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**Portfolio of Doctorate in Health  
Psychology**

**By Beatrice H. C. Chapman**

**For the Qualification of Professional Doctorate in  
Health Psychology**

**Department of Health Sciences  
City University**

**May, 2017**

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## **DECLARATION**

I grant powers of discretion to the university librarian to allow the thesis to be copied in whole or in part without further reference to the author. This permission covers only single copies made for study purposes, subject to normal conditions of acknowledgement.

## ABBREVIATIONS

<b>A&amp;E</b>	Accident and Emergency
<b>APA</b>	American Psychological Association
<b>BHBIA</b>	British Healthcare Business Intelligence Association
<b>BPS</b>	British Psychological Society
<b>CBT</b>	Cognitive Behavioural Therapy
<b>CCGs</b>	Clinical Commissioning Groups
<b>COPD</b>	Chronic Obstructive Pulmonary Disease
<b>CVD</b>	Cardiovascular Disease
<b>DH</b>	Department of Health
<b>DHP</b>	Division of Health Psychology
<b>FPH</b>	Frimley Park Hospital
<b>GP</b>	General Practitioner
<b>HBM</b>	Health Belief Model
<b>HCPC</b>	Health Care Professions Council
<b>IAPT</b>	Improving Access to Psychological Therapies
<b>IQ</b>	Intelligence Quotient
<b>OOHs</b>	Out of Hours
<b>PCC</b>	Primary Care Commissioning
<b>PCT</b>	Primary Care Trust
<b>MR</b>	Market Research
<b>MINT</b>	Motivational Interviewing Network of Trainers
<b>MAT</b>	Minor Ailment Schemes
<b>NCT</b>	National Childbirth Trust
<b>NICE</b>	National Institute for Health and Care Excellence

<b>NSA</b>	National Stroke Association
<b>RCT</b>	Randomised Controlled Trial
<b>SIDS</b>	Sudden Infant Death Syndrome
<b>TIA</b>	Transient Ischaemic Attack
<b>TPB</b>	Theory of Planned Behaviour
<b>UNICEF</b>	United Nations International Children's Emergency Fund
<b>USA</b>	United States of America
<b>UTI</b>	Urinary Tract Infections
<b>UK</b>	United Kingdom
<b>WHO</b>	World Health Organisation

## LIST OF PUBLICATIONS

- Chapman, B. & Turnbull, T. (2016). Health professionals' perceptions of inappropriate use of A&E services, *British Journal of Nursing*, 25(9), 494-497. DOI: <http://dx.doi.org/10.12968/bjon.2016.25.9.476>
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## **SECTION A: PREFACE**

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## **Putting Health Psychology into Practice**

This portfolio documents all of the experience, skills and knowledge I gained whilst undertaking the doctorate in health psychology. The majority of the practice placement for the portfolio was completed whilst in the position of research and project manager at Visions4health, a healthcare consultancy agency, where I was employed for over five years. Visions4health works with the National Health Service (NHS) and healthcare organisations. My role predominately involved conducting research into different aspects of health, working on large social marketing/behaviour change projects, managing projects, writing reports, presenting findings, as well as working in service development and strategic planning. Whilst employed at Visions4health I was seconded for six months by NHS Surrey's public health department (which later became Surrey County Council). I was later consulted to work for them on the behaviour change intervention, and I also worked for them on a voluntary basis. These workplaces provided interesting healthcare settings and plenty of opportunities to undertake the training and practice. I stopped working for Visions4health when I had my first child, and have since had my second. During this time I conducted and completed my research thesis and worked on writing and publishing my work.

There is a consistent thread across the portfolio which is healthcare services, patient experiences and patient outcomes. This thread encompasses a broad range of health psychology topics which are important in improving mental and physical health and ensuring services are run optimally. The portfolio includes work from a diverse range of settings and topics due to projects unfolding and interests developing, but the thread is consistent throughout. The applied role of health psychologists was also highlighted throughout the portfolio as this is a personal interest of mine. Health psychologists work in a range of applied healthcare settings offering expert knowledge and skills, which is increasingly important (British Psychological Society, 2013). The portfolio comprises of the research thesis, published work, professional practice components, and systematic review.

