents are illiterate, young and lack basic information accessing devices like mobile phones …. these parents live in a culture of superstition that precludes them from being exposed to the wider world…"*
>
> HCP 6: *"… such families may be unaware of the benefits of hygienic practices like the availability of cooking gas and clean and potable water … overcrowding is a major problem and indoor pollution is high …"*
>
> HCP 8: "… *there is a lack of basic knowledge amongst the poor families …. this leads them to be exploited by unregulated practitioners like village quacks and unscrupulous pharmacists thereby providing irrelevant and possibly toxic medications …. illiteracy also precludes them from using and using medications appropriately … often this leads to either overdosing or underdosing with its consequent ill effects…"*
>
> HCP 7: *"… we often advise an annual eye check-up for all … but none is interested … we advise that children with refractive eye problems need to wear corrective glasses all day and we strongly emphasise the need for sunglasses to protect the eyes in the blaring sun, but no one listens to us … however we are not able to reach everyone … it is not physically possible…"*

The medical professionals considered illiteracy and lack of access to relevant knowledge to be the primary barriers perpetuating this information gap. They apportioned some of this to cultural prejudices and socioeconomic factors.

> HCP 3: *"… lack of knowledge and illiteracy is the main reason why such poor families cannot access information …this is why these families can not recognise common eye problems and can't access low cost eye care that is currently made available … also, cultural prejudices play a role here. … young women who have eye problems may not be able to get married and therefore the family may choose not to seek treatments …. conversely, for a male child or the bread earner, such treatment may be sought relatively earlier …."*

Other factors like non-adherence to medical advice, flawed sociocultural practices, a lack of personal hygiene and high prevalence of indoor pollution were also highlighted as important in a contributory role.

> HCP 4: " *… the lack of adherence to medical advice in pregnancy particularly with a heavy work and lack of good antenatal care …. results in mothers who often are malnourished or undernourished, going into premature labour and the baby facing the consequences of prematurity …"*
>
> HCP 4: *"… strong but flawed prevailing sociocultural practices like the application of kohl to newborns is equally important …. taken together with crowding and a general lack of hygiene and indoor pollution, this may have an adverse effect of the state of eyes …."*

Importantly, a failure of proper implementation of the newborn eye check programme, widely adopted in the developed nations in the early detection of eye problems before it is fully manifest, was also highlighted as a missed opportunity in reducing information gap on eye care.

> HCP 4: *" … it is not that such universal newborn screening programmes do not exist but the implementation is patchy … it is sheer luck where you are born … privately in a modern facility or an inadequately staffed governmental institution … some are born at home or in the street!...early problems are not picked up and they come to the hospital at advanced stages of eye … this reduces the chances of curative medical options …."*

A general lack of general awareness on eye health hazards, consequences of visual impairment and blindness, and available eye care, were also identified as important barriers. Furthermore, a lack of awareness on protected rights of worker's employed in hazardous conditions, and a prevailing culture of mistrust and apathy towards healthcare organisation, were all to blame as barriers to access scientific information. In agreement with the medical professionals, the non-availability of an effective new born screening program was also emphasised as an important contributory factor.

> HCP 1:*" … many are not aware of the government schemes or the local availability of low cost eye care facilities … this relates to the general lack of*

> *awareness amongst the poorer sections of the society … this is particularly relevant to the women members of the society and may relate to the suppressed rights of women in a male dominated society…. or to familial disbelief that eye sight can vary by the day (night blindness) … or a lack of awareness of eye hazard either at home or at a factory site ...”*
>
> HCP 1:*“ …. We can make a difference to these children if they arrive through some sort of a screening process … often they arrive so late that no effective treatment can be offered … often such treatment is costlier at a later stage too … one has to understand that the workers are often not aware of their human rights and that certain work exposure (chemical factory, tanneries, construction, agricultural workers, etc) may lead to an increase in ocular problems…”*
>
> HCP 2: *“ … despite sincere effort from the health providers in implementing the national blindness prevention programme, the uptake is low … we get funding for the cataract operations from the government of India … however, there is a breach of trust between the health care providers and the community … the community is sceptical of implementation of a free eye care program … myths abound that our doctors practise operative skills and that the medicines are all counterfeit and harmful … government resources often get underutilised…”*

Difference in socioeconomic positions between the large city based tertiary hospitals and the largely remote deprived community were also considered as an important barrier in accessing scientific care. Apprehension, confusion and a feeling of being overwhelmed, coupled with misinformation opportunistically spread by individuals and organisations with vested interests, were also considered as powerful deterrents. A lack of community health worker support and insurance providers interested in supporting the financially challenged members of the deprived community, were also highlighted as an important barrier.

> HCP 9: *“ … coming from a remote village to the city is a big ask for many… they are bewildered, frightened and confused … coming to a large hospital make them feel subdued and overwhelmed with the size of the institution, with so many patients and staff around … this puts them off seeking proper help …”*
>
> HCP 9: *“… the myths spread through the media outlets (medical institutions are often vilified for their inadequacies in providing care and such stories abound on a daily basis) has an important negative impact that diverts them to less regulated outlets that are not trust worthy and does not follow scientific principles….”*

> HCP 10: *"… financial institutions to come forward in providing affordable, easy to understand and accessible insurance policies to cover for eye treatment … community health care workers have a bigger role to play too as currently their focus is limited to antenatal care and a handful of preventable diseases…".*

5.3.1.2 Perspectives of community advocates

Community health advocates acknowledged the existence of an information gap on eye health, but overwhelmingly pointed out towards inadequacy on part of the government and the health care providers as the primary reason behind it. They highlighted that, despite their personal academic and social positions, they remained unaware of key governmental programs designed to address the eye health needs of the population, in particular, the deprived communities. This was highlighted as a major inadequacy on the part of the government and healthcare organisations to put key eye health policies on a 'easily visible' and 'widely accessible' roadmap. Consequently, information on eye care was perceived as not reaching the deprived population. Whilst strongly critiquing the government and the healthcare providers, community advocates also highlighted the socioeconomic traits of the deprived population as an important contributory factor (Fig 5.5).

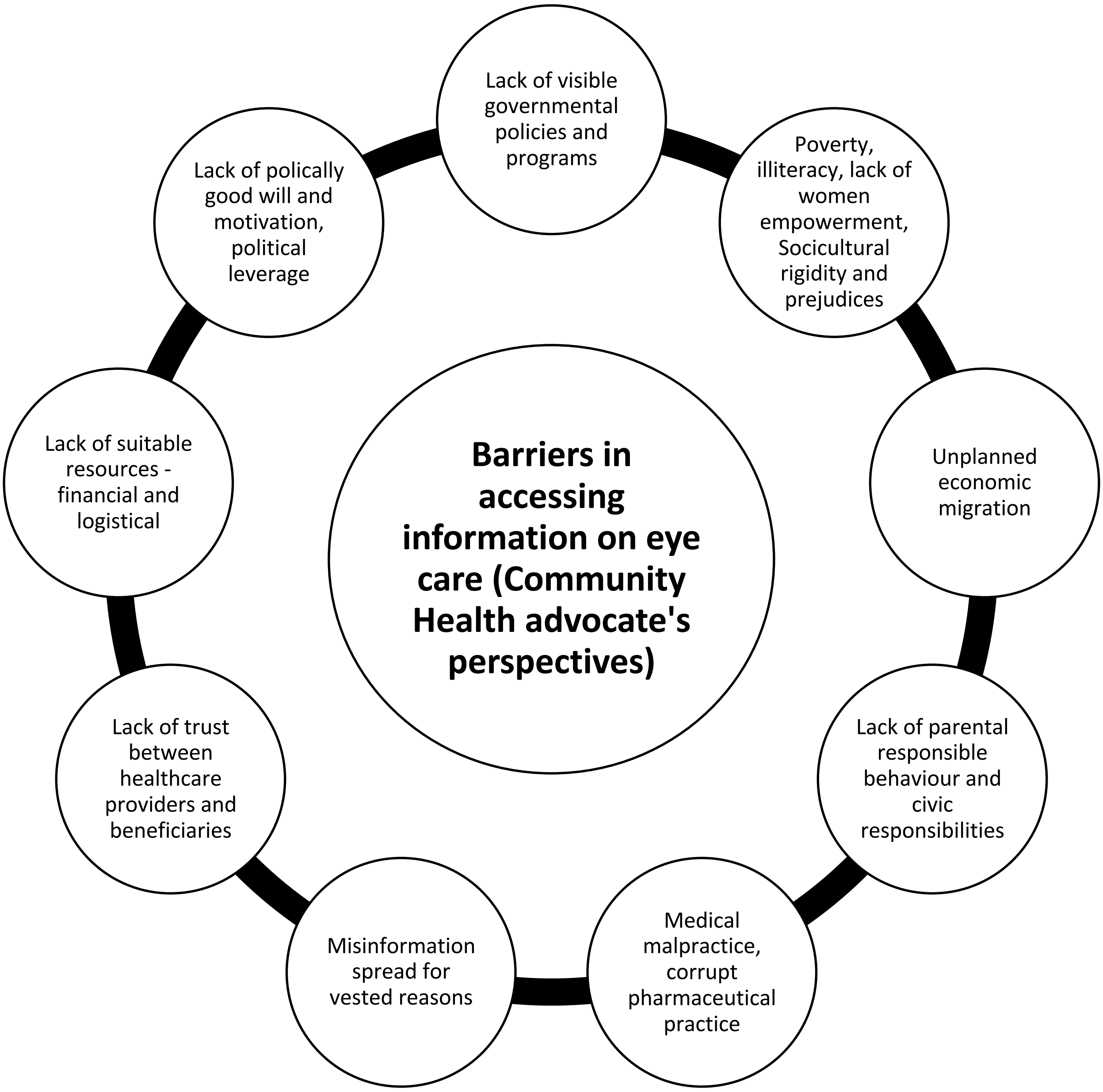

Fig 5.5. Information gap and barriers in accessing healthcare information on eye care (Community health advocates perspectives)

A lack of visibility of key governmental policies and programs on eye health was highlighted as an important factor in the creation and perpetuation of information gap.

> CA 5: *"… I have not seen much of a governmental policy myself despite heading this NGO for more than a decade … we have never been provided with instructions from the government, federal or state, as to how best to promote eye care and awareness of the risks of eye diseases and how to*

> *detect and treat them early … unlike what we see with childhood universal immunisation schemes and population control measures. I have also not seen much from the government and tertiary health care providers regarding promoting eye health … of course the deprived community is ignorant and does not have the means to access this information through alternative sources … there is an urgent need for visible and easy to understand national policies that can be incorporated into the working plans of NGOs like ours… if we are in the dark, so is the population at large …"*
>
> CA 9: *"… I am surprised that even being a government official working on similar issues, I am totally unaware of these national government programs on eye care …"*
>
> CA 2: *" … as the headteacher, I am not aware of any programs on eye health and we have not been asked to include this in our school health program …"*
>
> CA 3: *"… in my school, we have not been aware of an any national or state sponsored programs … we have not been approached by any healthcare provider to consider eye health promotion in or school health program …"*

Poverty, Illiteracy, sociocultural hierarchy and prejudices, a lack of women empowerment, were also highlighted as powerful barriers in effective eye care.

> CA 1: *"… if the population is educated and adequately supported, even the poverty stricken population would be able to understand the basics of improving eye care … if they are unable to access such information locally, they will express the desire to obtain the same from alternative sources … this would be the power of education in improving ignorance related to eye problems …"*
>
> CA 6: *"… despite our repeated advice on maintaining hygienic practices at home or advice to seek medical attention, this is often not followed through … mothers feel frightened going against their social norms and cultural practices … often a lack of a female voice in the family makes things complicated … mothers are often torn between contradictory advice from us and their family … of course, access to costly treatment is also a barrier and much of the household income is spent on the bread earner and the male child …"*
>
> CA 2: *"… female members in the family lack empowerment … they are dependent on other members of the house and often lack the say in expressing their needs … this may relate to their own health or to the health of someone else … this lack of independence is crucial in perpetuating the information gap … this is coupled with a lack of visible health information promoting eye health and accelerates the information gap further …"*

Frequent mobility and unplanned settlements for economic migrants, with poor sanitation and civic facilities were considered to be important in increasing disease burden and posed challenges in effective implementation of health promotion programs in these communities.

> CA 10: *"… illiteracy and lack of civic sense amongst these deprived communities is important … this might be related to the fact that most of these families have migrated from rural backgrounds to these unplanned urban settlements and are not able to adjust to these unfamiliar and harsh circumstances … their houses are small and poorly ventilated, the alleys are narrow and there is lack of free space … everything is hazardous over there for general health or eye health and is therefore a breeding ground for diseases…"*
>
> CA 6: *"… it is very difficult to contact them as communities as they are continuously moving … they don't often have a permanent address or telephone number … so, when it comes to contacting them, they are no longer there … so we are not able to reach them when needed…"*
>
> CA 5: *" … most they are labourers and are involved in the housing projects … as the projects finish, they move … we may never know where they had moved to .. whatever healthcare was offered here then gets discontinued …"*

A lack of parental responsible behaviour was also emphasised as an important hindrance in poor uptake of any health care program.

> CA 3: *"… despite the lack of clear and informative health provider strategies, one cannot deny the responsibilities of parenthood … in our school, whenever we have attempted promoting health, this has been accepted by the parents with little enthusiasm … often they are resigned to any ideas that eye related problems may be related to academic underachievement, instead, they cite that coming from a poor background is the reason for all their miseries … I feel that along with imparting good quality education to children, schools should also initiate proper parenting programmes …"*

The role of medical malpractice, corrupt pharmaceutical practices, misinformation spread by individuals and organisations with vested interests, political leverage and a lack of motivation, were also highlighted as important factors that contribute to nurture a culture of mistrust and distrust towards the healthcare organisations. This in turn, acts as formidable barriers in accessing good quality information on scientific eye care.

> CA 4: *"… village quacks are the main medical providers in remote areas in the absence of fully trained medical professionals (who often will not be physically stationed) … given their lack of formal training, village quacks often feel threatened by the arrival of proper evidence based information and professionals with training … this is compounded by the unscrupulous practice of some of the local pharmacies in providing regulated medicines … often a nexus exists between the quacks and pharmacists … any changes to this established arrangement is usually met with stiff resistance … the ignorant population is often a prey to circulating tales of falsehood … this allows them to keep a distance from proper care … this is a social problem and may not be sorted by improving governmental flow of information only … such governmental strategy should address educating and improving the practice of the village quacks and imposing sanction of defaulting pharmacies…"*
>
> CA 7: *"… if we print or arrange a TV program on health promotion, some of our political opponents are quick to accuse us of maligning current policies with a political motivation … this makes it difficult for us to get important information disseminated to the deprived population … equally, through the spread of fake stories by organisations with vested interest, individuals from these deprived settings are often prevented from approaching us for more information … the problem has a strong political element and needs to be solved by close political cooperation keeping petty party-politics at bay…"*

The issue of trust, between members of the deprived community and healthcare providers and supporting financial organisations, was highlighted by some community health advocates as an important obstacle in implementation of an awareness campaign.

> CA 9: *" … we definitely try to inform everyone about the current government policies and other health promotion events … however our access to these communities is limited … this may be related to mistrust and scepticism between us and them … these communities are apprehensive of our presence as often they believe that we are there to find illegal immigrants or detect illegal activities (which quite often they are involved in) … we are being projected as the police force … certain information is better accepted like that pertaining to childhood immunisation or birth control, but mostly people are reluctant to hear about anything else like eye diseases …I agree that female government officers have a better chance in developing rapport … however, one has to be worried about the personal safety of the government officers too…"*

> CA 8: *"… maybe such individuals have been cheated by scammers in the past which is why they hardly trust us … our visits are not warmly accepted but always with a bit of cynicism … this is compounded by the coercive efforts of the local money lenders who spread wrong messages in an effort to keep us away … this is because, such an arrangement benefits them immensely as they loan money at a high interest rate … it is sad that information related to valid products are not reaching the deprived population who would have benefitted immensely from these strategies …"*

A lack of available resources, locally and nationally, and time was also an important consideration impinging on the delivery of health promotion activities

> CA 3: "*… we would want to deliver more but then there is lack of time and resources and any grand ideas, are probably Utopian and at the best difficult, if not impossible to achieve …*"
>
> CA 5: *" … we critically lack suitable space … no dedicated rooms are available … without electricity or a fan in these hot weathers … often they have to sit on bare floor to hear us speak … lot of distraction happens in these informal environments … certainly, this all will not help them focus on our messages …"*
>
> CA 10: "… *the governmental agencies have limited resources and are vulnerable to be assaulted too … hence they tend to neglect this population … the drift gets bigger by the day. …"*

5.3.1.3 Perspectives of the deprived community

Members from the deprived community were highly aligned with the views expressed by the health providers and community health advocates, as to the barriers that precluded them from accessing appropriate eye care. The reported prevalence of eye problems was high in this community. Eye problems varied from untreated refractive errors to visual impairment and blindness secondary to serious infection, injury or being born premature. Most participants believed that their poor socioeconomic status, illiteracy and ignorance remained the most important barriers in accessing good eye care. In addition, sociocultural prejudices were also identified as significant contributory factor by many. Participants often felt trapped in an environment which precluded them from assigning sufficient priority to eye health and blindness, despite the devastation caused by loss of sight. Exploration of these obstacles in information flow pathway and the consequent information gap, led to the emergence of two key themes – a lack of availability of easy to understand, relevant and correct information on eye health, and, the difficulties in accessing any information that was made available (Fig 5.6).

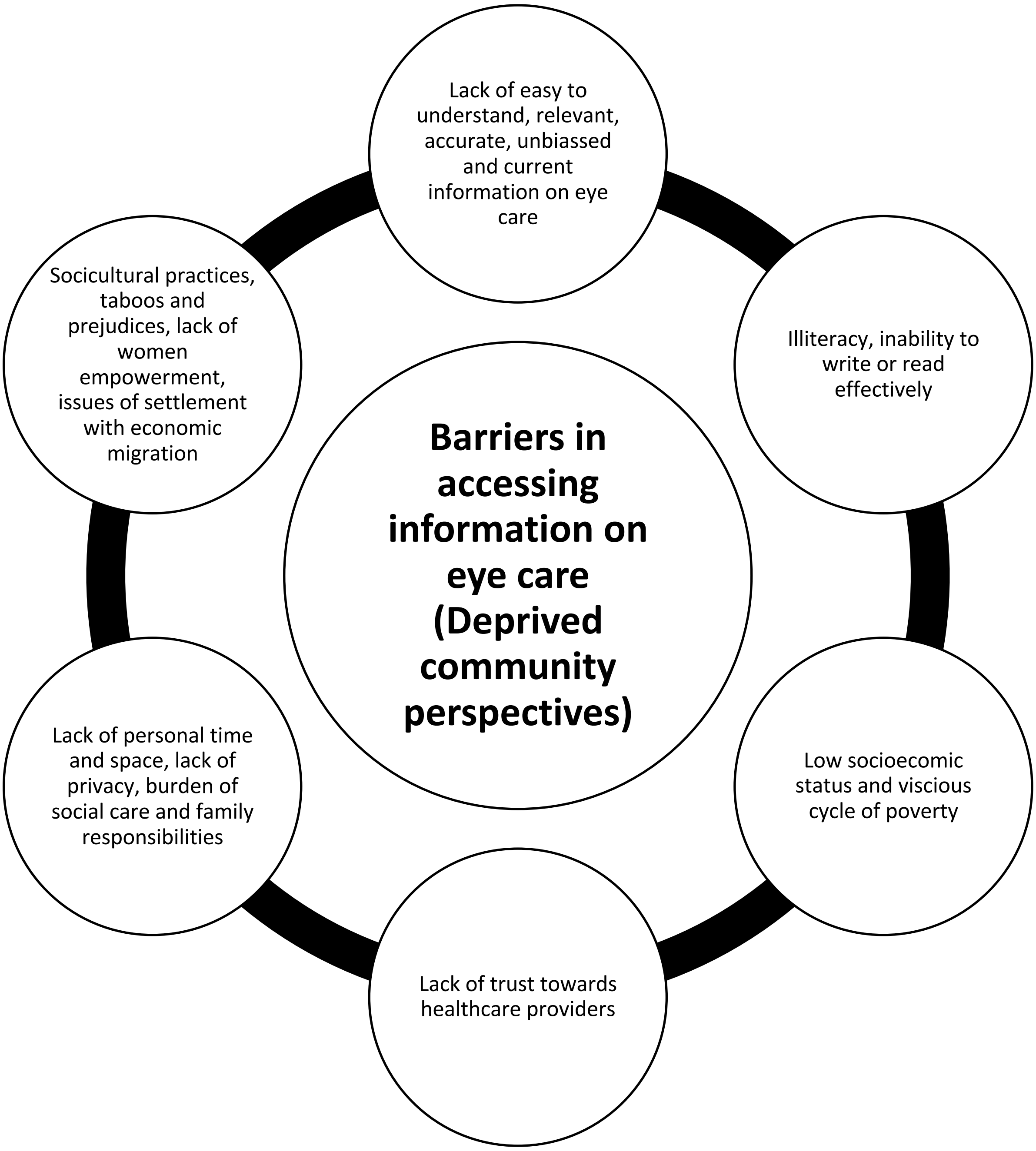

Figure 5.6. Information gap and barriers in accessing eye care information (Deprived community member perspectives)

All members of the deprived community reported that information on eye health was not readily available. It was apparent that the community has not been approached by the healthcare organisations and that the governmental agencies have not shown much interest either. These issues are barely mentioned by healthcare providers but do echo the concerns raised by the community health advocates.

> CSP 1: *"… no one comes here and we are not provided with any specific information about eye health … in our locality, we see no information visibly displayed …"*
>
> CSP 2: *"… I don't see anyone from the political parties or the corporation coming over and talking about these issues …"*
>
> CSP 3: *"… since we have moved from our villages where we used to be visited by ASHA health workers, the situation here has worsened … I don't recall seeing anyone providing any eye health information for the duration that I have stayed here …"*

The negative influences of poverty and affordability, Illiteracy and inability to read or write effectively was considered as an critical barrier by some participants.

> CSP 13: *"… we are poor people and can barely make our ends meet … my husband is the only bread earner for the whole family … how can we afford a phone that is expensive .. how can we afford the rental costs …"*
>
> CSP 2: *"… I am aware of those big eye hospitals a short walk from here … but as we are poor, we can't access any information from there …"*
>
> CSP 15: *"… I am illiterate and am not able to read anything but listening to a radio providing this information would have been helpful … however, I have not heard any programs related to eye health on the radio …my children sometimes read information for me but I don't find it comfortable…"*
>
> CSP 12: "… I can barely read and write … I prefer radio, pictures and videos …I don't see much in the television and radio channels …"

Some members cite a lack of trust towards healthcare providers as an important hindrance in accessing scientific eye care. This they report may be initiated and perpetuated by individuals and organisations with vested motives.

> CSP 4: *"… there is a lack of trust between us and health authority officials as often we see bogus people coming … these imposters con us and hence we are strictly instructed by our family members to stay far away from them … we also get warned about these insurance brokers as they are often regarded as cheats and money launderers …"*
>
> CSP 5: *"… I am aware that big clinics exist but they charge a lot of money … we do not trust them …"*
>
> CSP 10: *"…. we are restricted by the senior members of the family in accessing more information … we are told that such illnesses are not to be seen in our communities ... it is a disease of affluence and the information is there to fool us … we are also told that one should not go to a government hospital as we will not be treated well … we would rather trust our village quacks whom we have known for years …"*

Issues with accessing information on eye health was raised in the form of a lack of personal time, privacy and the overwhelming burden of household chores and responsibility of attending to the needs of other (particularly elderly) members of the family.

> CSP 1: *"…we do not have access to newspapers … our access to television is also restricted as my in-laws have their own programs to watch too … we squeeze ourselves into one room and the children also study there, therefore the television has to be switched off too … we are very busy and spend almost all our time attending to the chores of the household … my husband works elsewhere and I have to look after my old and disabled in-laws .. where is the time for anything else?..."*

Issues concerning long prevailing sociocultural practices and taboos, intrinsic or extrinsic to the study population, and a lack of women empowerment in male dominated environment, issues surrounding economic migration into poorly developed settlements and unfamiliarity of surroundings, were also highlighted by some members.

> CSP 10: *"… although I can read and write as I have been to school, my father-in-law does all the talking and we are not allowed to ask anything to anyone outside the home … I have a close family member with issues with eye sight… but I am worried that if my in-laws are made aware of this, and if they*

> *find out that I might have similar eye problems, I might be divorced … I am so frightened to even ask whether my eye sight will be affected like my relative, this may allow my family members and the community to know about my concerns …"*
>
> CSP 3: "…*my husband does not allow me to mix with everyone here as we do not understand the local language that well…"*
>
> CSP 2: *"…also, we have migrated from elsewhere, my husband is not willing to allow me to go and mix with others …"*
>
> CSP 8: *"… it is difficult to read wall posters as we then get subjected to a lot of taunts and humiliation from the local lads …"*
>
> CSP 19: *" … as we are tenants here and have recently moved, we are misfit and local people do not mix with us … how are we supposed to get this information …"*

5.3.2 Health promotion in eye health using social media

There was a widespread agreement amongst healthcare providers and community health advocates that social media may have an important role in bridging the current information gap about eye health amongst the deprived population. No such perspective were obtained from the members of the deprived community as they were not aware of social media. The following discussion details the stakeholder perspectives on the benefits, ease of use, accessibility, credibility, authenticity, trustworthiness of content, financial implications and finally, privacy and security of a social media based health communication portal.

5.3.2.1 Benefits of social media

Benefits from the use of social media based video assisted information dissemination strategies received universal support from both health providers and the community advocates. Stakeholders agreed that the appeal of social media lied in information being readily available at a minimal cost, easy to access (on a smart phone), at anytime and anywhere. It was envisaged that the availability of affordable smart phone technologies would facilitate the use of social media based health communication.

> CA 1: *"… with the advent of such cheap smart phone technology, it has become possible for the deprived sections of the society to acquire one …*

> *this is an era of smart phone revolution … now, almost anyone can have their hands on this technology…”*

It was also envisaged, unlike what may be achieved by traditional medium, the audio-visual capabilities of social media based platforms will increase its versatility in disseminating multimedia information on eye health. Moreover, stakeholders regarded the two-way communication capabilities of social media platforms as an unique advantage over traditional platforms in promoting dialogue between healthcare providers and their intended beneficiaries.

> HCP 9: *“…these people may find it difficult to approach us and this may relate to geographical, financial and social remoteness … connecting with the population that can benefit is a major issue and social media can help here … this will allow us to connect with the deprived communities remotely and a two way communication can happen … our specialist teams can connect with them and they can ask our doctors for further information as well…”*

Stakeholders highlighted another uniqueness of social media in that information thus disseminated may be accessed privately, by women and marginalised communities, otherwise subject to hierarchical and familial demands, at a time and place of choice. In such households, privacy is premium and traditional mediums like television and radio, remain under the control of the family head or the dominant family member. This discreteness and portability of information, is envisaged to be more acceptable to the traditionally shy population and be beneficial in having a deeper reach over other mediums.

> CA 2: *“…social media can help get the information across to those communities that really struggle with access issues … women may get this information privately and can access it when they are free from their routine chores which normally keep them preoccupied … this will prevent any confrontation between these women and their family members … they will get the information delivered to their home and they can access it any time …anywhere …at their convenience…”*

Social media was also seen as having a wider impact on the deprived communities. By allowing information access and by promoting networking, social media was considered as an important catalyst in improving social connectivity and pushing the agenda of social mobility.

> CA 7: *"… for me, the biggest appeal of a social media based information dissemination strategy has been to allow marginalised subjects to open their eyes … and their minds to wider possibilities … I guess that the urge to discuss and share information is a trigger for a great social change … increased connectivity within the community and with the information providers … and consequent upward social mobility…"*

5.3.2.2 Ease of use and accessibility of social media

Stakeholders agreed that social media has its appeal in being easy to use through user friendly interfaces but were divided as to its feasibility and intrusiveness as a health communication tool. Feasibility concerns were raised that were related to the cost of smart phone acquisition and its rental. Equally concerns were raised as to the lack of external funding to support this communication on an ongoing basis.

> HCP 1: *"…I can see the benefits of a social media based eye health information dissemination strategy and in principle, we want to be part of it … however, I have serious doubts about the accessibility of such information … the poorer section of the society that we cater for can barely survive .. how will they be able to afford smart phones and the data charges to access such information…"*
>
> HCP 2: *"… unless funds become available, we as health providers will not be able to provide them individually with smart phone technology … it simply is not possible on the grounds of cost implications …therefore the feasibility of such a project is put in to question…"*

The community health advocates however argued against this as they highlighted technological advancements and lowered costs as making this form of communication highly feasible. The role of governmental support in moving towards a 'digital revolution' was emphasised.

> CA 1: *" …each day brings a newer, faster and more advanced technology … it is getting cheaper by the day to acquire a phone with smart phone*

> *capabilities … data charges have been sliding down every day over the past decade … what was unaffordable to us even a few years back, is now highly accessible to people from the lower socioeconomic strata … and in my opinion, this would be the trend for the future … why can't we be more inclusive in our approach ? … we can certainly make this technology readily available to all … accessibility to healthcare information should not be an issue at all…"*
>
> CA 3: *" …we can certainly expect the government to be part of such a digital revolution … particularly when there is so much talk going on about minimising the digital divide … with so many support schemes available like provision of free bicycles for girls, etc, I am sure one should be made available for accessing this technology too…"*

Not all the community health advocates however agreed with this and concerns were raised as to the ability of the deprived community to assimilate and comprehend this form of health communication.

> CA 10: *"…it is feasible to access the technology but given the educational background, would everyone be able to use it to their benefit … maybe audio or video materials can be accessed and understood relatively easily but certainly without the necessary reading and writing skills, the process of proposed two - way communication would be in doubt …"*

Concerns were also raised by the healthcare providers regarding the intrusive potential of health communication through social media.

> HCP 1: *"…even with the availability of cheap technology allowing transmission of eye health information … will be this considered as intrusive by the families and the recipient society as a whole? … I am worried that we may be accused of entering their social environment without their permission …"*

Community health advocates however disagreed on the intrusive nature of social media as they did not regard this anymore invasive than traditional medium.

> CA 8: *"… it simply allows the information to slip through … it is like a drizzle of information percolating through the channels … it is not a whirlwind … it should not be regarded as an unwanted guest …"*

> CA 9: *"… we have already been providing healthcare information through standard channels like the television and radio … why should social media be any more intrusive than them? …"*

5.3.2.3 Credibility, authenticity and trustworthiness of social media content

Concerns were raised by all stakeholders as to credibility, authenticity and trustworthiness of information shared through social media. It was pointed out that, a poor quality eye care information that is not based on sound scientific evidence, has the potential of causing more harm than the current lack of information. Stakeholders unanimously agreed that eye care information should be simple and easy to comprehend, credible, trustworthy and originate from an authentic source.

It was highlighted that complicated information on eye care poses a challenge for the deprived community and is subject to misinterpretation with a potential for harm. Visual information was preferred over written textual matter.

> HCP 5: *"… the information has to be provided in simple local language with very clear instructions … it must be relevant to subjects with lower reading capabilities … otherwise there is every possibility that either no steps would be undertaken or wrong decisions taken …"*
>
> HCP 3: *"… as much of this population would have difficulties in understanding written text, pictures may come more handy …"*

It was highlighted that social media has the potential of sharing unscientific misinformation from individuals and organisations with vested interests. It was argued that learned bodies and governmental organisations were better placed in being the source of information on eye care, thereby eliminating false claims and promoting evidence based medicine.

> HCP 9: *"… the government is better placed to promote this form of eyecare as some organisations with a vested financial interest may like to gain from it too …we run a big institution here and yet, some dubious institutions that are well connected to the media, often steal the spot with information with little credibility …"*

> HCP 8: *"… preferential promotion of unscientific information with false claims is quite a major challenge particularly in the rural and marginalised populations … therefore reputable institutions and governmental bodies are better placed to act as trustworthy sources of information …"*
>
> CA 7: *" … this information should come from a credible source … a local healthcare provider of good repute or governmental organisations are better placed to provide such information …"*

The relevancy of information shared was also considered as important attributes in enhancing the credibility of information. Unrelated and irrelevant information were considered as major distractions with the potential of being overlooked.

> CA 7: *"… the information content should be tailor-made for the different groups within the population … information relevant to children may not be relevant for the older population …"*
>
> CA 3: *"… targeted information is important … sometimes we get to see irrelevant campaigning … people may get fatigued by the influx of such information to which they can't relate … there is no point in promoting eye care when there is an outbreak of dengue or other communicable diseases in the community …"*
>
> CA 9: *"… sometimes celebrities are there to provide such information … the population gets focussed on the celebrity and not the condition itself … also it undermines the role of healthcare officials … a better way would have been to design promotional material depicting the healthcare professionals themselves so that they are well accepted in these communities to which they deliver care…"*

Stakeholders also expressed concerns on the currency of eye care information. Outdated contact details, untraceable and unresponsive institutions, were considered as important in undermining the trustworthiness of information.

> CA 3: *" … when it comes to enquiries that are relayed back to the healthcare institutions as often such up to date contact details may be missing … authenticity of the information is very important … contact details provided have to be accurate … someone somewhere has to monitor incoming messages …"*

5.3.2.4 Financial implications of a social media based eye health intervention

Stakeholders held different views on the financial implications of social media based health communication on eye care although there was a broad agreement of using a free to use platform through a cheap smart phone technology. Concerns were specifically raised as to the cost of ongoing support for this communication channel on a long term basis.

Healthcare providers were too keen to point out that external funding is required to maintain this communication program. They attributed this to the cost of smart phone acquisition along with data usage costs, the human resource impact of preparing content material and addressing patient generated queries

> HCP 10: *"… it may be too expensive to buy and own a smart phone with good connectivity outright …it is highly unlikely that without financial support or subsidy, it would be possible for the poorer sections of the society to use this technology …"*
>
> HCP 2: *"… we are happy to design the content material and disseminate the same, but we are unable to provide the population with smart phones and help with its ongoing costs (rental charges, data charges, etc) … we are also unable to support this on a two way basis too as that would mean provision of trained staff who can attend these queries … this means that without proper financial considerations, it is difficult for us to provide ongoing support to any queries that might have come up as the result of this information awareness … I believe that the government is much better suited to enact this strategy …"*

Not all healthcare providers however shared this view. It was argued that alongside the governmental organisations, other stakeholders must also play a supportive role in making it effective.

> HCP 1: *"… if government can subsidise electricity and cooking gas … I believe that a strategy to promote digital inclusivity by the provision of subsidised smart phones with cheap rental packages may be the way forward … institutions like ours should also have a moral obligation to contribute to this effort by designing appropriate content material free of cost … this might be regarded as a gesture of our corporate social responsibility …"*

On the other hand, community health advocates remained less concerned about the financial costs incurred in developing and maintaining a social media based information channel on eye care. It was agreed that this form of communication should be initiated, funded, and maintained by a prioritised governmental strategy.

> CA 5: *"…as technology is getting cheaper by the day, the government can easily subsidise this – however the government has to consider this as a priority area …"*
>
> CA 1: *" … the intention has to be matched by governmental policy change …"*
>
> CA 7: *"… if government can ration food with a lot of subsidy … I firmly believe that a digital revolution can also be well supported … eye health has to go up the priority ladder …"*
>
> CA 9: *" …such a strategy need not mean a major change in infrastructure, but might involve merely adapting the existing infrastructure to suit the digital needs …"*
>
> CA 3: *"… we can keep costs low if we train up local members of the deprived community in the use of social media …"*

Not all community health advocates however remain convinced by the ability of the governmental agencies and other healthcare organisations in supporting health communication through social media.

> CA 8: *"… ours is such a vast country with so many poor people … how can a non-governmental organisation come up with a plan that can provide this … imagine, the work that would be generated with all those queries coming back to the institution ... that would put a lot of strain on the information provider and will not run efficiently without adequate funding arrangements … can the government really prioritise this over other needs …"*

5.3.2.5 Data privacy and security on social media

Given the existential crisis in India over widespread theft and misuse of personal data, stakeholders expressed concerns about the security and privacy arrangements of social media based health communication. However, there was a optimism prevailing amongst stakeholders about some state-of-art security technology, that should meet the privacy and security requirements of this way of communication. It is important to highlight that with the sole exception of one participant (CA 1 who had an academic background in computer sciences), none other were from an information and communication technology (ICT) background and hence were unable to comment on the technological aspects of these security arrangements. Rather, their perspectives were based on their personal use of social media and their limited experience of using social media in health and social care.

> CA 1: *"… data security is absolutely important … and data breaches do happen regularly in India and possibly elsewhere… some platforms are more secure than others … any health information programmes on social media based platforms would requires appropriate security measures.…"*

Healthcare providers pointed out their own institutional security arrangements, but were uncertain as to how this data can be kept safely for such a large scale project. It was envisaged that for a logistical challenge of this magnitude, highly professional agencies responsible for national security or financial sector may be necessary.

> HCP 10: *"…we have already been storing patient data on secured computers with restricted access … we ensure that the data is kept confidential with modern data protection software technology … however, how can such technology be generalised to the whole population and who would take overall responsibility to minimise the data breach, remain major questions … maybe some form of a national security agency that currently manages top security sensitive and classified data may come in handy here…"*
>
> HCP 9: *" … to maintain the security of a few thousand patients on our database is also a difficult task but we have strict policies in place … we even vet the personnel involved and restrict access to only a few people in this institution. However, to implement a program on a grand scale in a country so vast and diverse, it would be a major logistical challenge … but maybe some arrangements may be implemented by the national agencies that are responsible for similar data security arrangements, like those in banks and insurance companies and in the military services … however there might be cost implications too …"*

Community advocates expressed their overall concerns with online security and the cost implications of a system that ensures adequate security. The perspectives of the community health advocates on security arrangements of social media were somewhat limited and was related to their lack of ICT knowhow. Although some of them have been involved in storing simple demographic information on computers, most still used paper based records in their work places.

> CA 2: *"… we currently maintain a paper based register of demographic details of our school children and parents and they are kept in secure cupboards with restricted access … however, it is still possible for someone to have unauthorised access to the data without our approval … we simply can't afford to have an expensive technology in the current financial climate …"*
>
> CA 6: *" … we have a database of children and their family details attending our social project",* she says, *"however , those security arrangements are not that robust … I am worried that people with highly skilled IT knowledge like hackers can break in …"*

Optimism was also expressed by some of the community advocates who were already involved in handling other forms of sensitive data. Strict adherence to a code of conduct and personal integrity was highlighted as vital adjuncts to cyber security arrangements to ensure strict privacy and security of health communication shared by social media.

> CA 9: *"… we have always been working with sensitive data as we have been involved in many government projects … we have an implied code of conduct to respect confidentiality and that is our job … we think that the integrity of the system and personnel is as important as any other security arrangements …"*
>
> CA 8: *"… every day I have access to all of the finance related data of my clients and I keep them securely .. it is a question of trust … if I am not trustworthy, how can such relationships develop …personal integrity is as important as software enhanced technical advancements…"*

5.3.2.6 Choice of social media platform

Stakeholders were conversant with at least one of the major social media platforms. Mostly their personal experience lied with WhatsApp, Facebook and YouTube; participants were however unfamiliar with the use of other platforms like Twitter, Instagram or Snapchat. Healthcare providers preferred WhatsApp, and this was followed by Facebook and YouTube. Although WhatsApp remained the platform of choice for community advocates, YouTube was preferred over Facebook. Opinions and perspectives on WhatsApp is discussed in the subsequent section of this chapter (Section 5.3.3).

Stakeholder expressed familiarity with Facebook and YouTube as prominent social media platforms. The audio-visual capabilities of Facebook was considered suitable for the needs of sharing information on eye care. Additionally, the two way communication capabilities of Facebook was also considered beneficial.

> HCP 2: *"… the appeal of Facebook lies in its ability to carry audio-visual material relevant to eye health to those who need it … and this can be accessed on a phone at any time of convenience …"*
>
> HCP 1: *"… eye condition can be better explained by videos and pictures which Facebook can deliver … it is also a two-way communication tool allowing members of the deprived community to ask questions directly to the information provider …"*

Despite agreeing on their usefulness, stakeholders however did express significant doubts on Facebook. This related to ease of navigation across the interface, information control and issues surrounding accidental loss of privacy by people from with minimal literacy.

> HCP 1: *" … even to me, the Facebook interface may not be very easy to navigate … there are too many icons and accidentally one can lose privacy by clicking a wrong button …effective use of Facebook does involve the possession of some basic form of knowledge about social media …"*
>
> HCP 2: *" … even to a regular Facebook user like me, it is not easy to remain focussed with the flooding of information … controlling the input and output of information is quite challenging even to veteran users … consequently privacy remains a major concern and accidentally, private information may be disseminated with criminal consequences…"*
>
> CA 1: *" …without minimal literacy, it would be difficult for the members of the deprived community to handle this information … I think it is problematic and especially made difficult by the continuous incursion of advertisement information that may act as a continuous source of distraction …"*

> CA 10: *"… two-way communication would be challenging … I anticipate the members of the deprived community will not find it easy to post their queries to the right people … even I struggle with responding to messages …"*

Although YouTube was also considered as another possible medium with the capabilities of delivering audio-visual material on eye health, concerns were raised as to the accuracy of content matter, two way communication capabilities, support for native language usage and issues with downloading large file sizes in poor network coverages thereby limiting its overall usefulness.

> HCP 3: *"… it is nice to see a video posted in YouTube but how can one be sure about its accuracy and currency … what if the information is outdated … can such poorly literate individuals search for the right content? … I have great doubts … also, it is not a two-way tool, how will our patients ask us questions? …"*
>
> CA 6: *"… certainly YouTube is a nice place to watch audio-visual material on a mobile phone and at a time of convenience … some of these files are too big and may not download in areas with poor networks … also with so much advertising and other promotional information being pushed through … one can easily get lost and drift away from the information of interest … especially when there are so many interesting items on display…"*
>
> CA 2: *"… can one search in their native language in YouTube … even I am not sure … would it not be too much of an ask for members of the deprived community to access material in English? … without any significant improvements in linguistic capabilities I feel that the chance of this being successful in a country like ours is unlikely …"*

5.3.3 Information dissemination via WhatsApp

WhatsApp was overwhelmingly considered as a social media platform of choice by the stakeholders for use in health communication in eye care. WhatsApp was considered as a versatile platform delivering audio-visual eye care information and facilitating two way communication through a secured and user friendly interface. Most stakeholders did not anticipate any serious challenges in the uptake of this technology provided cheap smart phones and low cost carriers with subsidised data costs, were available to the members of the deprived community.

> HCP 1: *"… WhatsApp is such a versatile platform … it is so simple to use and so easily navigable … this would be beneficial for members of the deprived community as it is user friendly … it allows delivery of all kinds of multimedia materials that we would like to promote in eye health …these videos can be sent as small files too and be downloaded fast in lower network speeds for later offline viewing … at a time of convenience … anywhere … WhatsApp will also facilitate a two way communication, either through text, telephone or multimedia … this may happen in real time for all patient queries … these queries can be answered in real time or at a later time by a member of our team …"*

> HCP 3: *"… WhatsApp would be a highly workable platform … we can teach and provide them with good quality information …. equally, like in a proper clinical consultation, WhatsApp can allow the deprived community to ask us questions directly … in real time … in audio-visual capacity … this is really unique …"*

> CA 1: *"… with multiple linguistic capabilities and the capacity of inclusion of information from other media sources (like online news channels, etc) … with the end-to-end encryption and enhanced security features … with its advertisement free delivery systems where information is available in a controlled fashion and not interfered by external agencies … WhatsApp truly can match the needs of an affordable information delivery modality with high penetrance into the target hard to reach population…"*

Information topics distributed through WhatsApp

Stakeholders agreed on a wide range of topics to be considered for sharing through WhatsApp. Information on preventative eye care was considered as essential and regarded as the corner stone of any health information dissemination program. It was emphasised that routine eye care information would involve educating the population on the need for good eye care, avoiding potential hazards and attending local eye health assessment clinics on a regular basis to ensure early detection of eye problems. It was argued that this preventative approach would facilitate better eye health and help better management by early detection.

> HCP 7 : *"… the first thing is to take care of your eyes … we provide some educational sessions on our free peripheral clinics from our institute …however, there is a lack of a systematic approach to the problem … through WhatsApp short videos, we can prepare content that can reach the wider population …using traditional methods and help from ASHA health workers , we can only reach a handful in a given time period, but WhatsApp can make a difference here … we can reach larger sections of the population relatively quickly … also, we can repeat the program and make it interactive*

> *too… we might be able to monitor the uptake of this information by requesting the recipients to post us a message once they have gone through the information … all this will help in improving the practice of routine eye care and this will be an excellent preventative strategy before illness or injury happens …"*
>
> HCP 4: "… e*ye diseases can be managed in a great proportion of patients, if they arrive early to us … often they arrive so late that very little is possible … this is extremely unfortunate and a little bit of education to understand and detect common eye problems in children and adults could have made a major difference here …"*
>
> HCP 3: *"… glaucoma, a condition associated with increased pressure within the eyes, can be silent in presentation and subtle signs may not be detected unless someone is made aware … screening can help in these patients … we can reach the whole community with appropriate easy to understand information on WhatsApp to improve diagnosis and this early detection will help treat this condition more efficiently …"*
>
> HCP 1: *"… even with simple conditions like strabismus (squint), we get these referrals too late … we can correct the cosmetic defect later but the eye sight will not be fully restored as the eye sight development has not happened at all … WhatsApp can increase awareness so that these patients can be brought for earlier medical attention …"*

Stakeholders were keen on including the topic of posthumous eye donation. Eye donation campaigns have been in place for a while in India, and governmental and other non-governmental institutions, have been proactive in getting this information across. Nevertheless, this topic is not clearly understood by the general population and there is a lack of clarity on the procedural steps involved. Outdated poor quality information, pre-existing sociocultural notions coupled with serious misconceptions results in a poor uptake of this program. Even interested individuals or their family members struggle in organising posthumous eye donation arrangements in those crucial hours after death. Stakeholders argued for a easy to understand information on eye donation shared through WhatsApp highlighting its benefits and dispelling the myths.

> CA 2: *"… a lot of misconceptions and mistrust exists … superstitions are strife in the population … one believes that donating eyes may result in being born blind in the next life … detailed but easily understood scientific eye donation information would be crucial in dispelling the myths, as this is the community that will benefit the most … WhatsApp can ensure that such a message is delivered and accessed privately … WhatsApp has the ability to*

> *transgress the sociocultural prejudices that prevents the population from taking initiatives for eye donation … ”*
>
> CA 9: *“… even being a high ranking government officer in position for years … I still do not know how posthumous eye donations take place … who consents … whom to call at the time … I am fairly certain that I am not the only person here …WhatsApp will certainly empower interested individuals like me to get the most current information on eye donation and signpost me to the right authorities … we can also set up a direct connectivity with those healthcare information through WhatsApp … ”*

Stakeholders opined that information should be included to empower the community access eye care more efficiently and in a timely manner. It was argued that information provided should have current and accurate contact details and the real time two communication capabilities may come useful in crisis situations. Additionally, WhatsApp may be able to provide other forms of support especially providing information on financial and social matters.

> CA 3: *“ … when it comes to enquiries that are relayed back to the healthcare institutions … often contact details may be missing or not up to date … authenticity of the information is very important … contact details provided have to be accurate … someone somewhere has to monitor incoming messages …WhatsApp has the potential to allow this two way communication to happen in real time …”*
>
> CA 1: *“… what makes WhatsApp so appealing in the situations of crisis is its capacity of instantaneous delivery of current information … real-time communication between the healthcare provider and the patients family would be an extremely supportive step and can comfort the family in these hours of crisis… this is not possible using traditional media … also the message can get shared efficiently and quickly across the community in disease outbreak scenarios … ”*
>
> CA 5: *“… WhatsApp can support the family in understanding the implication of eye health emergency … what financial help might be available and where to seek support …what alternatives are available … where to complain if things are not met up to the standard …”*

In non-urgent scenarios, it was felt that information could be provided on accessing local care, especially from specialist pharmacies before definitive eye care become available.

> HCP 3: "… *WhatsApp can come very useful in getting tips and suggestions signposting to specialist pharmacists dispensing eyecare products and basic first aid steps … whilst awaiting medical input …"*

Some of the stakeholders wanted to include other information that would have help in allaying the anxiety of the deprived communities towards tertiary health providers.

> HCP 10: *"… WhatsApp can play an important role here… a short welcome video of the hospital and the admission process distributed on WhatsApp can allay any fear and apprehension that often is present …"*

5.3 Thematic analysis of learning outcomes assessments

The final stages of the study enquired about the deprived community member's perspectives, experiences and attitudes towards WhatsApp based eye health information dissemination strategy through focus group interviews post adoption of this new form of communication. Acknowledging that not all participants were forthcoming in expressing opinions, a few key themes emerged which is described here (Table 5.2).