### **Research Thesis**

The research, '*Exploring Women's Experiences of Breast-Feeding and Mastitis and the Impact of Formal and Informal Support*', was a qualitative study developed from a lack of research in the area of mastitis, breast-feeding and support. Ample evidence suggests

that breast-feeding is hugely beneficial for infants and mothers (Victora, Bahl, Barros, Franca, Horton et al., 2016); however the UK has some of the lowest rates of initiation and duration in the world (Health and Social Care Information Centre, 2012). Mastitis has been highlighted as one of the most common breast-feeding problems as well as being associated with breast-feeding discontinuation (Cusack & Brennan, 2011; Jahanfar, Ng & Teng, 2009; Scott, Robertson, Fitzpaterick, Knight, & Mulholland, 2008; Spencer, 2008). Additional research was therefore needed to understand more about women's experiences of breast-feeding and mastitis (Amir, Forster, Lumley et al., 2007; Cleminson, Oddie, Renfrew & McGuire, 2015).

The current study used grounded theory to explore 16 women's experiences of breast-feeding and mastitis, the formal and informal support that was available to them when they had mastitis, and how this impacted on whether or not they continued to breast-feed. The study showed that there were clear factors that precipitated women developing mastitis and with improved support and information there would be a lower incidence of mastitis. For example, enhanced support with breast-feeding problems such as a '*poor latch*' while women are still in the hospital would reduce the risk of women getting nipple fissures leading to mastitis. Overall the women's experiences of mastitis were very negative. It affected women during a time when they felt emotional and physically tired. Women in this study were very determined to breast-feed and in the main continued even when they faced huge difficulties. However, some women felt they could not continue, usually when they had recurrent episodes of mastitis, and were left feeling guilty and upset as they had wanted to continue. Improved information, support and early diagnosis of mastitis would reduce the incidence and severity of it. It was also found that women's expectations need to be set so that they do not feel like they are failing when breast-feeding does not go as well as they expected it to. Thus, providing better support and advice would lead to women having better breast-feeding experiences and continuing to breast-feed if this is what they would like and are able to do.

## **Publications**

In addition to the main thesis, 10,000 words of publications, consisting of a minimum of two studies were undertaken, as per City University requirements. All of the words written for the portfolio were published. The first main publication was commissioned by the Department of Health and explored implementation of respiratory guidelines. The publication looked at barriers and facilitators of implementing guidelines, and

explained how health psychologists are well placed given their broad range of skills to work as consultants on projects such as these. This was published in Health Psychology Update.

The second main publication was a qualitative investigation into healthcare professionals' perceptions of inappropriate use of emergency services in Surrey. This research was conducted as part of the consultancy competency and written and published as a separate piece of work (British Journal of Nursing, 2016). It was also accepted and presented as a poster presentation at the British Psychological Society (BPS) conference in 2017.

In addition to these two main publications, an interview was conducted with an experienced consultant health psychologist to provide insight into the applied roles psychologists can work in. This interview was published in January 2014 in The Psychologist.

Lastly, a book review of Dempster's A Research Guide for Health and Clinical Psychology (2011) was written and is available on the BPS website.

## **Professional Practice**

### **Consultancy**

Inappropriate use of emergency services is an on-going problem for the NHS, costing millions of pounds every year (Purdy, 2010). I was consulted by NHS Surrey, through my role at Visions4health, to work on a project with their public health department looking at healthcare professional's perceptions of inappropriate use of emergency care services. Qualitative research was undertaken and the outcome was to produce a report identifying groups of the population who were most likely to inappropriately use emergency services. The findings showed there were clear groups of people more likely to inappropriately use emergency services, such as parents with small children, younger people (18-30 year olds), those with long-term conditions, the Nepalese community, and those with alcohol and drug misuse problems. It was also found that there was a general lack of awareness of health services available in Surrey. The findings from this project led to the behaviour change intervention, which I was consulted to work on.

## **Behaviour Change**

I was consulted by Guildford and Waverley Clinical Commissioning Group (CCG, formerly NHS Surrey) to conduct a large scale social marketing/behaviour change intervention to reduce inappropriate use of emergency services using the findings from the consultancy. It was decided that an intervention targeting one of the main groups uncovered from the consultancy would be carried out to reduce inappropriate use of emergency services. One of the main groups found to be inappropriately using emergency services was parents with small children, and they were chosen to be the target group for the intervention. The intervention involved researching parents with small children's behaviour and knowledge, and designing and implementing an intervention that would help to support parents attend the most appropriate local NHS service for their child's condition. A baby booklet outlining common conditions and sign posting parents to the most appropriate local services was developed. Over 10,000 copies were printed and distributed across Surrey.