- Overall benefits of WhatsApp based health communication on eye care
- Benefits of WhatsApp in increasing awareness of eye problems in the deprived community
- Challenges anticipated by the deprived community in implementation of WhatsApp in health communication on eye care

Table 5.2. Thematic analysis of learning outcomes assessments

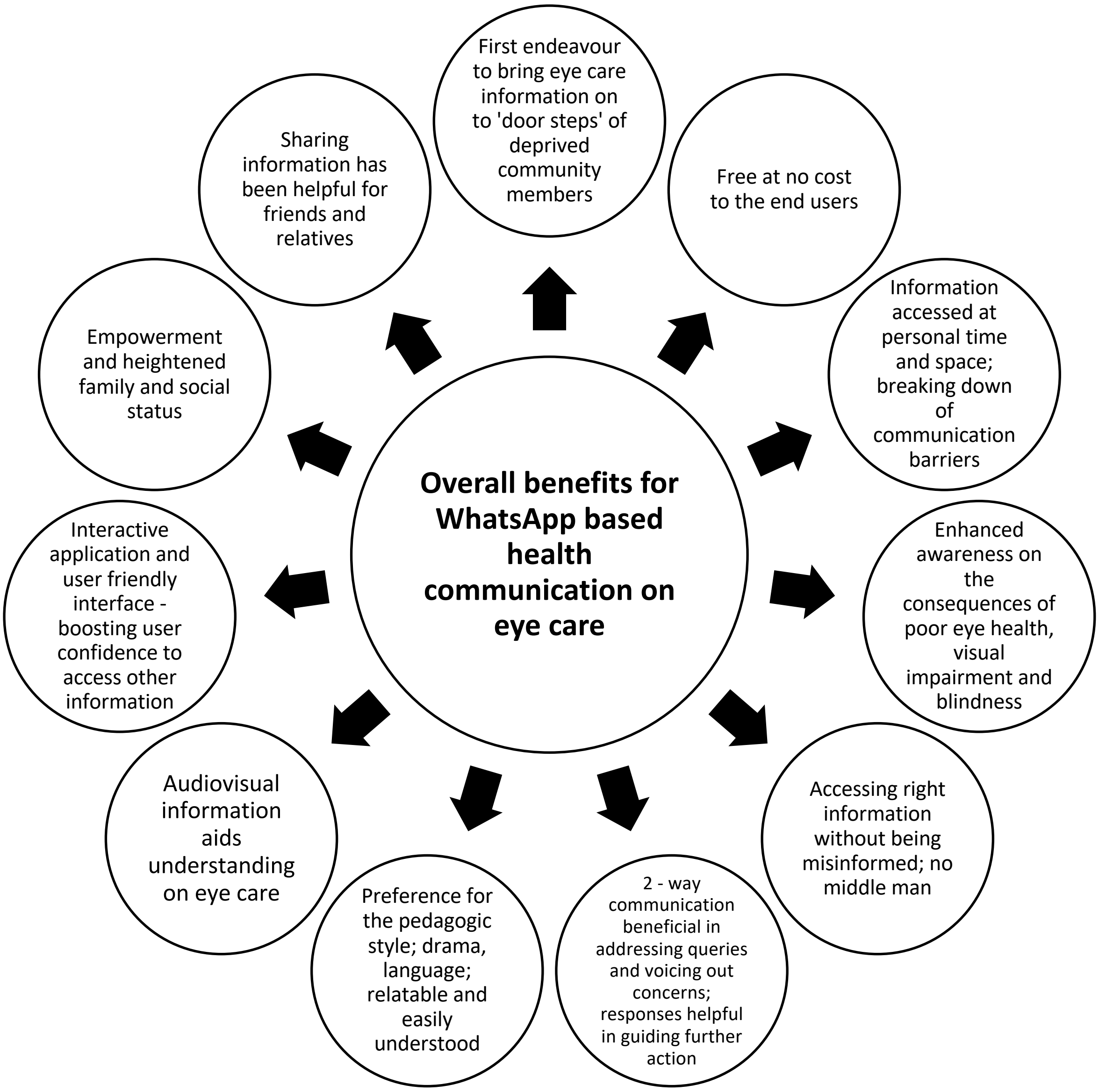

Figure 5.7. Overall benefits of WhatsApp based health communication on eye care (perspectives of the members of the deprived community)

5.4.1 Overall benefits of WhatsApp based health communication on eye care

All participants felt that these educational sessions had benefitted them in a significant manner and had made them much aware of the hazards of poor eye health (Fig 5.7).

Participants widely regarded this study as the first intervention of its kind to bring easy to understand and relevant information to their ‘door steps’. Participants regarded this exercise helpful as it allowed them to understand the problems of poor eye health and break down the communication barriers.

> CSP 1: “ *… I am ever so grateful to Didi (elder sister) that I was considered for this project … I had a lot of questions to ask but I found no-one to answer them … also, I was worried that asking too many questions may invite a lot of criticism … also, wrong information can come from wrong persons , we don’t even know them properly … these sessions were extremely helpful … and even though I may not remember everything, but I now know something … most importantly I know that if eye conditions are treated soon, eye sight can be restored … and that facilities do exist for even poor people like us…”*
>
> CSP 2: *“ … these sessions were an eye opener to us … I am illiterate and have always been frightened of people from the higher societies coming over and talking to us … during all these sessions, I never felt intimidated and I was never frightened to ask any questions … I am ever so grateful for Didi to have considered me for her project… I learnt so much … it means a lot for poor people like us…”*

Participants unanimously regarded that this project was helpful in getting the right information to them without any misrepresentation. In particular, they cited that this approach was helpful in dispelling the misinformation spread by village quacks and other unscrupulous individuals for ulterior motives. This accordingly, helped them to rebuild their trust on tertiary healthcare providers.

> CSP 1: *“ … we are mostly provided with wrong type of information … spread by people with vested interests … often that information is inaccurate and for us, there is no way to clarify the accuracy of this information … this project was so nice … it cut the middle man (touts) out … we got all the right information without any distortion …”*
>
> CSP 3: *“ … we have village quacks and also a number of other people in our community, who acts as touts for some big healthcare institutions in the city … they can rob us of our few possessions if we go there for any treatment … during these sessions, I felt that the information was accurate and that I could trust it … it was like taking a huge responsibility off my shoulder and that was such a big relief … I can now prepare myself accordingly considering this trustworthy information …”*

All participants were unanimous in highlighting the benefits of the two – way communication facility offered by WhatsApp over other traditional communication media. This allowed them to ask questions and voice out concerns whilst simultaneously receiving feedback information from tertiary healthcare providers. These rapid responses were helpful in providing them with guidance to seek appropriate eye care.

> CSP 7: *"… you can get some information on the radio or television, if you are lucky enough to get to sit to watch anything … but there is no way we can ask questions to those presenters unless you are sat there and those telephone lines are always busy … so questions still remain unanswered … from these sessions, I learnt that I can still ask questions to the information provider … in your own language and voice … it seems so easy to post a query, and I have received answers so fast … it is really good …"*
>
> CSP 8: " … *I have asked questions and I have received answers fast … I have benefitted from this immensely as I utilised that information to get my parents treated locally … it is of such benefit that all this information is provided free and that we poor people do not have the fear to pay for it … without this feedback, I would have to go to a local doctor or a quack who would have charged me a lot of money which we do not have …"*

The pedagogic style chosen for this study was preferred by the members of the deprived community as it made the information relevant and easy to relate to. The choice of dramatic narration, use of Bengali language, were considered as supportive in their learning process. As it was free to access with no cost implications; this was also cited as an important benefit by most participants. Moreover, that the information could be accessed at a convenient time and venue of choice was also regarded as appealing by the participants.

> CSP 4: *" … no questions asked … no big forms to fill in … all in my own language and in my own time … I like those dramas … as if they were happening in my own home …. in my own neighbourhood … no one even charges us any money for this … I really benefited from this…"*
>
> CSP 5: *"… one of the important benefits of this project was that I could work around it to free up my time, there was no one to disturb me … I am aware this is a research project but realistically, if information is provided like this, I can still access the same at my own free time …"*

The capability of WhatsApp in sharing audio-visual information was appreciated by the participants. The interface was considered as easy to use and of considerable appeal to participants whose first experience of interacting with the smartphone was during the learning sessions.

> CSP 6: *" … it is like watching a TV in a phone … the only difference is that it was on a small screen and that I could stop and play it in my own time .. by my own fingers … even, I can touch the screen and make it work … this is so nice …I can also share with someone else, maybe with my friend … my relative … my family…"*

This interactive experience has boosted the confidence levels amongst participants to use this technology to access more information on a wide range of issues.

> CSP 7: *"… some of us were even able to record ourselves whilst these sessions were taking place … it looks so easy and I felt so confident about this …"*
>
> CSP 9: *"… before taking part in this project … I was so worried … I do not have a phone for myself and the ones that I have seen are so simple ones … I was worried that all this would be very complicated for me … it has now all changed … I am fairly confident about understanding this and am hopeful to use it on my phone one day … when I get one …"*

Beyond the benefits of increasing awareness on eye health, members of the deprived community were also keen to highlight the wider benefits of this study. Some admitted that participation in these educational sessions had enhanced their social status, as they are now being considered as resourceful members in their families and the wider community.

> CSP 10: *"… nobody used to pay any attention to my concerns or advice in the past … no longer … with these information that I have gathered over the past few sessions… my family and my relatives now ask me for help and advice … this is really a nice feeling…"*
>
> CSP 24: *"… even in the neighbourhood, other people who had not been in this project have asked me about what I learnt … I have been able to provide them with information and advice from whatever I have learnt … my*

> *importance in the neighbourhood has certainly gone up … my words are certainly being taken with a bit of respect …*”

Through information sharing, some participants reported that this project has benefitted them in helping their extended family members and friends, resident geographically apart. The direction of flow of information seems to have changed too as now participants were able to share more information rather receive.

> CSP 22: *“… after these sessions … I realised that my mother had a similar problem … I advised her to be seen at a local health centre … she has been offered the right advice and is getting better from the right treatment … this project allowed me to act and seek help…”*
>
> CSP 15: *“… I learnt that resources do exist … this allowed me to help a friend of mine who is based elsewhere … in a different province … I suggested to her that she seek help as I hoped that similar systems may be in place in that region … it seems that I was right and my friend has benefitted immensely …”*
>
> CSP 18: *“… whenever we had any problems, we will ask our friends and relatives in our villages … they will then speak to our village quacks and get back to us … however, after these sessions, it is us who have been informing them with the right information … they now listen from us, as if the roles have changed …”*

5.4.2 Benefits of WhatsApp in increasing awareness of eye problems in the deprived community

During the interview of the focus group, it was apparent that all participants have benefitted by enhancing their awareness and knowledge about eye related problems (Fig 5.8).

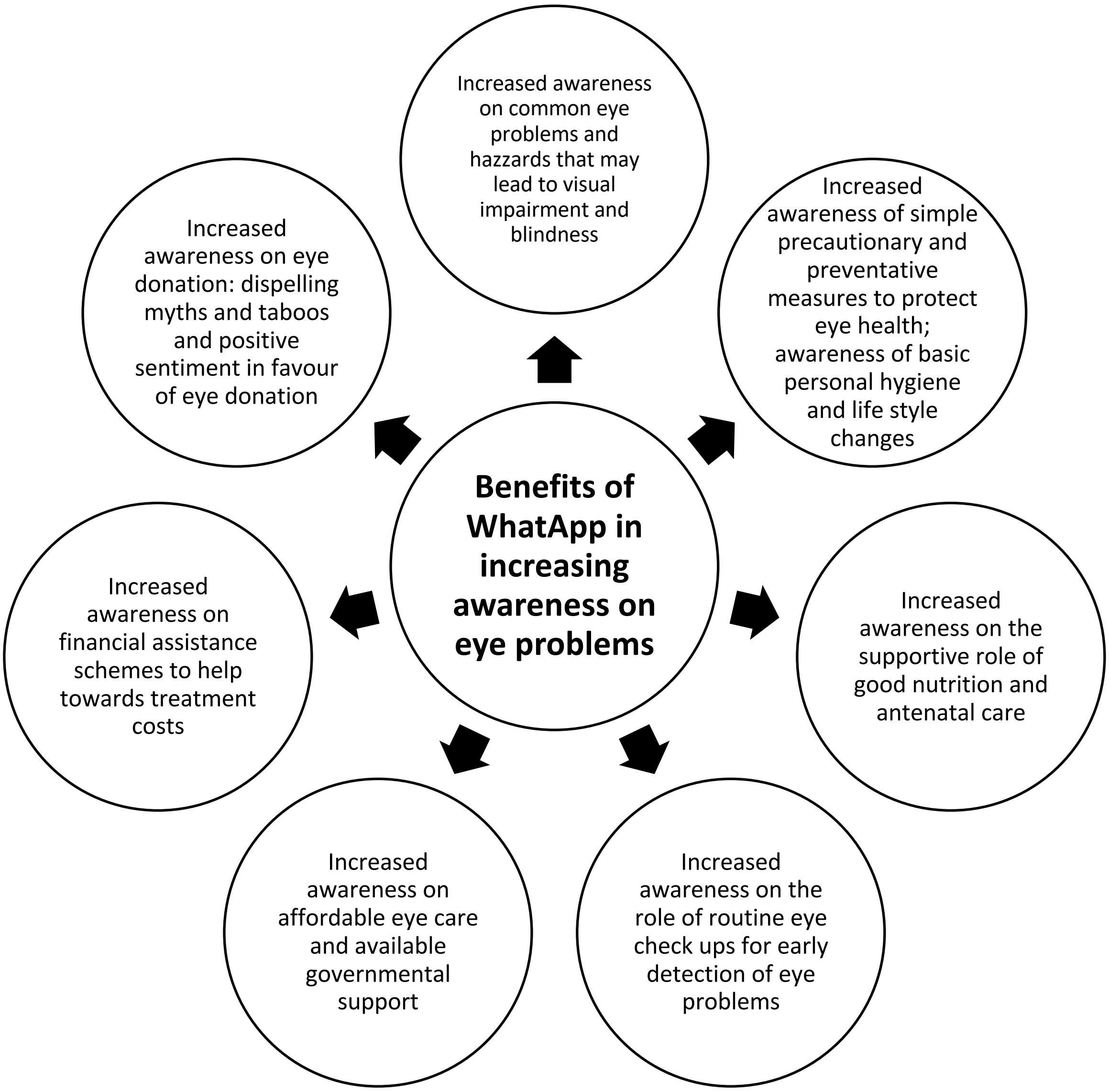

Figure 5.8. Benefits of WhatsApp in increasing awareness of eye problems in the deprived community

Many participants reported being unaware of common eye problems and hazards that might lead to a loss of eye sight. Some admitted that the ignorance about eye diseases was rampant in their communities and these sessions have helped in dispelling them.

> CSP 14: *"… we never knew that even playing in dust and dirt may lead to eye problems … often our children may go and play in the mud .. we will be more cautious next time…"*
>
> CSP 30: *"…no one in the family would believe that eye problems can affect anyone .. at any age … even little babies can be born with cataracts … I thought cataracts were only seen in elderly people …we need to be aware and act fast … we need to identify those dangers around us …"*
>
> CSP 22: *"… I learnt that worms and TB can affect eyes too … I thought they affected the tummy and lungs …"*
>
> CSP 20 : "… *I learnt that there are so many types of eye problems … there are so many ways how eye diseases can present … not always, the eye would become red or visibly different … as damage can also happen internally … like in diabetes and high blood pressure …"*

Most participants benefitted from knowing that simple precautionary measures, basic hygienic practices, and changes in life style may be associated with the preservation of eye sight. Some however, found it uneasy to go against social and cultural norms.

> CSP 18: *"… we saw those videos and pictures … I have come to know that even simple precautions may come in handy … I have been removing many dangers in my own home to make sure that it is safe for my child … I have also informed my family members to keep an eye on those dangers … previously, my relatives might have kept a bottle of acid or a pair of scissors within the easy reach of my child … not any more …"*
>
> CSP 25: *"… I have learnt that poor lighting conditions and work related exposure can affect eye sight … I would rather ask my husband to earn less rather than loose his vision…"*
>
> CSP 17: *"… never knew that even sharing the towel or the toilet may also allow spread of disease … even pets can spread disease … fumes from cooking oil can also be bad … even the kerosene stove can be dangerous … what can we do?..."*
>
> CSP 18: *"… we are told to apply kohl to our new-born baby's eyes soon after birth … however, I have now learnt wearing kohl is not good… I am worried that my family will not accept this…"*

The role of good nutrition and antenatal care was stressed. The avoidance of drinking illicit liquor, often a widely prevalent social malady, was also highlighted.

> CSP 16: *"… I now know that poor nutrition and a lack of vitamins can also affect eyesight … that one may not see at night if they have less vitamins in their body … also good antenatal care is important as babies that are born premature and small have more problems related to eye…*"
>
> CSP 15: *"… I have come to know that country liquor can result in blindness … I have talked about this with my husband who drinks regularly ... not sure whether he will ever listen to me ... after all, he may not be able to afford a proper one …"*

Participants agreed that these educational sessions have helped them in accessing information on affordable eye care and the availability of governmental support schemes. They also reported feeling more relieved and regaining some of their lost confidence with the governmental plans and programs. It was perceived that this approach helped in halting spread of misinformation that often resulted in wrong practices with dire outcomes.

> CSP 17: *"… through these educational sessions I have learnt that eye treatment exists for all … irrespective of age … rich or poor … for all religions and castes … for both men and women …"*
>
> CSP 14 : *"… we were always told that getting a treatment is not within the reach of our simple means … however, it seems now that some options does exist … hospitals can also offer affordable care if I have a BPL card … in those videos, it seems that people like us have been going to those big hospitals … I am feeling confidence in going to those hospitals for help should I need so … I have also come to understand that the government has made some plans to help us out … if only we would have known these things earlier …"*
>
> CSP 12: *"…sometimes we are told wrong things and are forced to go to our village quacks … like applying breast milk or honey or herbal leaves to affected eyes … I now know that it is not right … also, money and distance is an issue … the fear of getting ripped off is also an important issue with us … it is reassuring to know now that government has plans to help us in some ways … even locally some help may be available …"*

There was a widespread acknowledgement that routine eye check-ups may be extremely beneficial in detecting early eye diseases and result in better overall disease outcome.

> CSP 21: *"… learnt that loss of eye sight can be gradual … without us knowing … regular eye check-ups are beneficial in picking up signs before damage has happened… I had always held the idea that eye checks are only to be done if there is something wrong with your eyes … I have now learnt that this may be too long and the damage is beyond repair…"*
>
> CSP 20:*"… I have learnt that treating illnesses early is the right way forward … treating early can restore eyesight … however, if things are left until late, there are chances that the damage is permanent and vision would be lost …"*

Participants expressed satisfaction in knowing that they might be able to get some with help with the costs of treatment.

> CSP 27: *"… we are frightened of the costs of treatment for eye diseases … this is one reason, we find it difficult to approach hospitals … I was not aware that there are low cost health insurances available that can help me getting treatment free or at a reduced cost … I am now aware of government support like 'Ayushman Bharat' (the scheme launched by the Government of India) … I have also come to know that our state government has 'fair price medicine shops' where I can get the right medicines for the right costs … I am comforted by the government considering to help us as it takes away the pressure significantly …"*
>
> CSP 23: *"… I am now aware that even private hospitals have some low cost facilities for us … also other organisations can help us too … I am now aware that the we as poor people have the right to access good care too …"*

Finally, participants highlighted that these education sessions helped in increased awareness on eye donation, a greater understanding of the concept and that they felt positively towards it. Particular reference was made to the video highlighting the importance of eye donation as appealing to all.

> CSP 14: *"… I knew all wrong things about eye donation … I understood that this was sin and will affect my afterlife … I feel that there is a need for all to know the benefits of eye donation …"*

> CSP 30: *"… there is so much of bad information about eye donation … no one talks about the good things about it …"*
>
> CSP 25: *"… I (we) cried watching the video on eye donation … it was so powerful … I came to know that eye donation can have such profound effect … I feel so positive about eye donation…"*

5.4.3 Challenges anticipated by the deprived community in implementation of WhatsApp in health communication on eye care

Despite the acknowledgement of overwhelming benefits from WhatsApp based eye-health information, concerns and reservations were also raised by some of the participants (Fig 5.9).

Figure 5.9. Challenges anticipated by the deprived community in implementation of WhatsApp in health communication on eye care

Affordability of a smart phone and its associated costs were a matter of concern for many.

> CSP 22: *"…during these sessions, I learnt the use of smart phone … although, I have felt confidence in taking pictures and recordings video and posting messages, I am not sure whether I would be able to afford one … maybe, I am talking on behalf of my friends and relatives too … also, the charges for the line rental needs to be considered as that will certainly be affecting our family spending …"*
>
> CSP 17: *"… as we don't earn for ourselves … to argue for an expensive phone and the ongoing costs, may be too much of an ask to my family .. I wish such phones were available either free or at a very reduced cost …"*

Some cited this as a hindrance in sharing good eye care information amongst other members of the family or friends resident elsewhere.

> CSP 22: *"… if only we could have afforded cheap phones , I would had 2 … one for myself and for my parents in my native village … I could have shown them the pictures and made them aware of eye problems … it is not possible for me to afford this …"*

Participants reckoned that this study was 'one off' in nature and feared that would be 'soon forgotten'. Some felt that the lack of repetitive exposure to a new technology would be resulting in a loss of skills acquired in these educational sessions.

> CSP 23: *"… it is a very good way of knowing things that we were not aware of … this was made possible because the didi (staff) from the eye hospital came to talk to us with all those good information about looking after our eyes … we were encouraged to attend these sessions … there was no money to be paid too … however, will this ever happen in real life? … what if this is only a one off event and were are then forgotten?..."*
>
> CSP 14: *"… these sessions were so good but will it continue to happen? … for eye diseases and for other diseases too? .. we could have benefitted from such information for the health of our children too …"*
>
> CSP 14: *"… although we were shown and told many things, however not being literate, I will struggle to remember everything … also, as because I do*

> *not have access to these phones , I feel that I will lose what I have learnt using these phones very fast …"*

A lack of personal free time to access this information in a busy household was also highlighted.

> CSP 10: *"… we have specifically managed time to come here for these sessions but I am also aware that it I am working or have other commitments, how will it be possible for me to catch up … it would have been best if I had a smart phone … this would have allowed me to catch up at my own time …"*

Concerns were also expressed with the acquisition of the 'new' knowledge and its sociocultural implications in a disadvantaged, male dominated and prejudiced society.

> CSP 18 : *"… knowing about these conditions is good … I feel that I can now understand between what is right and what is wrong … but this is an issue within my family and my society … somehow, this is causing a friction between me and the family as I am saying things that are against our social norms … some of my family members are not liking it …"*
>
> CSP 22: *"… when I talked to my parents recently to get proper treatment … the village quacks were upset and threatened my parents saying that … 'don't come to us anymore as now your daughter knows everything' … I remain unsure how best to help others with these information…. "*

Amongst various topics discoursed, information on eye donation was accepted with some scepticism by the family members of the participants.

> CSP 25: *" … my family members do not understand about eye donation .. whenever, I have gone back to them, they tell me that I am being given wrong information … also, because I do not have a phone, I can't take the teaching sessions to them … it is a bit difficult …"*

Finally, the non-cooperative attitude of other traditional healthcare providers was also highlighted.

> CSP 27: *"… nice to know about the fair price medicine shops and available low cost eye care … however, whenever we have approached them, they have told us that we were wrongly informed … I know very well that they are not telling us the truth …"*

5.5 Chapter overview

In this chapter, all stakeholder groups concurred with the existence of a serious information gap on eye care that is initiated and nurtured by a complex multitude of factors. There was a overwhelming support from the healthcare providers and community health advocates for a WhatsApp based health communication channel in addressing this information gap. Post implementation of this new form of communication, benefits were observed amongst the members of the deprived community. This was specifically noticeable in the issue of enhanced awareness on eye diseases and its management, but the benefits were observed in other areas too. Nevertheless, despite beneficial effects of WhatsApp, some serious challenges were anticipated by the deprived community members.