## **Teaching and Training**

Teaching and training took place with two target groups, professionals and patients. The first case study involved a *'Patient Outcomes Master-Class'* that I developed and delivered to healthcare professionals working within or with the pharmaceutical sector. The training was designed to teach and train healthcare professionals about what patient outcomes are, why they are important, and what they entail. The training covered some fundamental health psychology topics such as help-seeking behaviour, patient-provider interaction and self-management. One-to-one and group sessions were conducted and when requested, more in-depth training about specific topics (modules) were delivered. The second case study arose from working with Surrey's public health department on the behaviour change project. It became apparent that stress was negatively impacting people's wellbeing and potentially leading to an increase in use of emergency services. I therefore designed a stress-management (one-to-one and group) training course for patients, and delivered it at a local general practice.

## **Systematic Review**

Whilst working at Visions4health I was commissioned to conduct a systematic review in the area of stroke that encompassed health psychology. Stroke is the third most common cause of mortality and one of the leading causes of adult physical disability in

England (Department of Health, 2007) and medical treatment is imperative for its management and reducing the risk of recurrent stroke (Menard, Smith and Taormina, 2011). I therefore conducted a systematic review investigating the impact that self-management interventions have on the outcome adherence to stroke medication. Six studies met the criteria for inclusion for the systematic review. The review found that self-management interventions were effective in improving adherence to stroke medication in the short term however, in the longer term these benefits were not maintained. This systematic review was published in 2014 in the British Journal of Nursing, and also presented as part of the booklet that was handed out to the delegates at the European Stroke Conference.

### **Conclusions**

To conclude, this portfolio includes all of the work, experience and skills I have attained over the last five years required for becoming a chartered health psychologist. I plan on publishing my thesis findings and am looking forward to pursuing areas of interest and my career as a health psychologist.

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## **SECTION B: RESEARCH**

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**RESEARCH**

**Exploring Women's Experiences of Breast-Feeding  
and Mastitis and the Impact of Formal and  
Informal Support: A Qualitative Study**

**Beatrice Chapman**

## Abstract

**Objective:** Mastitis is a common and painful condition experienced in up to 33% of breast-feeding women (Cusack & Brennan, 2011; Jahanfar, Ng & Teng, 2009; Scott, Robertson, Fitzpaterick, Knight, & Mulholland, 2008; Spencer, 2008). The period following having a baby may be emotionally and physically demanding due to the physical, hormonal and lifestyle changes a woman undergoes (Cusack & Brennan, 2011). Developing mastitis during this time may therefore be debilitating and has been found to be a common reason for discontinuing breastfeeding. This study aimed to explore women's experiences of breast-feeding and mastitis, the formal and informal support that was available to them when they had mastitis, and the impact it had on whether they continued or discontinued breastfeeding (Amir, Forster, Lumley & McLachlan, 2007; Cleminson, Oddie, Renfrew & McGuire, 2015).

**Method:** Grounded theory was used to analyse the data. Sixteen women who had experienced mastitis were included in the study.

**Results:** All of the women intended to breast-feed. However, they often experienced problems early on (i.e. engorgement and nipple damage) that were unexpected and left them feeling exhausted and emotional. These problems precipitated mastitis. Mastitis was for most, a very difficult experience sometimes leading to discontinuation of breast-feeding. Delaying help-seeking negatively affected health outcomes. Determination and receiving good advice and support were fundamental factors in breast-feeding continuation.

**Conclusion:** Improved support, communication, and advice with breast-feeding from the outset would reduce the risk of problems occurring and persisting, and potentially reduce the risk of mastitis developing. Early diagnosis and treatment of mastitis once it has developed is very important. Understanding that breast-feeding is a skill that often encompasses both ups and downs may reduce the pressure women put on themselves when they feel like they are failing because it is not going as well as they expected it to. Once mastered, women found breast-feeding to be a lovely bonding experience that exceeded their expectations.