CHAPTER 6. Discussion

6.1 Introduction

This chapter summarises findings from this study and compares and contrasts these findings with the existing literature. Subsequently, the chapter discusses the change in health related communication in the deprived community post WhatsApp intervention and proposes a framework of this change. Finally, the chapter proposes a framework of benefits and barriers in adopting WhatsApp for health communication in eye health.

Background

Over the century, considerable advances in eye care have ensued, however, much of the benefits are yet to be realised in the developing world where awareness of eye diseases, affordable remedial resources and access to eye care services is fractionated and beyond the reach of the most members of the deprived community. Much of this visual impairment and blindness arises from treatable common eye problems including unaddressed refractive errors, cataract, glaucoma, corneal opacities, diabetic retinopathy, and trachoma (Bourne et al., 2017). Poor eye health outcomes are also complicated by suboptimal eyecare service utilisation that is traditionally patchy in the deprived settings and is determined by the availability, accessibility, affordability, and acceptability of care (*World Report on Vision*, 2019). These observations are particularly relevant to India as it harbours the largest population with blindness and visual impairment in the world (Stevens et al., 2013).

Whilst there is a lack of robust data, recent estimates suggest that the prevalence of blindness and visual impairment is especially high and that women, older people, rural residence, and low socioeconomic status are more prone to significant eye health problems (Neena et al., 2008). Socioeconomic factors are an important determinant of eye care outcomes. Common with other developing countries, despite significant economic advances over the past few decades, it is estimated that approximately 22% of the Indian population lives in poverty, which reflects the largest concentration of poverty anywhere in the world (Gupta et al., 2014). Importantly, deprived communities carry a greater risk of blindness and visual impairment (Dandona and Dandona, 2001; Khanna et al., 2007; Ulldemolins et al., 2012). Amongst the multifactorial causal factors, a serious lack of awareness of eye diseases and paucity of information on accessible and affordable eye care, continues to pose a major challenge to health policy makers (Brilliant et al., 1991; Fletcher et al., 1999; Vaidyanathan et al., 1999; Dandona et al., 2000; Kovai et al., 2007; Marmamula et al., 2011). In line with global initiatives, the Government of India has demonstrated a strong commitment to addressing this issue by establishing the National Program for Control of Blindness (NPCB). This program has an ambitious goal of reducing blindness prevalence, and remains the single largest National Health Programme exemplifying the successful public-private partnership (PPP) model (Verma et al., 2011; Misra et al., 2015; Vemparala and Gupta, 2017). Additionally, India has also adopted a 'Vision 2020: The Right to Sight' program with the aim of blindness elimination by the year 2020 however it has yet to achieve its intended goal (Rao, 2000; *VISION 2020: The Right to Sight - India. A snapshot of our journey 2004 - 2018*, 2018).

Increasing the community's awareness of eye health remains an important measure improving eye health outcomes, and, the NPCB aims to enhance this by utilising print, electronic and social media (Vemparala and Gupta, 2017). Social media, in particular, is an important consideration here as it has the potential to facilitate rapid information sharing and provides a credible alternative to traditional media (O-Adewuyi, 2016). Furthermore, the appeal of social media lies in the fact that it can be conveniently accessed through widely available affordable mobile technologies, and offers potential for two-way communication between healthcare providers and a wider audience, including those from the disadvantaged groups. In recent decades, social media usage has risen exponentially in the Indian subcontinent (*Social media usage in India*, 2019). WhatsApp, the social media of interest for this study, has increasingly become popular in India. It is estimated that it penetrates 28% of the population, and is heavily used by those resident in rural communities. Despite this, very little research has been done on the use of social media platforms to promote community awareness of eye care. Moreover, no research to date has been undertaken on the use of WhatsApp as a key portal of eye health communication for members of deprived communities. Accordingly, this research sought to offer insights into the use of WhatsApp in eye health education in a community-based setting in a deprived semi-urban Indian setting.

This study aimed at exploring the potential benefits and barriers associated with WhatsApp as an information portal for enhancing community-based practice in eye health in deprived semi-urban settings. Potential benefits and barriers associated with the use of WhatsApp were explored from the perspective of the stakeholder groups, which included healthcare providers, community health advocates, and members of the deprived community. Most importantly, this study also explored the nature of communication and attitudinal changes in the deprived community as a result of an intervention associated with the adoption of WhatsApp in eye health, and proposed a framework of this change. Insights from the research intervention were subsequently reviewed in the light of prior research, in order to develop conceptual models of benefits and barriers of WhatsApp based information portal on eye care.

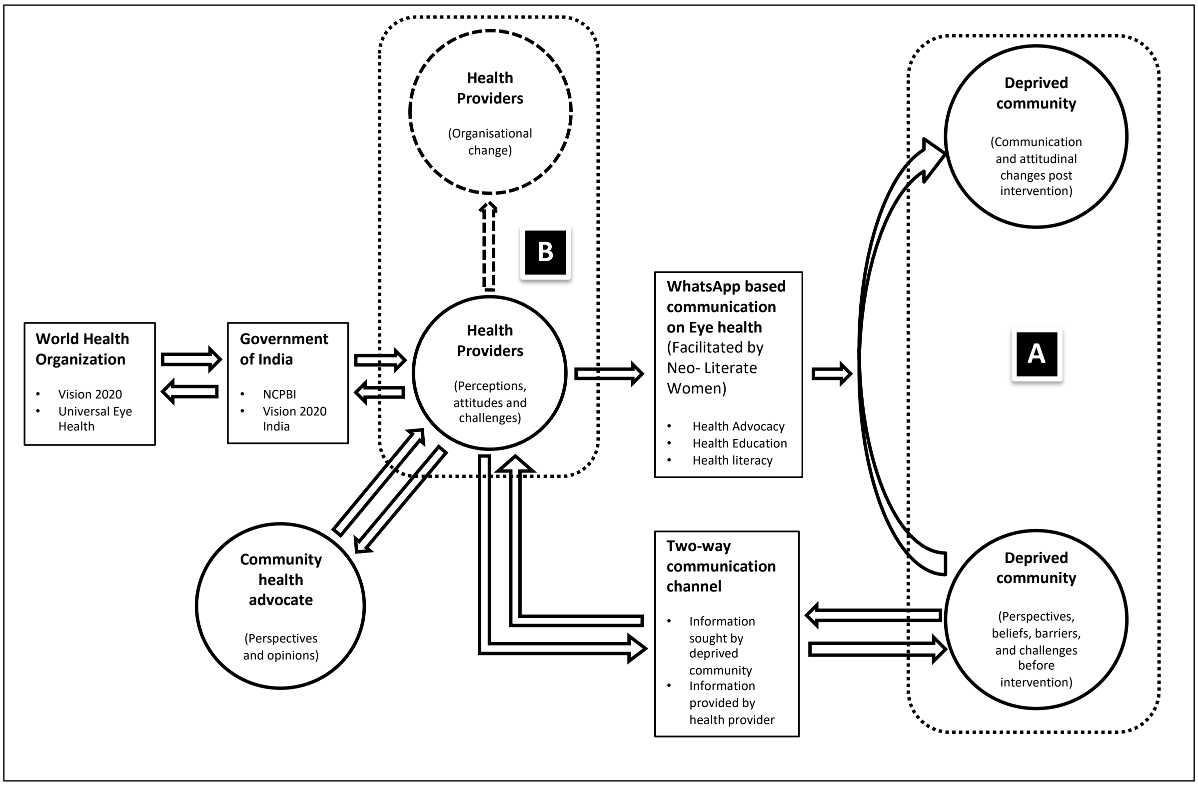

Fig 6.1. Summary of the processes, interactions, interventions and changes explored in this study

Fig 6.1 summarise the study and depicts the information sharing processes and the interactions between various stakeholders. It describes the traditionally flow of health information on eyecare from national and international health authorities to the healthcare providers. It provides the strategic position of the community health advocates in an advisory role to the health providers. Subsequently, it describes the novel WhatsApp based health communication portal (the intervention) for disseminating eye care information to the members of the deprived communities that is aided by neoliterate women facilitators. It also describes the two-way channel established by WhatsApp allowing the deprived community members to connect with the healthcare providers. Additionally, the communication and attitudinal changes noted post adoption of WhatsApp based health communication portal is schematically represented (Fig 6.1 Section A). Finally, the figure schematically proposes future research in exploring the organisational changes in the healthcare providers after a successful implementation of this intervention (Fig 6.1 Section B).

6.2 Summary of findings

6.2.1 Information gap on eye care in India

The first stages of this study explored the information gap relating to eye care on the basis of the opinions and perspectives of the key stakeholder groups (healthcare providers, community health advocates and members of the deprived community). There was a consensus from all stakeholder groups that not enough good quality, accurate, unbiassed, relevant and topical information exist on eye health in India. In addition, there was unanimous agreement that whatever information existed, it remained inaccessible and beyond the understanding of the vast majority of the population, particularly those belonging to deprived communities. However, stakeholders varied with their views on the nature of and reasons for this information gap, and how it might be remedied (Table 6.1).

	Healthcare provider	**Community health advocate**	**Deprived community**
Provider factors	Ineffective information dissemination strategy Lack of concerted and coordinated approach between allied key health workers Misinformation spread for vested and unscrupulous interests	Inadequacy of governmental strategies Lack of visible national and international programs on eye care Inadequacies of healthcare providers in promoting health communication agenda on visual impairment and blindness Mistrust towards end users Malpractice	Lack of accessible and easy to understand, relevant, unbiased and accurate information on eye health from the governmental agencies and healthcare providers Non visibility of governmental programs on alleviating visual impairment and blindness Non visibility of healthcare provider's campaign on improved health communication Misinformation spread by individuals and organisations with vested interests A lack of trust towards healthcare providers
End user factors	Lack of basic literacy, particularly digital literacy Extreme economic disparities Deep rooted sociocultural prejudices A lack of women empowerment Vulnerability of children, women and young parents Prevailing culture of distrust and mistrust	Lack of basic literacy and digital literacy Poverty Lack of civic sense and hygiene Innate stubbornness and unwillingness to change Frequent change of residence and unfamiliarity of the new surroundings. Strong religious beliefs Social and cultural taboos A lack of women empowerment	Illiteracy, lack of digital literacy Deep rooted ignorance Poor socioeconomic status Lack of Cultural prejudices Lack of women empowerment Lack of personal time and space Voices not been heard in their own community Being part of a migrant community A sense of hopelessness, frustration and fatigue as nothing changes A feeling of being socially isolated from the mainstream population
Other extrinsic factors	Public apathy Apathy from health insurance providers	Socio-political apathy, A lack of transparent and easily understood health insurance	Geographical remoteness, a lack of infrastructure

Table 6.1. Comparing the perspectives of the different stakeholder groups on the information gap in eyecare

Healthcare provider’s perspectives on information gap on eye care

The majority of healthcare providers attributed this information gap to the ineffectiveness of existing information dissemination strategies and to the innate socioeconomic complexities of the deprived communities. Healthcare providers reported that there was a lack of basic literacy, particularly digital literacy amongst the members of the deprived community. This was compounded by extreme economic disparities, deep rooted sociocultural prejudices, a lack of women empowerment, public apathy and a prevailing culture of mistrust that was fuelled in part by misinformation spread for vested and unscrupulous interests. It was reasoned that the deprived population lacked basic literacy, and thus cannot access traditional sources of information like print media, and lacked basic digital literacy (and smart phone access). Healthcare providers also emphasised the vulnerability of children, women and young parents. This resulted in self-medication and being treated by unqualified personnel, with deleterious consequences. Some also highlighted the lack of coordinated and concerted approach between allied key health care workers and apathy from health insurance providers. Inadequacies of other allied healthcare programs like the maternity and child health, which embeds a new born eye check screening program, were also mentioned by some. Healthcare providers were also quick to highlight that recent endeavours by the government have failed to alleviate the problem, and that deprived communities still did not access health services.

Community health advocate’s perspectives on the information gap in eye care

Community advocates recognised the role of underpinning issues like a lack of basic literacy, sociocultural complexities, a lack of women’s empowerment, prevailing culture of misinformation, mistrust and malpractice, but, highlighted governmental inadequacy and a lack of concerted effort from healthcare providers to put national blindness and visual impairment prevention strategies on an ‘easily visible and widely accessible’ roadmap. Unlike other widely visible national health programs like ‘Pulse Polio’ and ‘Universal Immunisation’, community health advocates expressed surprise on the existence of key policies on eye health. Contributory factors highlighted included poverty, innate stubbornness of the deprived population and their unwillingness to change, frequent change of residence and unfamiliarity of the new surroundings. Illiteracy, lack of civic sense and hygiene, strong religious beliefs, social and cultural taboos and a lack of women empowerment, may alone or in combination, as community health advocates argued, contribute and perpetuate the problem. Importantly, they also highlighted the overwhelming influence of socio-political apathy, resulting in a lack of focussed and concerted intervention. A dearth of transparent and easily understood health insurance programs were also identified as a contributory factor, resulting in the deprived community being exploited by individuals and organisations with vested financial interests.

Deprived community member's perspectives on information gap in eye care

Despite a high prevalence of eye diseases, it was apparent that very little awareness has spread to these communities. Members of the deprived community agreed with other stakeholders in acknowledging the contributory role of illiteracy, ignorance, poor socioeconomic background, existing cultural prejudices, geographical remoteness and being part of the migrant community, as the key factors in causation and perpetuation of information gap on eye care. However, they also highlighted a lack of accessible and easy to understand, relevant, unbiased and accurate information on eye health from the governmental agencies and healthcare providers. Echoing concerns raised by the community health advocates, deprived community members were not aware of national programs aimed at increasing community awareness of eye health. A lack of women's empowerment, personal space and choice were also stressed and members often felt trapped in an environment which did not allow them to assign importance to the potentially devastating effects of eye diseases and blindness. Deprive community members also highlighted the spread of misinformation by individuals and organisations with vested interests that prohibited receiving affordable and scientific eye care. This, they admitted contributed towards a culture of mistrust towards the healthcare providers. Collectively, a sense of hopelessness, frustration, fatigue and a feeling of being socially isolated from the mainstream population prevailed.

6.2.2 Stakeholder's perspectives on the use of social media in health communication on eye care

After having unequivocally confirmed the existence of a substantial information gap in eyecare in India, the next stage of the study aimed to explore the understanding, opinions and beliefs of the healthcare providers and community health advocates in the role of social media in mitigating this gap. It was anticipated that experience of the use of social media would be minimal amongst members of the deprived community, therefore, their opinions were deliberately not sought.

Both healthcare providers and community health advocates had favourable opinions regarding the benefits of social media as an effective tool for the dissemination of eye care information. They perceived the appeal of social media to be associated with the fact that information was readily available at a minimal cost, easily accessed at their ‘finger tips’, anytime and anywhere. For the healthcare providers, the audio-visual nature of social media platforms appeared particularly attractive for disseminating a variety of multimedia information relevant to eye health, since this could not be disseminated through traditional media. Other perceived benefits included discreteness, which, together with portability, may prove beneficial to these marginalised communities, as often they often have time and space constraints that limit their access to information. Stakeholders also agreed that social media would facilitate two-way communication, which coupled with discreteness, would provide a unique opportunity for these traditionally shy deprived communities to voice their concerns. Interestingly, and beyond its use in eye care, stakeholders opined that by sharing information, generic or personal, and with enhanced engagement, social media may also improve social connectivity and social mobility.

Acknowledging the possible benefits of social media, stakeholders held different perspectives on the feasibility of a social media based health communication strategy. Healthcare providers expressed concerns about smart phone ownership, data usage costs and whether this strategy would be regarded as intrusive by members of the deprived communities. Additional concerns were raised as to cost implications for healthcare providers in supporting this program unless external financial and logistical help was to become available. In contrast, community health advocates cited affordable technological advancements and support from the Government’s digital initiative as possible solutions to the posed challenges.

Concerns were raised as to the accuracy and relevance of content matter on eye health, as it was perceived that, poor quality, biased, unregulated and unscientific eye care information has the potential for more harm than that which ensues from the lack of information. Concerns were also raised as to the credibility and authenticity of such information, as this approach had the potential to be mis-utilised by unscrupulous institutions. Stakeholders agreed that eye health related information should be simple, easy to comprehend, audio-visual, accurate and trustworthy, unbiassed, relevant and originate from an authoritative source, preferably governmental channels or reputable national agencies. Stakeholders also argued for a live two-way communication feature occurring in real time, to help to achieve accuracy, currency and authenticity of information.

Stakeholders expressed worries about the financial implications of this approach. Healthcare providers were keen to point out that it may be beyond organisational financial interests and capability to provide members of the deprived community with affordable smart phones. Additionally, concerns were voiced about network usage costs, and the human resources needed to support a two-way communication portal. They perceived that external funding, preferably from governmental public health organisations, would be a key determinant of the success of this program. Community health advocates appeared more positive and envisaged minimal financial implications, but recognised that such a strategy should be initiated, funded by, and maintained by a prioritised governmental strategy. They also highlighted that much can be achieved through intelligent adaptation of the existing infrastructure thereby reducing implementation costs.

Widespread theft, misuse of personal data, and security breaches were identified as concerns by all stakeholders. Such misuse of breached personal information may have amongst all, unwanted consequences of affecting personal lives and loss of employment. It was agreed that a robust data protection arrangements, similar to that employed by the Ministry of Defence, or those in the banking and financial sector, needs to be in place to handle data privately and securely. Nonetheless, they were unsure as to the funding arrangements and safe-keeping custodians, with some indicating preference for governmental agencies. However, it needs to be emphasised here that, with the sole of exception of one community health advocate with knowledge of computing, such opinions originated not from deeper scientific understanding, rather their personal use of social media, thereby allowing the theoretical possibility of introducing bias.

6.2.3 Stakeholder’s perspectives on the use of WhatsApp in health communication on eye care

There was an overwhelming agreement amongst all stakeholders that WhatsApp was the social media platform of choice for eye care communication. WhatsApp was considered to be a workable and versatile platform, which was better suited than other popular traditional social media platforms. Its simplistic, user friendly interface, audio-visual capabilities, low network usage, and support for two-way communication (telephonic and multimedia) in real time were cited as a major advantages. The two-way capabilities of WhatsApp were considered particularly beneficial in medical crises, as it may be used to direct affected individuals to local eyecare centre and signpost towards available financial / social support systems. Widespread use and deeper reach into the rural communities were also important considerations in the choice of WhatsApp. Stakeholders did not anticipate any serious challenges in the uptake of this technology, provided affordable smart phones and low-cost networks were made available to the members of the deprived community.

Stakeholders agreed that the information on eye care to be disseminated must be authentic, unbiassed, correct and current. There was broad agreement on the choice of content matter for dissemination. General topics, such as preventative routine eye care, eye donation, and improved and efficient access to eye care were viewed as being likely to have the most impact. Healthcare providers were keen on providing information that raised awareness of eye health hygiene, common eye problems and the beneficial impacts of early diagnosis. The topic of posthumous eye donation was also highlighted to dispel misconceptions and mistrust and, to help and support interested donors in navigating through the process in stressful times.

6.2.4 Beneficial effects of WhatsApp based health communication in the deprived community

All participants from the deprived community reported having benefitted in a significant manner from the WhatsApp based health communication intervention carried out in this research. Participants reported being more aware of the risks posed by poor eye health and visual impairment and being knowledgeable on access to affordable eye care. This intervention was regarded as the first of its kind to bring brought understandable, acceptable, trustworthy and relevant information to their door steps without any misrepresentation or personal cost. The pedagogic style employed was overwhelmingly supported as they found it easy to understand and engage with. The choice of language, audio-visual nature of the content, and the short audio drama clips that they can personally identify and relate to, were specifically highlighted as key factors in keeping them actively engaged. Some of the participants regarded the information dissemination strategy helpful and hassle free as it fitted easily into their otherwise extremely busy daily schedule where personal space and privacy remained a major constraint to any information gathering or learning. The ease of use of the WhatsApp interface was also of considerable appeal to some of the participants. The resultant boost in confidence levels encouraged participants to consider using WhatsApp for seeking more healthcare information in the future. The two-way communication modality of WhatsApp was particularly appealing and the deprived community members viewed this as a significant benefit over health communication through other traditional platforms. Unlike, the inflexibility and didactic of traditional mediums, participants regarded the audience interaction as profoundly beneficial in airing out concerns and obtain further information. Information thus obtained, were then to be shared across with close friends and families.

Role of WhatsApp based health communication on increasing awareness of eye health in the deprived community

WhatsApp based health communication strategy was instrumental in increasing awareness amongst the deprived community members on eye care (Fig 6.2). Prior to this intervention, most participants admitted being unaware of common eye problems and hazards, which might potentially lead to blindness and visual impairment and some admitted ignorance to prevail at societal levels. As would be hoped, post intervention, all participants reported being benefitted in enhancing their awareness and knowledge about eye related problems. Participants reported heightened awareness of the preventative aspects of eye health and contributory role of simple precautionary measures involving life style changes, adequate nutrition, properly supervised antenatal care and routine eye checks. Additionally, they demonstrated an increased understanding on the availability of affordable eye care and supportive governmental programs. This allowed the deprived community members to regain some of their lost confidence in governmental policies. On the topic of eye donation, which is highly neglected and prejudiced, participants reported better understanding and felt positively towards being involved as a donor themselves.

However, WhatsApp should not be seen as the only solution to the health literacy crisis, but rather as a powerful adjunct to existing strategies, complementing existing means of health communication and forging new communication channels. WhatsApp, despite its universal appeal across all of the stakeholder groups in this study, has a number of challenges, as discussed in detail in section 6.6.2. However, it is important to acknowledge that such challenges are multifactorial in nature and differential in impact (Fig 6.2). For example, this study did not explicitly explore the level of literacy, or the levels of information literacy of the women participating in the study. Consequentially, the benefits of a WhatsApp based communication, may have different levels and types of impact. More specifically, the impact of any given WhatsApp based intervention may be highly dependent on the literacy, and information literacy of a community and its members.

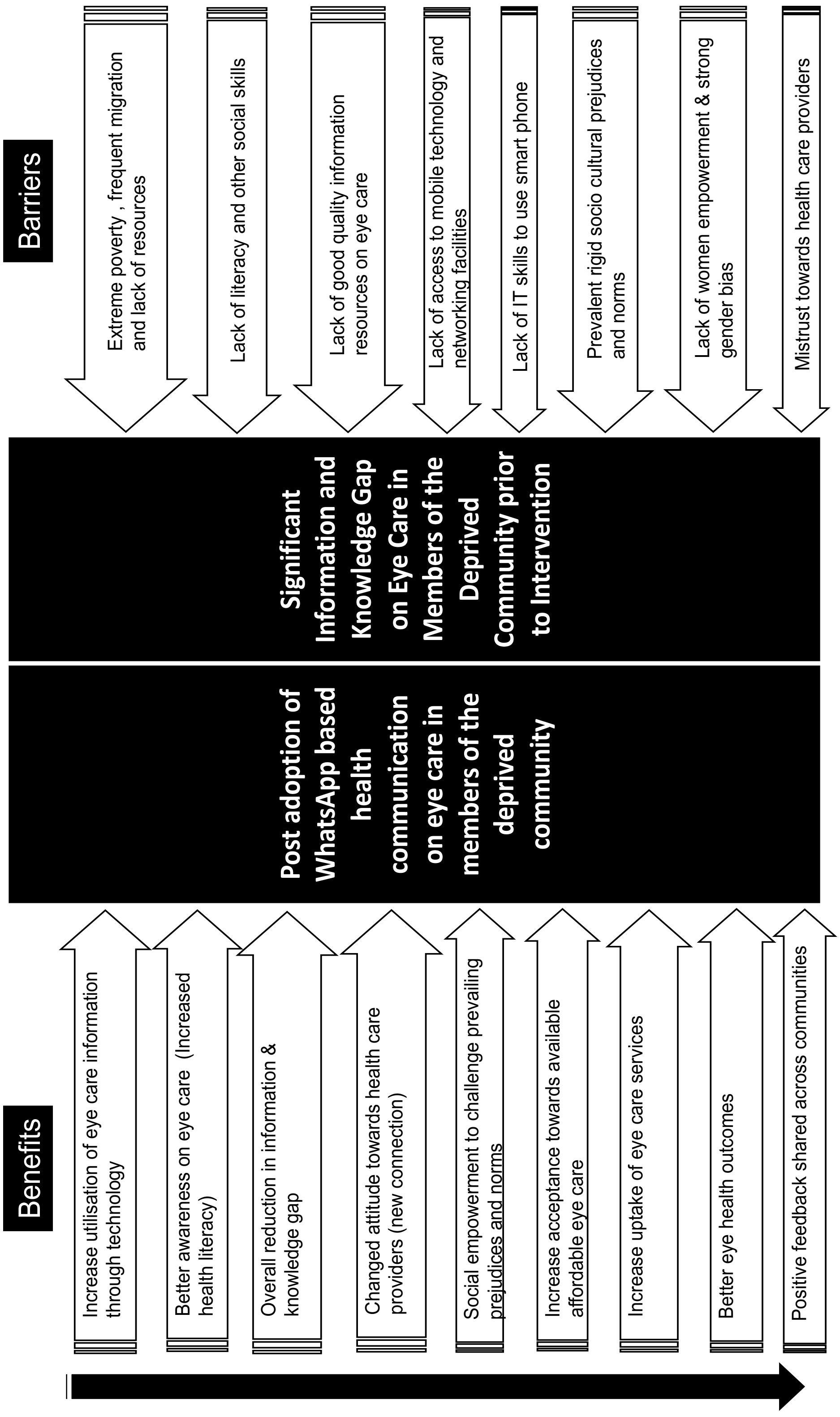

Figure 6.2. Benefits, barriers and changes in the deprived community after the WhatsApp-based intervention (arrow indicate possible sequence of events in time)

Communication and attitudinal changes towards eye care and healthcare providers exhibited by the members of the deprived community post WhatsApp based intervention

With the introduction of a new information channel, that supported opportunities for learning, it would be reasonable to anticipate some changes in the deprived community, regarding communication and attitude towards eye care and its providers (Fig 6.2). There is evidence to suggest that WhatsApp based health communication resulted in an enhanced awareness of eye care through increased information utilisation leading to a consequent reduction in participant's information gap. Increased health literacy resulted in deprived community members challenging prevailing norms and attitudes towards eye care, and, in particular developed an enhanced appreciation of the value of the contribution offered by healthcare providers. By being enabled to recognise myths and misinformation associated with eye care, deprived community members felt able to create an enhanced connection with healthcare organisations involved in the delivery of community eye care. WhatsApp based health communication significantly influenced the reduction of mistrust towards healthcare providers, and increased community acceptance towards affordable and scientific health care. Ultimately, there is a real possibility that such changes may be associated with improved eye health outcomes, and reduced disease burden in these communities. In addition, there is nascent evidence that suggests that deprived community members may share their positive experiences and increasing knowledge, thus disseminating information and practices across a wider community.

Importantly, the impact of this interventional study was not restricted to improvements in awareness of eye care practices. By empowering women, it made a modest contribution to challenging centuries of gender bias in India. This bias is particularly strong in deprived settings with deep rooted ignorance and sociocultural prejudices, that have ensured that women remain subjugated, and their voices and concerns unheard (Nussbaum and Glover, 1995; Mohapatra, 2015). Empowered with newly acquired knowledge, and the resultant boost in confidence regarding eye care and the use of new technology, participants were considered as resourceful within their families and the wider community. Information on eye care was actively shared by the participants with friends and relatives. Participants reported an increase in self-respect and power over their own lives, society and in their own community.

6.3 Methodological strengths of this study

This study has a number of methodological strengths that merits further consideration. Independently, these considerations formed the foundation of a well-designed qualitative study with validated outcomes. The qualitative interpretative study design allowed the investigator to understand the phenomenon from within without distorting and influencing the discourse. Based on an interpretivist paradigm, this research sought to perceive reality through pluralistic, interpretive, open-ended, and contextualised notions, with validity being assessed through concepts of trustworthiness and authenticity. Stakeholder opinions were sought through a mixture of approaches that included semi structured interviews of individual study participants and a focus group interview for the final evaluation. Through the pilot interview, that allowed *a priori* fine tuning of the interview questions, guided by the feedback from the initial participants (who were not included in the final analysis), allowed the researcher to continue refining and improving data collection approaches. This was instrumental in hinting at themes representing the 'core meaning' of interviewee perspectives and to appropriately undertake a thematic analysis later as the qualitative analysis method of choice. The validity of this study was also enhanced by the provision of a *thick, rich description,* that provided detailed extracts of participant's perspectives, allowing the reader to be transported into the setting to explore the phenomenon of interest. Researcher's awareness of current politics and socioeconomic of the geographical region and the study population, allowed the study to be fine-tuned and adapted as per the needs of the study. This researcher reflexivity may also be considered as an important advantage of this study in ensuring research validity. Research validity was further established by collaboration, prolonged engagement in the field, peer debriefing and the maintenance of an audit trail.

This interpretative approach allowed the researcher to explore the beliefs, opinions and perspectives from a perspective that would have otherwise remained elusive due to the shyness inherent to members of this community. The ability to be fluent in the native language (Bengali), be aware of the inherent sociocultural dynamics and based locally geographically, allowed the researcher to blend well with the research participants, thereby allowing them to relate and unfold with their understandings and perspectives. Consequently, they were keen on expressing their viewpoints freely increasing the validity and accuracy of the study. Other factors that increased the authenticity of the study include the involvement of neo-literate women facilitators, who belonged to the neighbourhood of the study population and were of similar socioeconomic background and the existing familiarity with the study venue for interviews and educational discourse (Surya Kiran School). Collectively, this encouraged the members of the deprived community to feel comfortable and remain actively engaged all throughout the duration of the study.

Another aspect of the contribution of this research is the choice of participants. In an effort to explore the issue of WhatsApp based health communication from a multifaceted viewpoint, a diverse range of healthcare providers were chosen. It was anticipated that despite their commonality in delivering eye care, coming from a varied professional perspective, their perspectives and opinions on the phenomenon of interest may vary. Consequently, this diversity of opinions and insights allowed the researcher to comprehend better the breadth of issue and consider remedial strategies. Similarly, the community health advocates were chosen from a diverse professional background with varied experiences and opinions. Informed by their personal professional backgrounds, the community health advocates were able to make a strong contribution that supported the researcher in her development of an understanding of the societal needs and appropriate remedial measures. The study population was representative of the deprived community settings and epitomise the issues faced by such communities, their sociocultural constraints, challenges encountered and opportunities anticipated. Therefore, findings from this research may be transferable to the wider communities in India and in other developing nations.

Uniquely, this study involved neoliterate women facilitators in disseminating eye care information through WhatsApp. These neoliterate women facilitators belonged to the similar socioeconomic background as of the deprived community participants.

This helped in establishing rapport with the deprived community members and the research process and to express beliefs, perspectives and opinions. This approach confers methodological superiority over a direct WhatsApp based approach as it humanises an otherwise technological intervention, encourages participation and is able to gather rich insights from a traditionally shy community.

Two-way communication used in the study methodology helped established a communication corridor between the healthcare providers and the deprived community members. Unlike didactic flow of information from healthcare provider to its intended recipients, this study allowed horizontal sharing of information thereby allowing end users to air their queries and concerns, and be heard and responded. This process helped both healthcare providers and end users in understanding their mutual needs, strengths and limitations and, devise and design appropriate remedial measures. This may be regarded as an important contribution as it would helped dispelling the prevailing myths and mistrust and, helped forming a bondage that is based on mutual trust and respect.

Finally, the pedagogic style incorporated in the dissemination of eye health information through WhatsApp in the educational session merits special consideration. Storytelling using colloquial dialect and easy to understand narration was used as a pedagogic method to get the message across to the informal adult learners (Caminotti and Gray, 2012). Collectively, these efforts resulted in an active and sustained engagement with these educational sessions and an highly enhanced uptake of information. The use of storytelling in this study may be regarded as an unique feature of this study.

6.4 WhatsApp based health communication on eye care

Social media has been used extensively in health communication, both by healthcare providers and end users. However, none of these studies have examined the role of WhatsApp in health communication on eye care, particularly in the context of the developing world. The vast majority of studies exploring the role of social media and health communication have been undertaken in the developed western world where digital literacy rates and healthcare infrastructure may differ significantly from those in the developing nations.

6.4.1 Providers use of WhatsApp in health communication on eye care

Social media has been used by healthcare providers in a variety of healthcare settings and over a range of health topics. Some of these uses have been in issues surrounding public health communication whilst others have remained more specific to their topic of interest. Amongst public health communication, social media has been used for information dissemination by poison control centres (Vo and Smollin, 2015), smoking cessation (Duke et al., 2014), and health promotion and public engagement on heart, diabetes and cancer related issues (Park et al., 2016). Primarily these studies have used social media to increase awareness of health issues of public interest. Others have used social media to recruit participants for HIV (Martinez et al., 2014) and HPV vaccination programs (Nelson et al., 2014). Along with increasing awareness, these studies aimed at making specific health programs more effective by increasing their capacity to reach out to the ‘hard to reach’ population. Social media has also been used in disease outbreak situations for crisis communication in Zika virus (Sharma et al., 2017; Vijaykumar et al., 2017), Ebola (Househ, 2016), bird flu (Vos and Buckner, 2016) and more recently, COVID -19 pandemic (Sesagiri Raamkumar et al., 2020). Primarily, social media has been used in these studies to provide rapid information on disease awareness and prevention, regular situation updates and ongoing public engagement. The role of social media based health communication has been explored in specific health conditions like hypertension education (Al Mamun et al., 2015), end of life issues (Nwosu et al., 2015), HIV education (Taggart et al., 2015), vaccination campaigns (Glanz et al., 2017), organ transplants (Ruck et al., 2019), diabetic care (Gabarron et al., 2018), skin cancer (Gough et al., 2017), awareness of medication usage (Benetoli et al., 2015) and physical activity (Cavallo et al., 2012). These studies have been conducted in specific healthcare settings in the developed world, and thus, it is difficult to generalise these findings for the developing world where much of the disease burden remains. Importantly, research exploring social media use in eye care communication is very limited. One study explored patient preferences and technology evaluation (Aleo et al., 2014), whilst others examined social media as an epidemiological surveillance tool (Gesualdo et al., 2015; Deiner et al., 2018). Only one other study has used social media as an interventional tool in eye care related health communication and this differs from the current study in its focus and outcomes explored (Sanguansak et al., 2017). Sanguansak et al explored the feasibility and efficacy of a two-way social media messaging to deliver reminders and educational information about postop care to cataract patients who attended a tertiary academic eye hospital. Stakeholder perspectives and end-user behaviour change was not explored in this study and it was not undertaken in deprived settings.

This study aimed to increase awareness of issues surrounding eye health, with a focus on visual impairment and blindness and remains unique in three ways; to the best of current knowledge, this is the first study to have used WhatsApp in facilitating eye care communication in deprived settings in India. Similar to studies using other social media platforms, WhatsApp based health communication was preferred over traditional media by the healthcare providers in this study. Acknowledging the challenges and constraints posed by traditional medium and influenced by previous research, it was reasoned that a WhatsApp based health literacy channel would improve the quality of health communication by enhancing overall reach, improved interactivity, increased usability, enhanced frequency and immediacy, and performance (Agichtein et al., 2008). It was also argued that WhatsApp would facilitate a dialogic transmission over monologue in real time and result in enhanced user engagement (McMullan, 2011). Given its inexpensive nature, healthcare providers perceived it better placed in addressing heath inequalities in eye care in resource limited settings.

At the outset, the healthcare providers expressed hesitancy in the adoption of a new form of communication. Such user behaviour from health care professionals is not surprising and there is evidence of this reluctance to participate in other studies,. This may be because, in general, health professionals have been slow to accept digital technology for health communication (Cooper et al., 2012) and have either opposed or expressed a lack of interest in social media (Keller et al., 2014). Others have cited concerns on privacy (Lofters et al., 2016), legality (Antheunis et al., 2013), potential for abuse (Bermúdez-Tamayo et al., 2013), a lack of skills and inefficiency related to an extra burden on time and resources (Antheunis et al., 2013). Similarly, in this study, healthcare providers cited time and financial constraints as their major barriers, but were happy to adopt this communication channel, if this was endorsed by governmental support. However, in contrast to these studies, healthcare providers appeared more accepting in adopting this means of communication and this may arise from their widespread familiarity with the benefits of WhatsApp based communication use in personal and professional communication, its novelty and their perceptions that it might be useful in reaching out to the disadvantaged population.

6.4.2 Two-way communication

WhatsApp was used for facilitating two-way communication between the healthcare providers and the end users. There was a broad agreement amongst healthcare providers that the success of social media based information portal lied in its unique capability of sharing information on a horizontal basis. It was agreed that such an approach would facilitate information sharing to the members of the deprived community and by increasing awareness of eye care, particularly of its preventative aspects, this will benefit clinical outcomes by early detection and scientific management. It was also perceived that such communication channels will help to break sociocultural barriers and will allow the traditionally shy and naïve members of the deprived community to ask questions in their own comfortable surroundings, at a time and venue of their convenience. Additionally, this approach would have the added benefits of understanding specific health needs pertaining to this community and develop services that are tailor made for this purpose. Also, it was highlighted that in crisis situations, as an inexpensive medium providing advice on real time, WhatsApp is expected to improve clinical outcomes. Despite these perceived benefits, concerns were also raised by healthcare providers about the costs involved, particularly, those required to fund necessary human resources to sustain this WhatsApp based health communication. It is however important to highlight that behavioural and attitudinal changes amongst healthcare providers to this form of communication were not assessed post intervention and should be explored in any future studies. From the perspectives of the deprived community, there was a widespread agreement on the beneficial use of this strategy over other traditional platforms. Post intervention, members reported this audience interaction feature as profoundly beneficial in airing concerns and obtaining further information. This allowed them to overcome their apprehension and shyness to develop into confident and resourceful members of their society. Barriers anticipated included a lack of mobile phone ownership, illiteracy with poor reading and writing skills, immediacy of information provision, and the social determinants that separate the healthcare providers from these deprived community members. Other studies exploring this two-way communication capability of social media platforms are inconsistent in their findings. Some early studies have shown limited interaction and user engagement, and that much of social media use was unidirectional with a flow of information from the organisation to the audience who are more likely to consume information than contribute to the dialogue (Ramanadhan et al., 2013; Thackeray et al., 2013). On the other hand, a strong desire to communicate with healthcare provider through social media over the recent years were noted in some other studies (Van de Belt et al., 2013; Russell et al., 2016; Rabarison et al., 2017). In this study, both healthcare providers and the members of the deprived community were keen on engaging and developing this two-way communication for mutual benefits. It remains unclear, as to whether these inconsistencies in user engagement patterns arise from the type of social media platform chosen, the appeal and relevance of the content matter or end user characteristics. Nevertheless, this interactive feature of WhatsApp facilitating two-way communication was accepted amongst all stakeholders, remained uniquely advantageous over traditional medium and well suited for the purpose of disseminating eye care related health communication and should be considered in all future research.

6.4.3 Post interventional change in attitude and health communication

This study demonstrated the influence of social media based intervention in changing user engagement that may lead to positive health outcomes. By increasing awareness of eye health, challenging the prevailing prejudiced sociocultural environment, and increased acceptance of affordable scientific health care, it is expected that the members of the deprived community would be better equipped to address the disease burden of visual impairment and blindness. These findings are broadly in agreement with some earlier studies where social media based health communication has attempted to address specific health problems.

Awareness creation had remained the major outcome in hypertension (Al Mamun et al., 2015), end of life issues (Nwosu et al., 2015), dengue education (Lwin et al., 2016), childhood vaccinations (Glanz et al., 2017), diabetic awareness (Gabarron et al., 2018), HIV communication (Taggart et al., 2015), organ donation (Ruck et al., 2019) and skin cancer (Gough et al., 2017). A heightened awareness of the health topic of interest was also evident in this study where participants, hitherto unaware of eye health issues, reported a better understanding of the preventative and treatment aspects of eye care.

Many studies have focussed on the measurement of behavioural and attitudinal change at the end of a research project or other intervention but a few have examined the longitudinal effect of such interventions. In post-op cataract patients, social media based information dissemination was associated with improved patient satisfaction towards healthcare provision over a standard approach (Sanguansak et al., 2017). However, no difference was noted on treatment adherence and other clinical outcomes. A resultant behaviour change was positively associated with health outcomes in some studies (Taggart et al., 2015; Glanz et al., 2017; Gabarron et al., 2018). In this study, the focus was on communication and attitudinal changes in the members of the deprived community as this allowed a better understanding of the phenomenon in its context. It was observed that, by increasing awareness of eye health, WhatsApp facilitated mitigation of the existing information gap and helped build confidence amongst study participants and to forge new relationships with healthcare providers and other community members. WhatsApp was thus instrumental in enabling community members to take risks and challenge long standing norms, helping them to move away from the vicious self-perpetuating cycle of ‘ignorance – poor outcome – ignorance’. This empowerment was not restricted to eye health only, but was also influential in strengthening social positions and balancing societal hierarchies. This social liberation may also be considered as an important outcome of this study. Implementation and evaluation of an ongoing programme of WhatsApp based health care support would provide a context for further exploration of the impact of WhatsApp based eye care interventions.

6.5 Factors influencing user engagement with WhatsApp based health communication

This study demonstrated a strong commitment amongst the members of the deprived community to engage with WhatsApp based health communication portal. The factors that drive this engagement can be clustered into two groups: host factors, and, end-user factors.

Host factors

The content matter and the style of engagement had a strong influence in the creation and sustenance of interest in the subject. Information on eye health related topics remains highly sought after in these communities as the disease burden remains unacceptably high. As no such information is easily available from alternative sources, the deprived community members found any discussion of the topic as relevant and valuable. This perceived benefit, may be regarded as an important reason for sustained user engagement with this study. This finding is in accordance to other studies that have demonstrated topic relevance as an important determinant of community engagement with health communication (Strekalova, 2016; Gui et al., 2018). Information was provided in a simple and easily understood manner and in the native language, often with the use of audio-visual content. Images and videos have been observed to attract higher levels of user engagement in a number of studies (Kite et al., 2016; Rus and Cameron, 2016; Strekalova and Krieger, 2017). This might be an important consideration in this study as the vast majority of deprived community members were unable to comprehend written information, consequently, audio-visual content remained a preferred source of information. Another important consideration in this study relates to its pedagogic style of heuristic (experiential) teaching and style of message framing. Story telling through audio-visual methods was employed in the educational sessions that portrayed personal experiences of individuals with eye care issues; these individuals belonged to similar socioeconomic and cultural backgrounds to whom the deprived community members could relate. Story telling is a powerful and established pedagogic method of getting the message across to adult informal learners with low levels of literacy (Caminotti and Gray, 2012) and remains largely unexplored in social media based health communication strategy. Message framing was specifically targeted at providing positive messages and called for increased user engagement, factors also used in other studies to enhance user engagement patterns (Strekalova and Damiani, 2018). This kept the members of the deprived community engaged as if the research discussed their personal problems and provided them with tailor made solutions.

The information provided was factual and accurate and this made it trustworthy to the study participants. This had an important role in keeping the deprived community members engaged with the study. Marketing and promotion amongst online health content were evidently high in some studies (Hale et al., 2014; Nelson et al., 2015), whilst trustworthiness low (Lee et al., 2014). Yet, trustworthiness of the online content and the source organisation, is of paramount importance in successful user engagement (Hether et al., 2014; Song et al., 2016; Yun et al., 2016) whilst marketing may have negative consequences (Kite et al., 2016). Long standing mistrust perpetuated by widespread misinformation spread by those with vested interests have rendered these communities sceptical of any information coming from healthcare organisations. Falsified claims and marketing motives, overt and hidden, have all being detrimental in building trust between healthcare providers and end users. That this study unambiguously stated its academic purpose with no marketing motives at the outset, and that the health information content was produced and distributed by Susrut Eye Hospital, a reputable healthcare provider in the region, was instrumental in keeping the audience engaged throughout the whole study.

End user factors

The intrinsic characteristics of the deprived community are also critical determinants in influencing this engagement process. WhatsApp was a novel medium in these communities that stimulated curiosity about the new way of communication, over other forms of traditional communication methods. This novelty, coupled with an information gap arising out of significant disease burden and lack of relevant, current accurate and unbiased information, helped in motivating participants to engage in order to increase their personal knowledge and to exchange advice through two-way communication facilities (Antheunis et al., 2013). Arising from long standing dissatisfaction with health professionals, there was an increasing desire amongst participants to remain better informed and to self-manage simpler eye health issues, as was noted in some other studies (Li et al., 2014; Alhuwail and Abdulsalam, 2019). Participants also engaged for emotional and social support, and bonded with the healthcare providers and the fellow participants, factors that facilitated their sustained involvement (Lu et al., 2017; Zhao and Zhang, 2017; Price et al., 2018; Gage-Bouchard et al., 2019). Most participants in this study were young and this could have motivated them towards engaging in the process of learning, leading to a subsequent change their attitude towards eye care and its providers. In other studies, a younger age has been associated with increased social media usage for health communication (Chou et al., 2009; Vyas et al., 2012; El Tantawi et al., 2019; Huo et al., 2019). The overall effect of these determinants were to acknowledge preferences, increase participant motivation and reduce communication barriers. As highlighted before, positive perception towards the health care provider and health topic might have also contributed in keeping the deprived community members engaged.

Other potential determinants of user engagement include heath literacy, ethnicity and socioeconomic status. Health literacy, particularly eHealth literacy, was very low in the participants. Previous studies have shown that eHealth literates have enhanced engagement with social media and make greater use of specialised medical information (Curry et al., 2014; Li et al., 2014), and digital technology usage (Manganello et al., 2017). In contrast, despite this lack of health literacy, members of the community exhibited a strong interest in digital health communication through WhatsApp. This may reflect the innate curiosity of the population studied or to other less understood sociocultural traits that were not explored in this study. Other studies have explored the sociocultural and ethnic determinants of user engagement with digital communication, but there is no consensus as to the key factors. Poor socioeconomic status and Hispanic ethnicity has been associated with lower rates of engagement in one study due to a lack of available time, and this may also apply to this study population (Stroever et al., 2011). However, other studies found Hispanic and African Americans to be more engaged with social media than their white counterparts (Hanson et al., 2014; Lumpkins et al., 2017), reflecting as yet unidentified factors that may influence this process including nationality and cultural preferences (Park and Park, 2014; Song et al., 2016). On the other hand, a recent study found no influence of racial/ethnic disparities on social media usage of health communication (Huo et al., 2019).

The precise influence of sociocultural determinants on the study outcome is difficult to understand as the study population belonged to the same ethnicity and were homogeneous from a socioeconomic, religious and cultural background. This therefore precluded any detailed understanding of the role of these important determinants on user engagement of the deprived community with WhatsApp. The subtleties of sociocultural characteristics underpinning this population and its overall influence on user engagement, needs to be explored through future research considering these demographic determinants in further detail over a wider geographical area.

6.6 Conceptual framework for benefits and barriers of WhatsApp in health communication for eye care

One of the objectives of this study was to propose a framework for the benefits and barriers of a novel WhatsApp based health communication portal on eye care (Tables 6.2 and 6.3). For the ease of understanding, these benefits and barriers may be grouped under structural and cultural factors. Structural factors imply spontaneous or planned pattern of actions and interactions that members undertake to achieve common goals, whereas cultural factors denote a system of assumptions, values, norms and attitudes that members have developed and adopted (through mutual experience and interaction) that enable them to make sense of the world they live in and behave accordingly (Janicijevic, 2013).

6.6.1 Benefits of WhatsApp in health communication for eye care

From a healthcare provider's perspective, WhatsApp may be used primarily for information dissemination purposes to improve health education, health literacy and for health advocacy on eye care. By sharing high quality, easy to understand, unbiassed and relevant scientific information on eye health issues, healthcare providers can expect deprived communities to be better informed about the problems associated with visual impairment and blindness. The multimedia capability of WhatsApp is more suitable than printed matter for sharing audio-visual information on eye care for informal learners with literacy issues. It is expected that WhatsApp would enable the information to reach further transgressing geographical barriers, be repeated frequently thereby reinforcing key messages and facilitate sharing amongst the community members. Consequently, it may be envisaged that this increased awareness of eye care would enable the deprived community to better manage their eye health issues. The two-way communication capability of WhatsApp may be particularly valuable during situations of health crisis and eye health related emergencies, where time is of the essence for successful clinical outcomes. Additionally, through information gathering and surveillance capabilities, WhatsApp may benefit healthcare providers in understanding the specific health needs of this hidden and hard to reach community, and develop responsive services, more suited to the needs of the disadvantaged population. Finally, with improved uptake and utilisation of eye care services, members of the deprived community are expected to achieve better eye health outcomes, as envisaged by NCPB and WHO.