# Introduction

## 2.1 Overview

Mastitis is a common and painful condition experienced in breast-feeding women (Cusack & Brennan, 2011). It involves an inflammation of the breast and is often accompanied by infection, resulting in breast pain, swelling, warmth, redness and signs of sepsis such as fever and chills. Mastitis is believed to be linked to milk stasis, infection due to cracked nipples, as well as stress and fatigue (Amir et al., 2007; Barbosa-Cesnik, Schwartz & Foxman, 2003). It affects up to 33% of breast-feeding women (Jahanfar et al., 2009; Scott et al., 2008; Spencer, 2008). The condition progresses rapidly and often leaves women feeling exhausted and tired (Mayo Clinic, 2016; National Institute for Health and Care Excellence [NICE], 2016). Mastitis usually occurs within the first three months postpartum but can occur later during breastfeeding. There is limited evidence why women are more likely to develop it then, other than this is a time when breast-feeding is being established (Khanal, Scott, Lee, & Binns, 2015). Mastitis can be very debilitating and has been found to be one of the main conditions affecting breast-feeding women and a common reason for discontinuing breastfeeding (Amir et al., 2007; Cleminson et al., 2015).

It is well established that human breast milk is nutritionally the best sustenance for babies (Victora, Bahl, Barros, França, Horton et al., 2016). Breast milk has been shown to offer protection against infection and malocclusion (Victora et al., 2016). It has also been shown to lower risk of both obesity and diabetes later in life and have a positive impact on cognitive development (Victora et al., 2016). The benefits of breast-feeding are not exclusive to the infants receiving breast milk. Evidence suggests that mothers who breast-feed have a lower risk of some cancers, including ovarian and breast cancer, as well as a lower- risk of postpartum depression (Victora et al., 2016). The psychological and physiological benefits of breast-feeding for both mother and child are clear, although there are potentially wider-reaching benefits.

Breast-feeding provides huge economic and environmental advantages to people and societies (Fairbank, O'Meara, Renfrew, Woolridge, Snowden et al., 2000). Unlike breast-milk substitutes, breast-milk does not require mass production or commercial transportation and is therefore environmentally safe (Rollins, Bhandari, Hajeebhoy, Horton, Lutter et al., 2016). Breast-milk substitutes leave a huge ecological footprint

due to the manufacturing, packaging and transportation and daily cleaning materials required to use them and moreover the cost of not breast-feeding accounts for billions of world gross national income every year (Rollins et al., 2016).

In the United Kingdom (UK), there is a huge drive in policy to encourage breast-feeding (Fairbank et al., 2000). However, the rates of breast-feeding are poor with just 17% of babies being exclusively breastfed at three months, and less than one percent at six months (Lancet, 2016; UNICEF, 2012a). Globally, low income and middle income countries, such as sub-Saharan Africa and south Asia, have considerably higher rates of breast-feeding compared to high income countries, such as the UK and United States of America ([USA], Victora et al., 2016). Therefore, more needs to be done to understand some of the factors that frequently result in women stopping breast-feeding in the UK.

Mastitis has been found to be a significant reason for stopping breast-feeding (Schwartz, Gillespie, Bobo, Longeway & Foxman, 2002). There is a dearth of research exploring the psychological effects of mastitis and little is known about the support offered to women who develop it, nor the advice they are given regarding continuing or discontinuing breast-feeding. National guidelines state that women should be advised to continue to breast-feed when they get mastitis, yet some evidence suggests that this is not always the case (Amir & Ingram, 2008). Based on the lack of evidence, this study aims to explore women's experiences of breast-feeding and mastitis; the formal and informal support that was available to them when they had it, and the impact this had on whether they continued or discontinued breastfeeding. It is hoped that enhanced knowledge and understanding of mastitis and women's experiences of it will lead to better advice and support that could help women to continue to breast-feed if this is what they would like and are able to do.

## **2.2 Breast-Feeding Background**

### ***2.2.1 Breast-Milk***

Human breast milk composition is complex and uniquely suited to the human infant (Ballard & Morrow, 2013). It provides the total food, nutrition and active immunity tailored for a baby (Renfrew, McCormick, Wade, Quinn & Dowswell, 2012a) and is composed of proteins, fats, carbohydrates, minerals, vitamins, digestive enzymes and hormones, as well as immune cells, stem cells and bioactive molecules (Martin, Ling, & Blackburn, 2016). Bioactive molecules have very powerful properties that protect