WhatsApp is perceived to be a low cost platform requiring a modest investment in existing infrastructure and this makes it attractive to healthcare organisations. WhatsApp may also be used to initiate and sustain professional communication amongst healthcare providers. By addressing the information gap on good eye care WhatsApp has the potential to bridge a link between healthcare providers and deprived community members. This approach would be expected to mitigate the mistrust and distrust between the stakeholders, facilitate better relationships through mutual respect and understanding, and foster favourable attitudes, ultimately steering them to be strategically aligned in the process of addressing the burden of eye care. Such generous acts of breaking down sociocultural barriers in health communication may also have the added benefit of increasing organisational visibility and promote its philanthropic image.

For the members of the deprived community, WhatsApp appears to be an appealing tool for information seeking on eye care. Unlike other mediums, WhatsApp can be accessed at a time and place of convenience, which suits well to the needs of individuals community members who have significant constraints on personal time, space and privacy. Audio-visual nature of information, accessed through a easy to use interface requiring minimal ICT skills, and availability at no extra cost, is expected to be easily assimilated by informal learners, thereby significantly impacting on their information gap on eye care. Two-way communication facility of WhatsApp encouraging the deprived community members to address queries and concerns in real time, is expected to reassure them, and consequently, this benefit can help change attitude favourably towards healthcare providers whilst facilitating bonding. Overall, positive experience thus gained from affordable eye care, is also expected to be shared widely, possibly through WhatsApp, and this is expected to have an wider impact in the society. This enhanced engagement is expected to benefit these individual members, and the society as whole in reducing the disease burden of visual impairment and blindness. Beyond eye health, reinforced with this newly acquired knowledge and social network creation, WhatsApp would also have the wider benefit of empowering individuals, particularly women from these disadvantaged backgrounds, and would encourage individuals to challenge prevailing socio-cultural norms.

	Healthcare provider's benefits of WhatsApp in health communication on eye care	**End user's (members' of the deprived community) benefits from WhatsApp based communication**
Health communication on eye care	Information dissemination for increasing health education on eye health, increasing health literacy through supportive information, and health advocacy for better eye outcomes through affordable eye care Provision of authentic, relevant, unbiased and current information on eye care in an easy to understand, culturally sensitive native language Multimedia capability is expected to be better suited for informal learners with limited ability to comprehend written text Improved reach of portable knowledge, transgressing geographical barriers and remoteness Enhanced frequency and easy repeatability of information sharing for a 'hard to reach' population 2 way communication facilitation in real time offers help and support in heath crisis and emergency situations Surveillance on disease burden, monitoring healthcare utilisation and information gathering on end user preferences	Tool for accessing information on eye health to address information gap (to obtain current, relevant, accurate, honest and unbiased scientific information) User friendly and easy to use app that requires little personal ICT knowhow Freely available at finger tips, particularly important in deprived communities with constraints on travel infrastructure and loss of income for medial consultation Convenience: easy to obtain information in personal time and space, bypassing social and cultural barriers Easy to understand and stimulating information delivered through multimedia format Two-way features allows individuals to voice out concerns in real time Right information available in right time helps navigating through eye health emergencies
Structural and cultural	Low cost and minimal logistic infrastructure; low ICT skills set required – easily implemented Changing healthcare provider attitude towards deprived community, create a responsive service tailor made to the needs of people from deprived community Address the existing mistrust between healthcare providers and deprived community - bridging the link Altruistic organisational behaviour: breaking down traditional sociocultural and social communication barriers Improved organisational promotion and increased visibility; improved organisational image	Easily assimilated information through Informal learning, individual becomes a resourceful member of the community Empowerment to challenge prevailing norms, post queries and seek answers in real time Favourable attitude towards healthcare providers; better utilisation of healthcare resources with improved outcomes Increased satisfaction with health care providers Perceived benefits is shared across communities, wider benefit to the society Familiarity towards a new way of communication will enhance digital literacy and reduce digital divide

Table 6.2. Benefits of WhatsApp in health communication for eye care

6.6.2 Barriers of WhatsApp in health communication for eye care

Despite the perceived benefits in WhatsApp based health communication on eye care, considerable barriers remain (Table 6.3).

From the healthcare provider's perspective, although a lack of financial and logistical support, stands out as the most important barrier challenging implementation, other factors may also have an important role to play. Structural organisational difficulties include limited ICT infrastructure, underdeveloped communication strategy, and a lack of prioritisation. Social media is not embedded in most healthcare provider's organisational strategy, and many express reservations of its use in healthcare settings. A lack of clear guidance from governmental organisations, coupled with the absence of a lack of social media based communication strategy, remains an important structural barrier in the implementation of WhatsApp. Cultural factors like a rigid organisational hierarchy, may not encourage staff keen on newer ideas, to voice out concerns in support of including WhatsApp in existing communication strategy. Irrational concerns and widespread apprehension on issues surrounding misinformation, privacy and legality, a lack of necessary skills, perceived ineffectiveness of social media, damage to institutional reputation and negative publicity, continue to be strong cultural barriers to widespread WhatsApp use amongst healthcare providers.

For the members of the deprived community, the main barriers in implementation relates to extreme poverty and low levels of smart phone ownership, illiteracy (including non-existent digital literacy) and geographical remoteness. Non familiarity to this form of communication may also result in a mismatch and reduced acceptance amongst members of the deprived community. Additionally, sociocultural factors including a lack of personal time and privacy, deep rooted mistrust towards healthcare providers, sociocultural taboos, fear of being rendered a social outcaste and of reprisal from powerful community members, may alone or in combination, contribute to act as effective barriers in WhatsApp's wider implementation.

Amongst the members of the deprived community, there is a genuine worry that familiarity to the new technology and the new form of communication will result in increased confidence levels, social empowerment and possibly, social mobility. They felt uneasy about this newly acquired social empowerment to challenge deeply rooted sociocultural practices, prejudices and taboos, perpetuated by ignorance and individuals with vested interests. They expressed apprehension of the consequences of the inevitable friction that would result from unsettling the community hierarchy and long established practices. They felt worried about punitive methods that may be undertaken towards them in the form of domestic abuse and psychosocial isolation; an ill-fated and unwanted consequence of a strategy intended at improving lives. This constitutes a formidable barrier in the implementation of any strategy that is intended at social empowerment and may not be specifically restricted to the issue of eye care.

	Healthcare provider	Deprived community
Structural	Limited resources (hardware, software and personnel, lack of managerial commitment, lack of focus in the long term healthcare delivery strategy) Lack of funding and financial initiative in adoption of social media based health communication tool Overall poor quality of communication strategies; between health providers and the target population: between various health care professionals A lack of management of social media communication: lack of clear protocols and guidance; Social media not embedded in the existing organisational processes leading to lack of training and knowledge exchange A lack of clear guidance from the federal and state governments; a lack of tailor made support to implement existing policies as the health provision needs vary between centres and geographical regions	Lack of appropriate, current, authentic and easy to understand information on eye care (information gap) Unskilled and illiterate population; a lack of understanding of their rights and entitlements Financial constraints (not being able to afford a smart phone or network subscription) Digital inequalities and unequal reach of communication because community members are not acquainted with social media Remoteness; poor infrastructure and network coverage
Cultural	Concerns with change and its implications; ‘let things run as it is’ or ‘why bother’ culture; perception of a lack of empowerment by junior staff to make any contribution to future strategy of the healthcare provider Strong hierarchical and rigid organisational structure with little allowance to air grievances by relatively junior healthcare professionals with fresher perspectives Irrational concerns with costs of implementation of new health communication strategy using social media Apprehension of information misutilisation by the recipients and its adverse consequences and attending negative publicity; patient consenting issues Apprehension of a lack of skills to cope with appropriate smart phone technology and the necessary skills to accept social media based health information Perceived ineffectiveness of social media based health communication Lack of fit of social media culture (horizontal, informal and many-to-many) with the existing culture of communication between health providers and deprived communities (hierarchical, formal and one-to-many) Ineffective communication on social media due to challenges related to the adaptability to the (changing) social media landscape, fitting communication to each platform’s target group and features Risks to institutional reputation and legitimacy due to heightened visibility of health provider activities on social media	Not used to this style of communication (mismatch) Long standing and deep rooted mistrust towards governmental policies and health care organisations; limited willingness to engage; fear of being cheated, emotionally and financially Long standing isolationist perspectives; ‘we are different’ ‘they are different’ beliefs Unrealistic fear of costs involved, or of hidden marketing motifs A lack of personal space and time; a lack of personal privacy; poor women empowerment in a male dominated society Sociocultural taboos; fear of unknown; fear of being considered as an outcaste in the society; fear of going against prevailing norms: fear of reprisal from community members with vested interests Enhanced fear of being made aware of health problems previously under recognised thereby increasing levels of anxiety secondary to this newly acquired knowledge

Table 6.3. Barriers to effective health communication in eye care using WhatsApp

6.7 Chapter overview

This chapter summarises the main findings of this study, compares and contrasts this with existing research and highlights its uniqueness. It also highlights the methodological strengths and the robustness of findings. Post adoption of WhatsApp based health communication strategy, it proposes a framework of change in health communication and attitude in end-users and postulates the key determinants of this successful end-user engagement. The final sections of this chapter, describes the conceptual frameworks for benefits and barriers of a WhatsApp based health communication channel on eye care.

CHAPTER 7. Conclusion and Recommendations

7.1 Introduction

This chapter provides a short summary of the research undertaken and how the research findings answers the key aims and objectives of this study. Subsequently, it provides a statement highlighting the study's contribution to existing knowledge and theory. Finally, the practical implications of this study and its limitations are discussed before presenting directions for future research.

7.2 Research Summary

Visual impairment and blindness are important and often preventable public health problems impacting the global population, but India shares a major and disproportionate disease burden. Health communication on eyecare is an important aspect of all programs involved in the mitigation of this disease burden. Social media represents computer mediated interactive technologies that facilitate creation and sharing of information and ideas. Inexpensive and ubiquitously accessed, social media has gained popularity exponentially in developed and developing countries, and remains a preferred communication platform over traditional media. The audio-visual capabilities of social media platforms and its horizontal information sharing capabilities have transformed a monologue into dialogue and renders it attractive for health communication, especially for populations resident remotely with little healthcare infrastructure. Amongst many such social media platforms, WhatsApp enjoys unique popularity, particularly in the developing nations, and that may be attributed to its simple-to-use interface, multimedia capabilities and the facilitation of two – way communication capabilities. Social media has been used extensively in health communication across a wide range of health topics, largely in the developed countries. Nevertheless, there is limited research of its use in eye health, particularly in the Indian subcontinent. Importantly, no study has systematically evaluated WhatsApp in promoting health communication on eye care in India, specifically in its largely deprived population. This context compelling argued for the rationale behind this study in exploring the role of WhatsApp based health communication portal on eye care in the development of a community based practice in eye health in deprived semi-urban settings in India. This study involved the creation of a link between healthcare providers and the deprived community using WhatsApp as an information portal on eye care that was assisted by a group of neo-literate women facilitators.

Analysis of stakeholder's opinions and perspectives in this study, which included healthcare providers, community health advocates and the members of the deprived community, identified and confirmed the presence of significant information gap on eye care, multifactorial in aetiology and one that needed a systematic and multifaceted approach in its mitigation. Amongst the healthcare providers and the community health advocates, there was an overwhelming support for social media based health communication on eye care to address this knowledge gap, but concerns with affordability, equipment cost, security and privacy remained. Specifically, amongst all other major social media platforms considered, WhatsApp remained the platform of choice to disseminate this health communication on eye care. Exploration of the perspectives of the members of the deprived community after establishing the WhatsApp based communication channel revealed this to be a feasible and highly acceptable communication strategy. Members of the deprived community found this information dissemination strategy to be beneficial in mitigating the information gap and providing enhanced awareness of eye problems and affordable eye care, which, in turn, had the potential for reducing visual impairment and blindness. There was evidence of a change in eye heath related communication and attitudinal changes towards eye care amongst the members of the deprived community. Although, not the main focus of this study, there was also evidence that involvement in the intervention contributed wider socioeconomic benefits associated with the consequent empowerment of members of the deprived community to start to challenge sociocultural norms and prejudices. Notwithstanding the benefits identified, this research also identified barriers that existed in the widespread implementation of WhatsApp as a vehicle for information dissemination on eye care.

7.3 Revisiting the aims and objectives of this research

This study explored the potential benefits and barriers associated with WhatsApp based health communication in enhancing the community based practice in eye health in deprived semi-urban settings. The study aimed at contributing to the knowledge, theory and practice regarding the benefits and barriers of WhatsApp usage in supporting eye health care in deprived semi-urban settings. These were to be achieved through a set of objectives that are highlighted below:

7. To conduct a literature review of the uses of social media in health care (Fig 3.2)
8. To profile the demographic context of the deprived community, including their access to information on eye health
9. To gather insights into healthcare provider's and community advocate's views on the benefits and barriers associated with health communication via social media for eye health (Table 6.1)
10. To explore the nature of communication and attitudinal change associated with the adoption of WhatsApp for eye health (Fig 5.7, 5.8 and 5.9)
11. To propose a conceptual framework of the communication and attitudinal change associated with the adoption of WhatsApp for eye health (Fig 6.2)
12. To propose a conceptual framework of the benefits and barriers associated with the adoption of WhatsApp for eye health (Table 6.2 and 6.3)

7.4 How this study met its objectives

Chapter 3 reports on a comprehensive review of the literature on the uses of social media in health communication across various health care settings (**Objective 1**). Early on in this literature review, it became apparent that the research on the use of social media in eye health is scarce and limited to a handful studies. Importantly, there was a paucity on research of using a WhatsApp platform in establishing health communication, particularly in the deprived settings. Therefore, the literature review was extended to review the wider use of social media based health communication in all healthcare settings. This review of the literature identified some key themes in research into social media use in health communication. Healthcare providers have used social media primarily for the dissemination of public health information, such as disease outbreaks and as an interventional tool in specific health conditions. Social media has also been used to gather information on healthcare use and for professional communication between healthcare provider team members. End users used social media in seeking and sharing health related information and in providing opinions to influence this process, positively or negatively. End users also used social media in establishing a two way communication channel with the healthcare providers. Despite a volume of research in other health issues, limited research exists in the use of social media in eye care. Amongst the handful of studies, one evaluated technology utilisation and patient preferences, two others examined the role of social media in epidemiological surveillance, whilst only one study explored the use of social media as an interventional tool in post-op cataract education. The latter did not explore the perspectives of stakeholders and change in health communication and attitude in end-users. Moreover, the focus and the scope of the study was different from the current study and was not conducted in deprived settings. This literature review also identified the determinants influencing the engagement processes of end users and healthcare providers with social media based healthcare communication channels.

The second objective of this study was to provide the demographic context of the deprived community, including their access to information on eye health and this is detailed in Chapter 4 and 5 (**Objective 2**). Only women participated as their partners did not consent to take part citing work related commitments. Information on the socioeconomic context of the deprived community and their existing beliefs and opinions on eye health were ascertained through semi-structured interviews carefully designed to frame questions that community members could relate to. This generated useful insights into the wider circumstances of the community, which might impact on their ability or willingness to engage to social media based eye health promotion. Altogether, 30 women participated in this study with an average age of 27.6 years (median 27 years). Respondents were mostly married, practised Hinduism, with either no formal education or educated up to primary levels. Approximately a quarter had attended secondary school. A quarter of the participants identified themselves as locals whilst others had migrated from elsewhere, primarily for better job prospects. On an average, there were 5 members in their household, 2 of whom were children. Only a minority of these participants were in active employment with most households earning between £55 - £100 per calendar month (some earning less) and all of them had BPL (Below Poverty Level) certification from the Government of India. Only a few reported living in a permanent dwelling that was owned outright, whilst others reported renting in thatched or tile roofed houses and semi-permanent makeshift settlements. Mostly, home comprised of only one room that included a kitchen space, had electricity supply, had a television and radio but drinking water was sourced from outside. Primarily the cooking fuel was kerosene and vehicle ownership was limited to the possession of a bicycle in 3 households. Access to information on eye care by the members of the deprived community had been described in Chapter 4. As smart phone ownership was low, information on health topics were accessed through television, radio and wall-posters. The burden of eye diseases was high, and despite the presence of a village medical unit providing basic medical care, the nearest specialist eye unit was based in the city, almost 5 miles away (more than an hour by bus).

Chapter 5 details the insights of healthcare provider's, community advocate's and deprived community member's views on the benefits and barriers of health communication using social media for eye health (**Objective 3**). This was achieved through the descriptive and thematic analysis of data obtained through semi-structured interviews. Descriptive analyses indicated that healthcare providers and community health advocates were mostly unaware of the existence of national and international organisations working in this field of information dissemination in eye care. However, both groups favoured the importance of awareness enhancement strategies as an effective interventional tool in addressing the burden of eye diseases. Specifically, they agreed on the beneficial role of social media based health communication portal on eye care. There was also an overwhelming agreement that WhatsApp was capable of supporting two-way communication between the providers and the end users. Detailed thematic analysis confirmed the existence of a significant information gap on eye health amongst the deprived community. In addition, despite an overwhelming overlap and concurrence of opinions, there were a number of subtle differences between the perspectives of healthcare provider and community health advocates. In particular, healthcare providers identified multifaceted issues including illiteracy, especially digital illiteracy, poverty, access to technology, lack of personal hygiene, prevailing sociocultural taboos and prejudices, a lack of women's empowerment and a lack of knowledge on protected employment rights, as primary factors behind this information gap. Additionally, they highlighted the inadequacies of the current governmental strategies and a lack of cohesion between various healthcare programs. On the other hand, the community health advocates, whilst also acknowledging these barriers, also felt that there was a lack of any genuine and persistent effort on part of the healthcare provider to mitigate information gap. A prevailing culture of mutual mistrust between healthcare provider and end users was mentioned by both groups. The remainder of the findings from the thematic analysis focussed on the stakeholders opinions on the benefits of social media, issues with its ease of use and accessibility, the credibility, authenticity and trustworthiness of content matter, financial implications and concerns with data privacy and security. All stakeholders re-confirmed WhatsApp as their chosen social media platform and opined about the eye health topics to be included for dissemination. From the deprived community member’s perspectives, poor socioeconomic status, illiteracy and ignorance remained the most important barriers in accessing good eye care. A lack of trust towards healthcare providers, prevailing sociocultural norms and a lack of women empowerment were also identified as major barriers. Broadly, these perspectives were in agreement with the healthcare provider and community health advocates with a single exception. Deprived community members reported a lack of coordinated approach from healthcare organisations and governmental agencies in promoting eye care.

Post adoption of WhatsApp, this research explored the nature of change in eye health communication in the deprived community and their attitude towards healthcare providers. This also helped in formulating a conceptual framework for these observed changes in communication and attitude in the recipient community (**Objectives 4 and 5**). This was achieved through a focus group interview with members of the deprived community that sought to develop understanding of the processes associated with accessing WhatsApp based eye care information and its perceived benefits. Furthermore, the focus group explored the assimilation of the newly acquired knowledge, the importance of word-of-mouth and participants future intentions of social media usage. Finally, this informed the changes that the participants intended to make as a result of their engagement with the intervention, and their perceptions of the barriers associated with use of this new form of communication (Chapter 4). Chapters 5 and 6 describe the key themes emerging from the focus group interviews. These themes formed the basis for proposing a framework of the changes associated with the adoption of WhatsApp (Figure 6.2). The members of the deprived community reported having benefitted from the WhatsApp health communication channel on eye care. Further, they observed that this approach, freely accessed, at a time and venue to suit their circumstances, was the first endeavour to bring accurate and unbiased eye care information to their ‘door step’. The audio-visual capability of WhatsApp in depicting eye problems, its interactive and user friendly interface, the pedagogic style of storytelling and importantly, its two way communication capabilities that helped them to raise queries and concerns, remained key factors in its popularity amongst the end users, as well as supporting their sustained engagement with the project. Perceptions of mistrust towards governmental initiatives and healthcare providers, based on their previous experiences, were mitigated significantly, and a new form of communication channel was established between the healthcare provider and the end users. In addition, the newly acquired unbiased knowledge on scientific and affordable eye care and WhatsApp use boosted the confidence of the members of the deprived community. In addition, their newly acquired knowledge was widely shared across friends and extended families. This, in turn, heightened the status of the women in their families and in society and empowered them to challenge other prevailing sociocultural prejudices and norms.

The final objective of this study was to propose a conceptual framework of the benefits and barriers associated with the adoption of WhatsApp for eye health (**Objective 6**). Based on the findings from the study, Chapter 6 proposes this conceptual framework through a tabular matrix (Table 6.2 and 6.3) for healthcare providers and the deprived community, grouped by structural and cultural factors. Briefly, WhatsApp may be used for information dissemination to improve health education, health literacy and for health advocacy on eye care. By sharing high quality, easy to understand, unbiassed and scientific information on eye health issues, healthcare providers can expect deprived communities to be better informed and better manage their eye health issues. The multimedia capability of WhatsApp is better suited to the learning needs of informal adult learners with low levels of literacy and the information dissemination may be repeated without incurring additional costs, and is expected to be widely shared across geographical barriers. The two-way communication capability of WhatsApp may be invaluable in addressing eye health queries in real time, gather healthcare utilisation data to inform changes in developing a responsive health strategy and in eye health emergencies for improved clinical outcomes. For the deprived community, WhatsApp is a sociocultural appealing platform for seeking health information on eye care. WhatsApp remains important in increasing awareness of issues surrounding eye health and affordable eye care. The two-way communication encourages communication between traditionally shy communities to healthcare provider, fosters bondages by dispelling mistrust and share positive experience. Despite the advantageous of this novel communication channel, considerable barriers remain. From a healthcare provider's perspective, financial and logistical challenges remain paramount but a lack of prioritisation of an effective communication strategy, a lack of governmental leadership and support, unyielding organisational culture and rigid organisational hierarchy remain formidable obstacles. From the end users perspective, the main barriers in implementation relates to extreme poverty, low levels of smart phone ownership, illiteracy (including non-existent digital literacy), geographical remoteness, a lack of personal time and privacy, deep rooted mistrust towards healthcare providers, sociocultural taboos, fear of social outcaste and reprisal from powerful community members. The importance of these frameworks lies in signposting policy makers and future researchers in identifying and exploring areas of practice that can address these issues and formulate remedial measures.

7.5 Research contribution

This study makes several noteworthy contributions to the knowledge, theory and practice of information science, specifically in the use of social media based health communication on eye care in deprived settings of the developing world. Moreover, this study also makes some important methodological contributions in the use of qualitative methods to generate a multiple facetted perspective of the stakeholders from a varied background, the use of neoliterate women facilitators and the adoption of a specific pedagogic style.

7.5.1 Contribution to knowledge

The use of social media in health communication

There is limited research in the use of social media, specifically WhatsApp in eye health related health communication. This study uniquely contributes to the existing knowledge of social media based health communication on eye care information dissemination in deprived settings. Social media has been used in health communication across a range of health topics. Through a robust review of the existing literature, this study summarised the use of social media in health communication across a wide range of health topics. More specifically, this research summarised social media use in eye health related communication. Importantly, the role of social media in eye health has been limited and scientifically unexplored in published research. One study explored patient preferences (Aleo et al., 2014), whilst two examined social media in epidemiological surveillance (Gesualdo et al., 2015; Deiner et al., 2018). Only one study has used social media based health communication in eye care (Sanguansak et al., 2017).

The literature review also informed that social media based health communication has been restricted primarily to the developed world settings with different social, cultural and economic milieu and differing expectations towards health communication. In the developed world, there is usually an overabundance of information that may often be inaccurate and/or confusing; however, the end users are allowed choices through a variety of communication media outlets, traditional and online. On the other hand, in the deprived settings, the information gap often results from a genuine lack of accessible and accurate information and may be intricately related to underlying factors like illiteracy, poverty and sociocultural prejudiced behaviour. Furthermore, the availability of healthcare infrastructure, mobile phone technology and in particular, smart phone usage are widely different across these healthcare settings as compared to the developed world. Only a handful of studies have explored the role of social media in the developing world settings, particularly explicitly engaging with in the deprived population. Findings from these studies may not be transferable to other countries or specific communities (including deprived communities) as sociocultural factors, economic determinants and end user expectations towards healthcare providers are unsurprisingly different between countries and communities. For the communities suffering from high levels of deprivation, these fundamental differences, compounded by affordability and accessibility of healthcare, result in an unique set of conditions that hinder effective management and treatment of the disease burden,

Identifying information gap on eye care and contributing factors

This study provided unique insights from the perspectives of healthcare providers, community health advocates and deprived community members on the presence of information gap in eye care and the factors that contribute to its existence. This may be regarded as an important contribution of this research in describing the information needs on eye care; this constitutes acknowledgement of an existential problem that awaits remedial measures. Stakeholder perspectives on the use of social media in health communication has been examined in some earlier studies (Antheunis et al., 2013; Nelson et al., 2015; Lu et al., 2017). Similar to other studies, opinions, perspectives, and beliefs on the existence of information gap on eye care were collected from two major role players; namely, the healthcare providers and the end users. However, unlike any other preceding study, this study also gathered information from community health advocates, a stakeholder group that have never been explored before. It was anticipated that the opinion from a group of individuals who were not affiliated to either groups and yet able to bridge the gap between the healthcare provider and the deprived community, would come instrumental in shaping the formulation of such health communication channel.

Stakeholder perspectives on the use of social media and WhatsApp in health communication on eye care

Another important contribution from this research relates to the rich insights gained from the healthcare providers, community health advocates and the deprived community members perspectives, opinions and beliefs on the use of social media and WhatsApp in addressing this information gap on eye care. Opinions were collated on a comprehensive range of issues on social media (WhatsApp) usage that included its overall benefits, ease of uses, accessibility, content related credibility, authenticity and trustworthiness, privacy and security of data and financial implications. This is the first such study to have explored the perspectives of stakeholders in the establishments of health communication portals using social media platforms, that may be used in the addressing the information gap in eyecare in deprived communities. It is important to highlight herein that the perspectives of community health advocates, who remained neutral to the actual information sharing processes, allowed unique insights that would have otherwise remained unexplored and may be regarded as an important and unique contribution of this study. WhatsApp, the choice of social media platform merits special consideration. Previous research into the use of social media in promoting healthcare has been limited to Twitter, Facebook and YouTube. What's app is widely used, particularly in deprived settings in India, and is also particularly attractive for communities living in remote locations. It's simplicity, versatility and two-way communication capability, not offered by the other social media platforms, makes it appealing as a medium of information dissemination. Yet, the potential for WhatsApp in health communication remains largely unexplored. Importantly, WhatsApp's potential for healthcare communication in eye care, especially in deprived communities remains unexplored. Exploration of perspectives of healthcare providers and community health advocates favoured WhatsApp as the preferred communication channel. The use of WhatsApp in delivering eye care information in this study remains a major contribution of this research.

Contribution of WhatsApp based health communication on eye health related communication and attitudes in end users

This study uniquely attempted to explore the nature of communication and attitudinal change associated with the adoption of this new form of communication (Fig 6.2). Specifically, this study demonstrated that this strategy effectively increased awareness of eye health issues in the deprived community, decreased mistrust towards government and healthcare organisations, increased confidence towards healthcare utilisation and effective sharing of eye care information and experiences with this new communication channel. This is an important contribution of this study to the existing knowledge. The two-way communication capability of WhatsApp merits further consideration. This capability of WhatsApp in facilitating horizontal sharing of information between stakeholders has not been explored before in eye health and is an important contribution of this research. Two-way communication was mutually beneficial to the healthcare providers and the end users. Two-way communication helped the end-users to voice out queries and concerns, be satisfied with responses, enhance knowledge and awareness of eye health, dispel myths and help bonding with healthcare providers. Overall, this allowed the members of the deprived community to overcome their apprehension and shyness to develop into confident and resourceful members of their society. For the healthcare providers, it was an unique opportunity to assess and address specific health needs posed by the community by systematic adjustments in health care delivery programs. It has to be acknowledged that a formal exploration of these changes in healthcare provider strategic behaviour was beyond the scope of this study and needs exploring in future research. This study also highlighted the challenges anticipated by end users in the effective implementation of a WhatsApp based health communication channel for eye care. Beyond the benefits on health promotion, this study was able to highlight the wider changes noted in the societal dynamics, particularly that related to women empowerment and social mobility. However, further studies focussing on these aspects are required to clarify the precise nature and determinants of the changes observed.

7.5.2 Contribution to theory

Use of social media in health communication

Through a critical review of the current literatures, this study proposed a diagrammatic framework of the domains of social media use in health communication and its underlying information sharing processes (Figure 3.2), and the determinants influencing end user engagement. This may be regarded as an important theoretical contribution of this research.

Change in end-user health communication and attitudes post implementation of WhatsApp based information channel in healthcare

This study explored change in health communication and attitudes in the members of the deprived community post implementation of the new form of communication as this involved new trust on healthcare providers and social media. One of the important theoretical contributions of this study relates to the proposal of a theoretical framework for this change and is represented diagrammatically (Fig 6.2).

Factors influencing user engagement with WhatsApp based health communication

This research demonstrated a strong engagement pattern of the members of the deprived community with the WhatsApp based health communication portal on eye care. Other studies have also explored user engagement patterns using other social media platforms across a variety of health topics, but WhatsApp use in eye care is largely unexplored (Antheunis et al., 2013; Hether et al., 2014; Li et al., 2014; Strekalova, 2016; Alhuwail and Abdulsalam, 2019). By exploring in detail factors that influence user engagement with WhatsApp based health communication portal, and, comparing and contrasting what is already known, this research uniquely contributed in developing the understanding of relationships between deprived community and healthcare providers.

Developing a conceptual framework of benefits and barriers of WhatsApp based health communication on eye care

One key objective of this research involved the development of a conceptual framework of benefits and barriers of a WhatsApp based health communication portal on eye care. A detailed and deeper understanding of the opinion analysis of healthcare providers and community health advocates, and the benefits and challenges voiced out by the members of the deprived community, allowed the synthesis of a key framework of benefits and barriers in the implementation of WhatsApp based health communication channel in eye care. This framework, based primarily on findings from this research, also forms the template for further research and policy making and thus, may be regarded as an important theoretical contribution of this study.

7.5.3 Methodological contributions

In the context of research involving social media use in eye health, this study had some unique methodological contributions. The adoption of qualitative study methods, specifically thematic analysis of qualitative data obtained through semi-structured interviews, and focus group interviews, although commonly used as a social science research methodology, has not been used in exploring health communication processes in eye care research settings. This may be regarded as an important methodological contribution of this study. Specifically, two other methodological contributions merits further highlighting. This study involved neoliterate women facilitators in disseminating eye care information through WhatsApp. This unique approach over a direct WhatsApp based intervention, helped build up a strong rapport and allowed enhanced participant engagement with the research process and express deeper perspectives. The use of human facilitators in social media based health communication is limited and has not been explored in eye health related health communication to gather rich insights from traditionally shy members belonging to deprived communities. Another important methodological contribution of this study involved the use of ‘story telling’ as a pedagogic method for eye health communication using simple, easy-to-understand audio-visual information. Although, storytelling has been used as a pedagogic method to get the message across to informal adult learners (Caminotti and Gray, 2012), this approach remains unexplored in social media based health communication strategy across all health conditions including eye health.

7.5.4 Contribution to practice

This is the first study that has explored the reach and impact of digital communication on eye care in the deprived community and has several practical implications for policymakers and healthcare providers that is discussed below.

Implications for policy makers

Despite the disease burden of visual impairment and blindness in India, the impact of remedial measures in India have been patchy, and unable to reach the population at large, particularly those from a disadvantaged background. Health communication on eye care using traditional media is limited in a socioeconomically heterogeneous population where illiteracy, digital divide, lack of empowerment, socio-cultural prejudices and poverty can act as powerful impediments. This study demonstrates that WhatsApp can provide an unique medium that requires a minimal skill-set for effective use, utilises a low cost infrastructure and has a wider penetration into the disadvantaged ‘hard to reach’ population where the eye disease burden remains disproportionately high. WhatsApp based health communication is highly acceptable to both healthcare providers, and deprived community members, which makes it an ideal medium for information dissemination. Its simplicity, multimedia capability and two-way communicability remains an attractive option for effective health communication on eye care. Multimedia information is better suited for informal learners with low levels of literacy over other traditional mediums. This research has also demonstrated that WhatsApp based health communication is highly effective in breaking existing communication barriers, raising awareness of eye care, and, impacting favourably on eye health communication and attitudes towards effective eye care and its providers. Importantly, from a policy maker's perspective, the appeal of a WhatsApp based health communication technology on eye care, comes with a favourable cost-benefit ratio. Nevertheless, there is a clear need for central leadership and strategic guidance for healthcare providers regarding the use of WhatsApp in health communication on eye care. Post-implementation, this strategy should be regularly evaluated for its impact on desired outcomes. Additionally, the unique set of determinants identified in this study that influences user engagement, would come beneficial for the policy makers in developing any community programs that focuses on eye health in deprived settings.

On a wider note, these research findings may be extrapolated to other areas of public health importance. Specifically, a WhatsApp based communication strategy might be effective in increasing awareness of vaccine preventable diseases, improve acceptability and uptake of vaccination programs, and other preventable infectious illnesses like tuberculosis, malaria, dengue and cholera. In addition, this strategy may also be appear beneficial in increasing awareness of good antenatal care, and on lifestyle changes required for the prevention of non-communicable diseases like diabetes and hypertension. It is anticipated that the findings from this study may potentially be transferable to a wider population, particularly those resident in other parts of the developing world, where eye disease and other health issues present a significant challenge to people's health and welfare.

Finally, although not its specific focus, this study demonstrated the evolution of a naïve and shy population into confident individuals questioning existing socio-cultural norms. This empowerment is uniquely important and must be considered in any governmental social policy aimed at empowering individuals and societies.

Implications for healthcare providers

For healthcare providers, this research demonstrated the suitability of WhatsApp based communication for eye care. Despite widespread agreement in favour of WhatsApp based health communication on eye care by healthcare providers, hesitancy was expressed at the outset in the adoption of a new form of communication and this has been observed by other researchers (Cooper et al., 2012; Antheunis et al., 2013; Bermúdez-Tamayo et al., 2013; Keller et al., 2014; Lofters et al., 2016). Subsequently, healthcare providers appeared more accepting in adopting this means of communication and this may arise from their widespread familiarity with the benefits of WhatsApp based communication use in personal and professional communication, its novelty and their perceptions that it might be useful in reaching out to the disadvantaged population. This needs to be explored further in future research. As this communication channel was simple to use, required low-cost infrastructure and appeared easily implementable without recourse to major financial support, it has a considerable appeal to be included in any health promotion strategy to address eye health inequalities. From a technical perspective, WhatsApp allowed multimedia capability, which a healthcare provider would find suitable in disseminating audio-visual information on eye health. As medical science is ever changing and newer evidence emerge regularly, there is a need for creation of accurate, unbiased, relevant, current and easy to understand content matter that is tailor-made for the deprived community. This responsibility rests primarily with the healthcare providers and necessitates major long-term commitments. With the widespread reach of WhatsApp, a healthcare provider can expect to achieve wide reach across society, help establish a strong link whilst understanding local needs and developing responsive and resource efficient services.

The two-way communication capability of WhatsApp would allow healthcare providers to be in touch with their intended audience in real time, advising and supporting with accurate unbiassed information in situations of crisis. This important feature of WhatsApp can be particularly useful as it will help healthcare providers to understand end-user needs. This will then lead to the design of tailor-made services with efficient use of limited resources that allow targeted delivery of healthcare interventions. Two-way communication would also facilitate continuous feedback that will allow fine-tuning of the service provision. This would also facilitate end users in obtaining information and receiving prompt answers. This will be extremely useful in health emergencies, where first aid management and prompt access to care is associated with a better outcome. Of course, the logistical challenges in manning this communication channel to provide real-time advice, is an important consideration.

Post implementation, there is strong need for ongoing evaluation and continued input from community health advocates, from diverse backgrounds and holding varied opinions. As was evident in this research, feedback remains an important resource in creation, delivery, and adjustments to this communication channel. Emerging from a perspective independent of both healthcare provider and deprived community, community health advocates can enrich any narrative as they represent the collective beliefs, opinions and perspectives of the wider community. In a wider roll out of health communication on eye care targeting the wider community, healthcare providers should play a central role.

Beyond the immediate benefits of having desirable health outcomes, this new form of communication has wider implications for the healthcare providers. WhatsApp can help healthcare providers to understand the health needs of the society in their sociocultural context. Information gathered through WhatsApp can help in dispelling mutual misunderstanding and forge stronger relationships that are based on trust and respect. This endeavour may also result in an improved organisational increased visibility and image.

7.6 Limitations of this study

This study has a number of limitations that merit discussion.

1. The first limitation of this study is that it is difficult to contextualise it with regard to the wider value of such an intervention in a policy context, due to the lack of information on the level and nature of current eye care provision in India.

2. This study focussed on women because the male population chose not to participate citing work commitments. Acknowledging, that women empowerment is pivotal to their families' eye health, a wider intervention that also encompassed men and other family members, including grandparents might have provided broader perspective on the suitability of an WhatsApp interventions for deprived communities.

3. This study could have engaged more specifically with debates regarding the nature and importance of information literacy. The Information Literacy Group of CILIP (The Chartered Institute for Library and Information Professionals) defines information literacy as "the ability to think critically and make balanced judgements about any information we find and use … It empowers us as citizens to reach and express informed views and to engage fully with society" (*CILIP Definition of Information Literacy 2018*, 2018). More specifically, this study could have sought to assess participants' levels of information literacy both prior to and subsequent to the intervention. This would have offered valuable insights into the impact the intervention. However, the circumstances surrounding the development of this intervention militated against such an approach. Specifically, given the innovativeness of the project and the sensitivities associated with enlisting the support of not only the women, but also the community health advocates and the health care providers, the researcher did not feel confident that any formal assessment of information literacy would have been acceptable to these various groups. Future studies in the health information arena, should draw more strongly on the frameworks and debates in the information literacy arena. Information literacy is an essential prerequisite in undertaking all activities in the healthcare sector (Foster, n.d.) including activities that enhance health literacy (Mahmoudi and Taheri, 2015) Poor information literacy will result as an additional barrier to the implementation of any health literacy program in a disadvantaged population. In the Indian context, there is a lack of comprehensive estimates of information literacy in the general population and in particular, in deprived communities. Nevertheless, given the low level of the overall national literacy rate, with 287 million illiterate adults or 37% of the global total (*10 Facts on illiteracy in India that you must*

know | Oxfam India, 2015), interventions that contribute to enhancing information literacy rates have to potential to make a significant difference. In the longer term, improving health in India, will depend of the inherent information literacy competencies of the population being studied.

4. This study was specific to one deprived community in India. The participants were very enthusiastic regarding not only the opportunity to learn how to take better care of their family, but also benefitted from a modest level of empowerment within their communities as a result of their learning. However, others who were invited to participate in the intervention were prevented from doing so as a result of shyness, family pressure, and other disincentives. Such shyness on the part of participants belonging to the deprived settings is not unusual (Johnson, 2000; Smith and Stein, 2017; Sony Thilakan, 2018; Mishra et al., 2020). This restricted profile of participants may also be an impediment to further research and, in general, to reaching some members of deprived communities with healthcare advice.

5. Only one of the study participants amongst the healthcare providers and the community health advocates had an information and communication technology background. Hence, one of the impediments in this study was that not only were those in need of healthcare advice, but the medical and healthcare professionals were new to the use of social media in their professional roles. Hence, it is important to acknowledge that their comments and other input to this study came from the personal perspective of a medical and healthcare professional. Nevertheless, they were interested in the study to the extent that they were prepared to participate and explore the potential of such an intervention.

6. There were also two other types of methodological constraints on the data collection processes associated with the intervention. First, all interviews with the women in the deprived community were conducted in Bengali. Whilst the interviewer/research student is also a fluent speaker of Bengali, as well as English, translation from one language to another did present some challenges. This was particularly the case when it came to translating some

English language terms (used by the healthcare providers) into Bengali, in order to conduct the interviews with the women from the deprived community. However, this limitation is not unique to this study, and the researcher took care to ensure that translations in either direction were managed as effectively as possible. On another issue, the healthcare providers were interviewed in a busy hospital environment and community health advocates were interviewed at their chosen venue, often their home and not a standardised interview venue. Consequently, in some cases, other distractions may have affected the quality of these interviews, although it is not unusual for interviews to be conducted in natural settings. However, the researcher is confident that the interviews and their transcripts give a good representation of the interviewee’s views. This was affirmed by the researcher by re-visiting the interviews and transcripts on a repeated basis to ensure representativeness of the extract during the thematic analysis.

7.7 Directions for further research

This research was successful in addressing the scope, benefits and barriers of using WhatsApp based health communication in eye care. During this research and beyond its scope, new ideas emerged that may be considered in future research in this field. Some of these ideas are outlined below as directions for future research.

Although not intended, the study population consisted of thirty women members of the deprived community and a lack of male participation may be regarded as a limitation. To avoid bias, future studies need to ensure that there is an equitable distribution of participants across the genders. This would necessitate considerable planning that would include amongst all, prior intimation well in advance and financial compensation package for time offered.

This research specifically explored communication and attitudinal changes in the deprived community post adoption of WhatsApp based health communication on eye care. At the outset, healthcare providers held a strong collective opinion of the information gap on eye care being contributed mainly by the characteristics of the deprived community. During the research, the two-way communication between the healthcare providers and the members of the deprived community, encouraged the former to be more aware of the health needs of the end users in their sociocultural context. This newly gained rich insight and understanding must have resulted in attitudinal and cultural change in the healthcare providers and this was never formally explored in this study. Any future study should be robust enough to explore this organisational, cultural and attitudinal changes along with the benefits gained and barriers faced. Such changes may be incorporated in policy making exercises as examples of best practice and shared widely.

Future research should also undertake a baseline assessment of information literacy competencies of the population being studied as the measure of the impact following any similar intervention would vary by this. This endeavour will allow comparisons being made across similar disadvantaged populations based geographically distanced with differing levels of information literacy and allow estimation of the magnitude of this effect prior to the actual interventional process.

Uniquely, this study involved community health advocates as independent campaigners for eye health and their opinions and perspectives shaped the outcomes of this research. However, their attitudes and behavioural changes post implementation of WhatsApp based health communication channel were not systematically explored in this study. Given their important role as a key stakeholder, any future study should explore this and feedback provided to the healthcare provider in making finer adjustments to their existing health policies.

Traditionally, health communication on eye care has been achieved through a variety of mediums and this study adds to the repertoire of such portals that may be used in eye health promotion. A formal comparative study in future should evaluate these various modalities from the perspectives of efficiency, acceptability, reach and their ability in attaining the desired outcomes.

WhatsApp in this research was primarily used as a health communication portal on eye care in deprived settings. However, the utility of WhatsApp on other health conditions in the wider population remains unexplored and must be the subject of future research. Additionally, it’s role needs to be systemically explored in diverse population groups situated geographically apart. Such and extensive exercise would allow the findings to be transferable to other health domains involving other communicable and non-communicable diseases of public health importance in India and beyond.

In this research, WhatsApp was used for information dissemination on eye care. As has been evident in the literature review, social media may be used for information collection on healthcare utilisation and information governance purposes. Thus, there is scope of WhatsApp to be studied as an information gathering tool to inform healthcare provider about the specific health needs of the society and develop responsive and resource efficient services. This role of WhatsApp needs to be explored further in future research.

Financial planning is an important mainstay in any policy making activity. This study did not specifically explore the financial aspects of a WhatsApp based health communication channel. A well designed study in the future should include principles of health economics and undertake a formal cost benefit analysis to understand the financial benefits of this portal. This should also incorporate a head-to-head comparison of WhatsApp and other mediums traditionally used in health communication in eye care. Information thus obtained would be helpful in developing and designing efficient services in resource restraint settings.

7.8 Chapter overview

This chapter summarises the research and systematically highlights as to how the stated research objectives were met. It highlights the study's contribution to existing knowledge, theory and methodology. It highlights the study's contributions to practice and practical implications for policy makers and healthcare providers. Finally, the study's limitations are discussed along with directions for future research.

CHAPTER 8. References

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CHAPTER 9. Appendices

Appendix A

Questionnaire for healthcare provider

Background of the project

Blindness in India is an important health issue with a significant detrimental effect on the society. My project involves the use of WhatsApp, a cost effective social media platform, to disseminate eye health related promotional information from a tertiary eye care centre to a section of the deprived community and assess its benefits.

Demographic information

1. Name ☐
2. Gender
    - 2.1. Male
    - 2.2. Female
3. Age
4. Designation
    - 4.1. Doctor
    - 4.2. Nurse
    - 4.3. Allied healthcare professional
    - 4.4. Administrative officer
    - 4.5. IT officer
    - 4.6. Other
5. How long in this job
    - 5.1. < 5 years
    - 5.2. 5 years

Mobile phone and social media usage

6. Mobile phones usage
    - 6.1. Do you use or have access to web enabled ‘smart’ phones?
    - 6.2. Do you use it to access ‘social media’ platforms?
    - 6.3. If you access ‘social media’, please indicate which platforms:
        - 6.3.1. Facebook
        - 6.3.2. Twitter
        - 6.3.3. Snapchat

    6.3.4. Instagram
    6.3.5. WhatsApp
    6.3.6. YouTube
    6.3.7. Others, please specify

6.4. If you use social media, please tell us the reason why you access it (tick as many as apply)

    6.4.1. Leisure and entertainment
    6.4.2. Communication with friends and family
    6.4.3. Communication within work groups or professional colleagues
    6.4.4. To access information
    6.4.5. To share information

Health promotion in eye health using social media

Please indicate your agreement for each of the following statements
1 = Completely disagree 5 = Completely agree

		1	2	3	4	5
1	Disease prevention by increasing awareness is an important aspect of mitigating disease impact					
2	Increasing awareness is an important aspect of preventing eye disease					
3	Increased awareness is particularly relevant to the deprived communities and social media may have an important role to play					
4	A number of health focussed organisations, nationally and internationally, have been disseminating information in promoting eye health to prevent blindness					
5	Promoting awareness through free to access technologies is:					
5.1	relevant					
5.2	beneficial					
5.3	achievable					
5.4	cost effective					
5.5	intrusive					
5.6	under-resourced					

6	Indian governmental strategy of encouraging dissemination of heath related information by social media portal is:					
6.1	relevant					
6.2	beneficial					
6.3	achievable					
6.4	cost effective					
6.5	intrusive					
6.6	under-resourced					
7	Video based information disseminated through social media platforms to the target deprived community may be useful in achieving this aim.					
7.1	Amongst video based technology platforms, the following may be useful:					
7.1.1	WhatsApp					
7.1.2	Facebook					
7.1.3	You Tube					
7.1.4	Twitter					
7.1.5	Instagram					
7.1.6	Snapchat					
7.1.7	Others (please specify)					
8	About WhatsApp:					
8.1	WhatsApp has the capability to provide two-way communication between the providers (your team) and the Deprived community.					
8.2	WhatsApp utilises, texts, audio and video messaging capabilities.					
8.3	WhatsApp is a workable social media platform					

8.4

Please give your opinion of using WhatsApp in disseminating health information considering the following:
Will it work? How will it work? What will work – price, technologies, platforms
Which? Where? Who? When?

Communication between Susrut and the target deprived community

9. Does Susrut communicate health information to the deprived community?

Yes
No
Not sure

10. Does Susrut have a written policy of communicating health information to the deprived population?

Yes
No
Not sure

11. What are Susrut's main ways of communicating to the deprived population

    11.1. News adverts
    11.2. Radio
    11.3. TV
    11.4. Adverts
    11.5. Internet / website
    11.6. Health workers
    11.7. Other

12. Does Susrut implement any specific two-way communication method to help with health promotion

Yes
No
Not sure

13. Does Susrut evaluate the impact of the disseminated health information

Yes
No
Not sure

14. As women are the primary carers at home, does Susrut implement any specific program to support women ?

Yes
No
Not sure

15. Does Susrut have access to relevant and up-to-date information resources (pertaining to eye health) to educate patients. If not what should be done about it?

Yes
No
Not sure

16. Can you suggest ways of improving communication between Susrut and deprived communities?

Type of information to be disseminated to the target deprived community

In your opinion, what aspects of information on preventive eye health, are useful and relevant to the target community.

Please indicate your agreement for each of the following statements
1 = Irrelevant 5 = Relevant

		1	2	3	4	5
17						
17.1	Routine eye care					
17.2	Early symptoms of eye disease					
17.3	Common eye problems in children (e.g Vitamin A deficiency, congenital glaucoma, eye injury, conjunctivitis, eye tumours, etc)					
17.4	Common eye problems in adults (cataracts, glaucoma, eye infections, injury, retinopathy, etc)					
17.5	Eye donation after death					
17.6	Who to contact in an emergency or when concerns arise					
17.7	Where to access further information					
17.8	Other topics (not listed above)					
18	What is your opinion of opening up a tele-clinic (e.g. 2 hours a month) dedicated to answer some of the non-urgent queries posed by the Deprived community					

Appendix B

Questionnaire for community health advocate interview

Background of the project

Blindness in India is an important health issue with a significant detrimental effect on the society. My project involves the use of WhatsApp, a cost effective social media platform, to disseminate eye health related promotional information from a tertiary eye care centre to a section of the deprived community and assess its benefits.

Demographic information

1. Name
2. Gender
   - 2.1. Male
   - 2.2. Female
3. Age
4. Profession

Mobile phone and social media usage

5. Mobile phone usage
   - 5.1. If so, do you use or have access to web enabled ‘smart’ phones?
   - 5.2. If you use smart phones, do you use it to access ‘social media’ platforms?
   - 5.3. If you access ‘social media’, please list the categories accessed
     - 5.3.1. Facebook
     - 5.3.2. Twitter
     - 5.3.3. Snapchat
     - 5.3.4. Instagram
     - 5.3.5. WhatsApp
     - 5.3.6. YouTube
     - 5.3.7. Others, please specify
   - 5.4. If you use social media, please tell us the reason why you access it (tick as many as apply)
     - 5.4.1. Leisure and entertainment
     - 5.4.2. Communication with friends and family
     - 5.4.3. Communication within work groups or professional colleagues
     - 5.4.4. To access information
     - 5.4.5. To share information

Health promotion in eye health using social media

Please indicate your agreement for each of the following statements
1 = Completely disagree 5 = Completely agree

		1	2	3	4	5
1	Disease prevention by increasing awareness is an important aspect of mitigating disease impact					
2	Increasing awareness is an important aspect of preventing eye disease					
3	Increased awareness is particularly relevant to the deprived sections of the society and social media may have an important role to play					
4	A number of health focussed organisations, nationally and internationally, have been disseminating information in promoting eye health to prevent blindness					
5	Promoting awareness through free to access technologies is:					
5.1	relevant					
5.2	beneficial					
5.3	achievable					
5.4	cost effective					
5.5	intrusive					
5.6	under-resourced					
6	Indian governmental strategy of encouraging dissemination of heath related information by social media portal is:					
6.1	relevant					
6.2	beneficial					
6.3	achievable					
6.4	cost effective					
6.5	intrusive					
6.6	under-resourced					
7	Video based information disseminated through social media platforms to the target deprived community may be useful in achieving this aim.					
7.1	Amongst video based technology platforms, the following may be useful:					
7.1.1	WhatsApp					

7.1.2	Facebook					
7.1.3	You Tube					
7.1.4	Twitter					
7.1.5	Instagram					
7.1.6	Snapchat					
7.1.7	Others (please specify)					
8	About WhatsApp:					
8.1	WhatsApp has the capability in providing two – way communication between the providers and the Deprived community					
8.2	WhatsApp utilises, texts, audio and video messaging capabilities.					
8.3	WhatsApp is a workable social media platform					

8.4 Please give your opinion of using WhatsApp in disseminating health information considering the following:

Will it work?
How will it work?
What will work – price, technologies, platforms
Which?
Where?
Who?
When

Type of information to be disseminated to the target community

In your opinion, what aspects of information on preventive eye health, are useful and relevant to the target community

Please indicate your agreement for each of the following statements
1 = Irrelevant 5 = Relevant

		1	2	3	4	5
9						
9.1	Routine eye care					
9.2	Early symptoms of eye disease					
9.3	Common eye problems in children (e.g Vitamin A deficiency, congenital glaucoma, eye injury, conjunctivitis, eye tumours, etc)					
9.4	Common eye problems in adults (cataracts, glaucoma, eye infections, injury, retinopathy, etc)					
9.5	Eye donation after death					
9.6	Who to contact in an emergency or when concerns arise					
9.7	Where to access further information					
9.8	Other topics (not listed above)					

Appendix C

Deprived community Basic demographic data capture sheet

Demographics

1. Name
2. Age (years)
    - 2.1. 18 – 25
    - 2.2. > 25 – 40
    - 2.3. > 40 – 60
    - 2.4. > 60
3. Primary role in the family
    - 3.1. Mother
    - 3.2. Daughter
    - 3.3. Wife
4. Carer
5. Residence
    - 5.1. Postcode
6. Religion
7. Marital status
    - 7.1. Married
    - 7.2. Unmarried
    - 7.3. Widowed
    - 7.4. Divorced
    - 7.5. Single
8. Highest educational attainment
    - 8.1. Not been to any formal school
    - 8.2. Studied upto primary level
    - 8.3. Studied upto secondary level
    - 8.4. Studied upto secondary level plus
9. Occupation status
    - 9.1. Unemployed
    - 9.2. Home maker
    - 9.3. Employed (specify)
10. Monthly income
    - 10.1. Individual
        - 10.1.1. < Rs 5000
        - 10.1.2. Rs 5000 – Rs 10000
        - 10.1.3. > Rs 10000
    - 10.2. Gross for the family
        - 10.2.1. < Rs 5000
        - 10.2.2. Rs 5000 – Rs 10000
        - 10.2.3. > Rs 10000
11. Any hazardous work performed in the premises or close to premises
12. Home ownership

   12.1. Owned privately
   12.2. Government provided
   12.3. Private rental
   12.4. Other
13. Family size
   13.1. Adults
   13.2. Children
14. Home room numbers (excluding kitchen)
   14.1. 1 room
   14.2. 2 room
   14.3. > 2 room
15. Household fuel
   15.1. Coal based
   15.2. LPG based
   15.3. Wood based
   15.4. Electricity based
16. Availability of electricity
17. Availability of potable drinking water
   17.1. At home
   17.2. From outside source
18. Vehicle ownership
   18.1. None
   18.2. Cycle
   18.3. Motor cycle
   18.4. 3 or 4 wheeler
19. Pet ownership
20. Current disease burden
21. Smoking habits
   21.1. Personally
   21.2. Passive smoking
22. Drinking habits
23. Chewing tobacco products
24. Other recreational drugs
25. Television ownership
26. Radio ownership
27. Telephone ownership

Mobile phone use

28. Do you use mobile phones?
29. If so, do you use or have access to web enabled ‘smart’ phones?
30. If you use smart phones, do you use it to access ‘social media’ platforms?

Social media use

31. If you access ‘social media’, please tick the media used (multiple answers possible)
    - 31.1. Facebook
    - 31.2. Twitter
    - 31.3. Snapchat
    - 31.4. Instagram
    - 31.5. WhatsApp
    - 31.6. Other
32. If you use social media, please tell us the reason why you access it (multiple answers possible)
    - 32.1. Leisure and entertainment
    - 32.2. Communication with friends and family
    - 32.3. Communication within work groups or professional colleagues
    - 32.4. To access information
    - 32.5. To share information
    - 32.6. Other

Health information sources

33. Do you get any health related information on your mobile phones (texts, other notifications)
34. Do you get any health information from any other source (agency worker, WHO worker, etc)

Eye health information

35. Do you have any issues with eye health?
36. If so, what problems do you face with eye health
    36.1. Eye injury
    36.2. Eye infection
    36.3. Blindness and visual impairment
    36.4. Other
37. Have you attended any eye clinics recently (past 3 years)
38. If you have attended a eye clinic, which type:
    38.1. Government free clinic
    38.2. Charitable free clinic
    38.3. Private hospital clinic
    38.4. Private specialist clinic
39. Do you get eye health information from these clinics
40. Do you get eye health information from any other source
    40.1. Community health workers
    40.2. Government agencies
    40.3. Media (newspaper, television and radio)
    40.4. Other
41. Do you get any health information about eye health on your mobile phones from: (Tick all applicable)?
    41.1. Susrut
    41.2. Sight Saver
    41.3. Lions Club
    41.4. Red Cross
    41.5. Age UK

42. Susrut is preparing to deliver important eye health related information to you (free of cost) through the use of mobile social media application technology. How interested would you be in knowing about it:

Appendix D

Focus Group Interview Questionnaire

WhatsApp Project Final evaluation questionnaire.

We would appreciate your opinion and comments about our program – what went well, what did not and what can be improved?
এই প্রোগ্রামের বিষয়ে আপনাদের কি অভিমত - কি কি ভালো লাগলো, কি কি ভালো লাগলো না আর কি কি করলে আরও ভালো করা যাবে ?

Did you find it difficult to get in touch with our team?
দিদিদের সাথে যোগ যোগ করতে কি আপনাদের কোনো অসুবিধে হয়েছিল ?

What was your preferred option - hearing this information from our team directly on a face to face contact or through an audiovisual interaction using the mobile app?
এইরকম প্রোগ্রামে কি ভবিষ্যতে চললে আপনাদের ভালো লাগবে ? মোবাইলে প্রোগ্রাম করার আর দিদিদের মুখে কথা সোনার মধ্যে কোনটা আপনাদের ভালো লাগবে?

What would be your opinion if such an interactive option remain available over a 24 hour period?
এইরকম ব্যবস্থা যদি ২৪ ঘন্টা চালু রাখা যাওয়া যায়, তাতে কি আপনাদের কি মতামত ?

Did you know about eye related health problems before being part of this study?
আমাদের প্রোগ্রাম শুরু হওয়ার আগে আপনারা কি চোখের অসুখের ব্যাপারে জানতেন ?

Did you know about the treatment for eye diseases before being part of this study?
আমাদের প্রোগ্রাম শুরু হওয়ার আগে আপনারা কি চোখের অসুখের চিকিৎসার ব্যাপারে জানতেন ?

Did you know about the services available for eye health before being part of this study?
আমাদের প্রোগ্রাম শুরু হওয়ার আগে আপনারা কি চোখের অসুখের চিকিৎসা
ব্যবস্থা পরিষেবা সম্পর্কে জানতেন ?

From this study, what have you learnt about the diseases that may affect the eyes?
চোখের অসুখের বিষয়ে দিদিদের মোবাইলে কি কি জানতে পারলেন ?

From this study, what have you learnt so far about taking care of your own eyes? After having all this information, how would you like to protect you and your family members from developing eye problems?
দিদিদের মোবাইলে চোখের যত্নের ব্যাপারে কি কি জানতে পারলেন? এই খবর গুলো পাওয়ার পর
আপনি আপনার পরিবার ও পরিচিতদের জন্যে কি কি করতে চাইছেন ?

How did you benefit from being made aware about the role of governmental private eye hospital and in the ways they can support you ?
সরকারি ও বেসরকারি চক্ষু বিশেষজ্ঞ প্রতিষ্ঠান কি ভাবে সাহায্য করতে পারে তা আপনারা জেনেছেন
দিদিদের মোবাইলে - এটা জেনে কি কি লাভ হলো আপনাদের ?

In an emergency, what steps can you undertake to treat an eye problem ?
চোখের জরুরি অসুবিধে হলে আপনি কি কি করতে পারেন ?

Long term problems with the eyes can be detrimental, how would like to manage such problems at home and in your neighbourhood?
চোখের কোনো দীর্ঘ দিনের সমস্যা ফেলে রাখা উচিত নয় - আপনার পরিবার ও পরিচিতদের চোখের
সমস্যা হলে আপনি কি কি করবেন ?

What are your thoughts about regular yearly eye check-ups?
প্রতি বছর ডাক্তারের কাছে চোখ দেখানো দরকার - এই বিষয়ে আপনি কি ভাবছেন ?

As you now know the importance of eye donation after death, would you spread this important message amongst your family members and your neighbourhood?

মৃত্যুর পরে চোখ দানের প্রয়োজনীতা আপনি শুনেছেন - আপনি কি এই গুরুত্বপূর্ণ খবরটিকে আপনার পরিবার ও পরিচিতদের মাঝে জানাবেন ?

Appendix E

Participant Information Sheet

Department of Languages, Information and Communications
Faculty of Humanities, Languages and Social Science

Geoffrey Manton Building
Manchester Metropolitan University

Participant Information Sheet

WhatsApp in health communication: the case of ocular health in deprived settings in India

Invitation to research

We would like to invite you to take part in a research study. My name is Chandrani Maitra and I am I am currently undertaking this research as a PhD student registered at Manchester Metropolitan University, Manchester, United Kingdom, under the guidance of my supervisory team, Professor Jenny Rowley and Dr Esperanza Miyake, Department of Information and Communication, Faculty Of Humanities ,Languages and Social Sciences at the Manchester Metropolitan University. Our research project intends to explore the role of WhatsApp in ocular health education in deprived settings in India.

India has almost a quarter of the entire global burden of blindness and this poses a major challenge for India's healthcare agenda. Disability resulting from blindness results in lower employment and lower productivity. Much of this blindness is preventable and there is a serious lack of easily available information. Over the past decade, the use of social media has increased significantly in India. WhatsApp is a widely used social media platform that is now accessed by millions of Indians from all socioeconomic backgrounds. In this research study, I would be exploring the use of WhatsApp technology in developing the community based practice of eye health promotion in a deprived semi urban setting in India. The research aims to explore the nature of behavioural change associated with the adoption of social media for eye health. It will also attempt to understand the usage and challenges of WhatsApp in promoting eye health.

Why have I been invited?

You have been contacted because you are a valuable member of the community. Your active role in the community will help development of a community of practice of using social media in promoting eye health in deprived semi urban setting in India.

Do I have to take part?

It is up to you to decide. We will describe the study and go through the information sheet, which we will give to you. We will then ask you to sign a consent form to show you agreed to take part. You are free to withdraw at any time, without giving a reason.

What will I be asked to do?

In an effort to gain your insights, the study process would involve me collecting information about your beliefs and thoughts in the current provision of ocular healthcare in India. This would be achieved through the form of semi structured interviews using a questionnaire and some of the data maybe audio recorded for further transcription purposes. This interview should not take more than 30 - 60 minutes.

For a select group of participants (also known as the focus group), after the initial information gathering, you would be requested to attend 5 dedicated sessions of teaching focussing specifically on various aspects of ocular health and their remedial strategies. This would be achieved by using audio-visual material disseminated through WhatsApp on a smart phone. Each session would take approximately 60 minutes where we would ask for your feedback and answer your questions. These sessions would be held on monthly intervals in a place local to you. These sessions may be recorded (audio and visual) for further research analyses. The final session would involve me asking you (the focus group) as to what have your learnt from all the study sessions. Again this would not take more than 30 – 60 minutes of your time and may involve audio-visual recording.

Are there any risks if I participate?

There is no conceivable risk in participating in this study

Are there any advantages if I participate?

Taking part in this project has no materialistic benefits in the forms of rewards or financial compensation to you as the participating individual. However, it is anticipated that this study may result in the creation of a social network of learning about the issues of ocular health problems and the level of supportive management currently available. However, information collected from this research would be used to develop and augment the theories of learning and may have a positive benefit on the society as a whole.

What will happen with the data I provide?

When you agree to participate in this research, we will collect from you personally-identifiable information. The Manchester Metropolitan University ('the University') is the Data Controller in respect of this research and any personal data that you provide as a research participant. The University is registered with the Information Commissioner's Office (ICO), and manages personal data in accordance with the General Data Protection Regulation (GDPR) and the University's Data Protection Policy. We collect personal data as part of this research (such as name, telephone numbers or age, sound recordings and photographs when indicated). As a public authority acting in the public interest we rely upon the 'public task' lawful basis. When we collect special category data (such as medical information or ethnicity) we rely upon the research and archiving purposes in the public interest lawful basis.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained.

We will not share your personal data collected in this form with any third parties. If your data is shared this will be under the terms of a Research Collaboration Agreement which defines use, and agrees confidentiality and information security provisions. It is the University's policy to only publish anonymised data unless you have given your explicit written consent to be identified in the research. **The University never sells personal data to third parties.**

We will only retain your personal data for as long as is necessary to achieve the purpose of the research. All forms of written data would be stored securely in the University Department with secure access whilst electronic data would be kept securely on University computers with access specific to the research team. Audio-visual data would be held securely on a University computer with secure access to the research team. Every effort would be used to maintain participant confidentiality and anonymise data. This information would be stored securely for ten years post collection and disposed off carefully afterwards in accordance to the University Data handling guidelines.

For further information about use of your personal data and your data protection rights please see the University's Data Protection Pages (https://www2.mmu.ac.uk/data-protection/).

What will happen to the results of the research study?

The findings from this project is expected to be disseminated through conference poster and proceedings, lectures and publications in peer reviewed journals. These would not include any participant identifiable data.

Who has reviewed this research project?

This study has been fully reviewed by Professor Jenny Rowley and Dr Esperanza Miyake, Department of Information and Communication, Faculty Of Humanities ,Languages and Social Sciences and the University Ethics Research Committee at the Manchester Metropolitan University.

Who do I contact if I have concerns about this study or I wish to complain?

If you have any concerns regarding the personal data collected from you, our Data Protection Officer can be contacted using the legal@mmu.ac.uk e-mail address, by calling 0161 247 3331 or in writing to: Data Protection Officer, Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH. You also have a right to lodge a complaint in respect of the processing of your personal data with the Information Commissioner's Office as the supervisory authority. Please see: https://ico.org.uk/global/contact-us/

You may also contact our Research Ethics Committee for further concerns or complaints at:
Faculty of Arts and Humanities, Research Ethics and Governance Committee
Telephone +44 (0)161 247 6673
Email: artsandhumanitiesethics@mmu.ac.uk.

Further Information please contact :

Chandrani Maitra, PhD student
Professor Jenny Rowley, PhD Supervisor
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Manchester.
M 15 6LL
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THANK YOU FOR CONSIDERING PARTICIPATING IN THIS PROJECT

Appendix F

Interview consent form for healthcare provider and community health advocates

Consent Form

Title of Project: WhatsApp in health communication: the case of eye health in deprived settings in India

Name of Researcher: Chandrani Maitra

Participant Identification Code for this project: 4531

Please initial box

1. I confirm that I have read and understood the information sheet dated 17.07.2019 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason to the named researcher. ☐
3. I understand that my responses will be sound recorded and used for analysis for this research project. ☐
4. I understand that the interviews may be video recorded and / or photographed and used for analysis for this research project ☐
5. I understand that my responses will remain anonymous. ☐
6. I agree to take part in the above research project. ☐
7. I understand that at my request a transcript of my interview can be made available to me. ☐

Name of Participant	Date	Signature
Researcher / Name of the Person. taking consent	Date	Signature

Appendix G

Interview consent form for participants from deprived community

Consent Form

Title of Project: WhatsApp in health communication: the case of ocular health in deprived settings in India

Name of Researcher: Chandrani Maitra

Participant Identification Code for this project: 4531

Please initial box

8. I confirm that I have understood the information sheet dated 17.07.2019 (Version 2) for the above study that was translated to me in Bengali / Hindi. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily ☐

9. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason to the named researcher ☐

10. I understand that my responses will be sound recorded and used for analysis for this research project ☐

11. I understand that the interviews may be video recorded and / or photographed and used for analysis for this research project ☐

12. I understand that my responses will remain anonymous. ☐

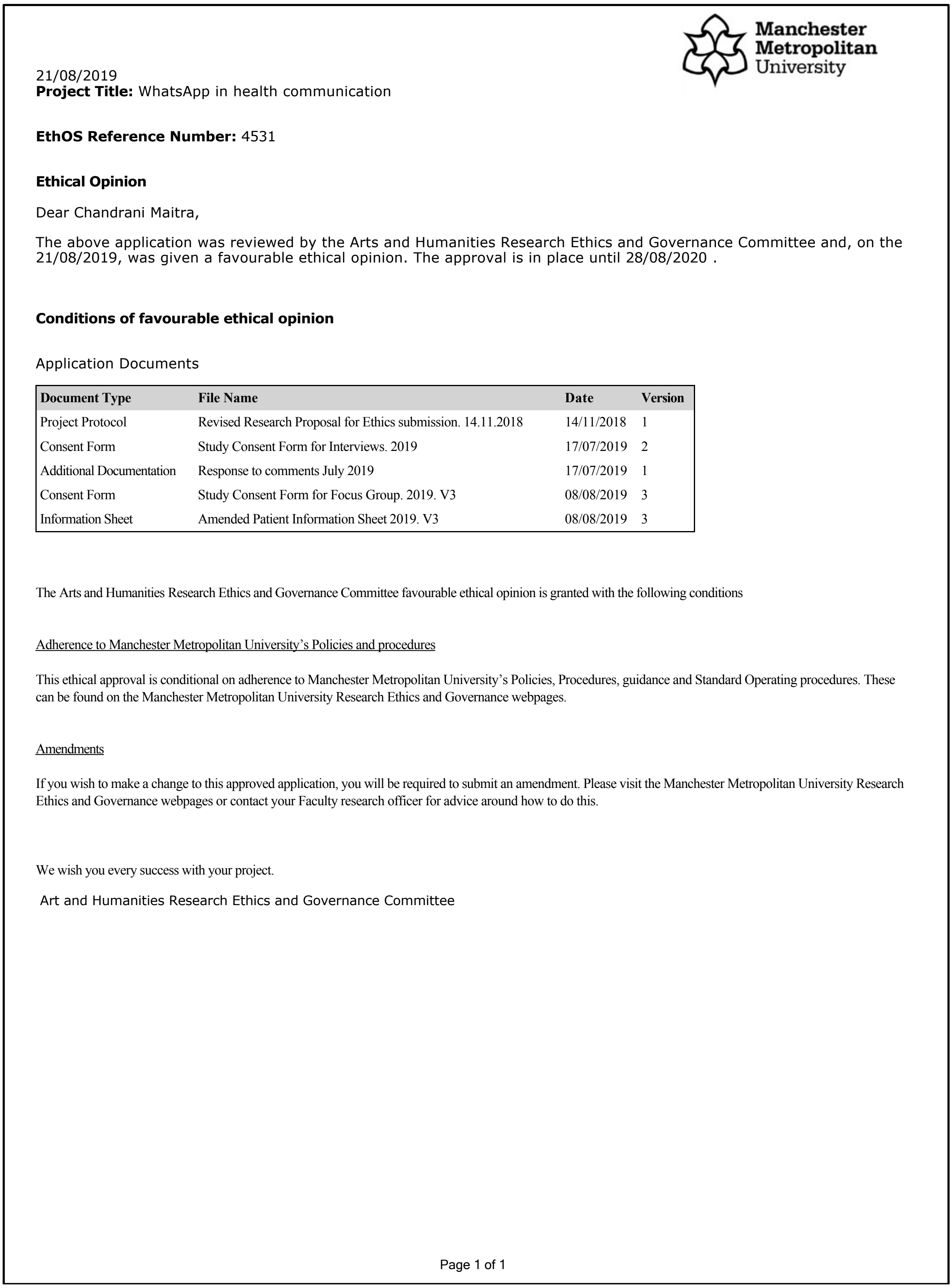
13. I agree to attend the 6 dedicated sessions of teaching focussing specifically on various aspects of ocular health and their remedial strategies which may involve audiovisual recording (for focus group only) ☐

14. I agree to take part in the above research project. ☐

Name of Participant	Date	Signature / Fingerprint
Researcher / Name of the Person. taking consent	Date	Signature

Appendix H

Ethical Approval Decision Letter



21/08/2019
Project Title: WhatsApp in health communication

EthOS Reference Number: 4531

Ethical Opinion

Dear Chandrani Maitra,

The above application was reviewed by the Arts and Humanities Research Ethics and Governance Committee and, on the 21/08/2019, was given a favourable ethical opinion. The approval is in place until 28/08/2020 .

Conditions of favourable ethical opinion

Application Documents

Document Type	File Name	Date	Version
Project Protocol	Revised Research Proposal for Ethics submission. 14.11.2018	14/11/2018	1
Consent Form	Study Consent Form for Interviews. 2019	17/07/2019	2
Additional Documentation	Response to comments July 2019	17/07/2019	1
Consent Form	Study Consent Form for Focus Group. 2019. V3	08/08/2019	3
Information Sheet	Amended Patient Information Sheet 2019. V3	08/08/2019	3

The Arts and Humanities Research Ethics and Governance Committee favourable ethical opinion is granted with the following conditions

Adherence to Manchester Metropolitan University's Policies and procedures

This ethical approval is conditional on adherence to Manchester Metropolitan University's Policies, Procedures, guidance and Standard Operating procedures. These can be found on the Manchester Metropolitan University Research Ethics and Governance webpages.

Amendments

If you wish to make a change to this approved application, you will be required to submit an amendment. Please visit the Manchester Metropolitan University Research Ethics and Governance webpages or contact your Faculty research officer for advice around how to do this.

We wish you every success with your project.

Art and Humanities Research Ethics and Governance Committee