against infection, inflammation, and promote organ development, healthy microbial colonisation and immune maturation (Ballard & Morrow, 2013). In addition, they have a prebiotic effect in that they can kill or inhibit the growth of pathogens (Infant Nutrition Council, 2016). The composition of human breast milk changes across several stages of lactation. For example, during pregnancy and in the very early days after a baby is born a mother produces distinct fluid called colostrum (Martin et al., 2016). This is yellowy orange in colour and very thick and sticky in consistency. Colostrum is highly concentrated in nutrition and antibodies, low in fat and high in essential protein and carbohydrates and it is especially easy for a baby to digest in the new-born stage of life (La Leche League International, 2016). Furthermore, it contains developmental features such as epidermal growth factors and stem cells (Martin et al., 2016; Peterson, 2016). Antibodies and leukocytes provide a natural and safe vaccine protecting a new-born from viruses and bacteria, primarily in the throat, lungs and intestines (Martin et al., 2016). The stem cells' function is to repair and regenerate in order to help growth, development and maintain homeostasis (Peterson, 2016). Additionally colostrum has a laxative effect which helps a baby excrete excess bilirubin, which in turn helps to prevent jaundice. It is therefore specifically tailored to the new-born to protect and help them to stay healthy (La Leche League International, 2016).

Transitional milk is the stage of lactation following colostrum. This milk usually lasts between five days postpartum and two weeks and it has some of the characteristics of colostrum but antibodies decrease and the volume of milk increases as the infant's nutritional requirements grow. Although antibodies decrease following the colostrum stage, breast milk always provides immunological protection against many viruses and bacteria (Martin et al., 2016). Transitional milk is high in calories, fat, lactose and water soluble vitamins and it is tailored to provide the nutritional and developmental needs for a growing baby (American Pregnancy Organisation, 2016; Martin et al., 2016). By around four weeks, breast milk is usually considered fully mature (Martin et al., 2016). It contains more water than transitional milk in order to quench a baby's thirst (Martin et al., 2016).

Breast milk is also dynamic in nature, adapting to the needs of the growing infant. For example, within a feeding session there is firstly foremilk which is thin with a high content of lactose designed to satisfy a baby's hunger, followed by hind-milk which is creamier with a high fat content and designed to help a baby gain weight, grow and

develop (Martin et al., 2016; American Pregnancy Organisation, 2016). Depending on the age of the infant the composition will change. For instance it has been found that the protein and fat content of milk will decrease after three to four months of lactation and then again after six months, thus providing the infant the nutrients necessary in each stage of development (Martin et al., 2016). In contrast to this, the protein, fat and lactose content are fairly constant after 21 days post-partum in order to maintain a constant osmotic pressure, and aid absorption of minerals and calcium (Martin et al., 2016). Additional research has found that a mother's milk supply and composition is personalised for her baby and adapts to meet the needs of her infant (Ray, 2014). Hormones are released when a baby sucks on a mother's nipple. These hormones send a message to the breast to '*let down*' or release the milk. This '*let down reflex*' can happen when a woman sees or hears her baby, or can even be triggered when a woman thinks about her baby. The more a baby feeds, the more milk a mother will produce, ensuring her baby is getting the right amount (Australian Breastfeeding Association, 2016). A further example of how mother's milk is personalised for an infant is demonstrated when an infant or mother are unwell. When this occurs, the immunity cellular components in the mother's milk dramatically rise until they are both healthy again (Peterson, 2016; Hassiotou & Geddes, 2013). Additionally, it has been found that women who have premature babies produce milk that is higher in protein and levels of bioactive molecules compared to those who deliver at full-term (Underwood, 2013). This difference in milk is found to be specifically suited for the premature infant as they are in greater need of nutritional and immunity protection and therefore, the maternal body responds to her baby through breast milk composition, making every mother's milk different (Underwood, 2013).

Research has been conducted to understand breast milk, and components are still being identified, developed and tested for medical application (Ballard & Morrow, 2013). Increasingly factors are being discovered that show beneficial attributes in breast milk and recent advances in research have examined the role of pluripotent stem cells found in human breast milk and their use for regenerative medicine (Hassiotou, Geddes, Blancafort, Filgueira & Hartmann, 2015).

### ***2.2.2 Infant Formula***

Infant formula is the main substitute for breast milk (Martin et al., 2016), where a mother chooses not to breast-feed or is unable to do so. It has been produced to mimic

the nutritional composition of breast milk. There are three main compositions of formula; cow milk based formulas, soy milk based formulas, or specialised formulas. In general the cow and soy milk provide a base, and then iron, nucleotides and various compositions of fat blends are added, as well as fatty acids and sometimes probiotics (Martin et al., 2016; Zou, Pande, & Akoh, 2016). Furthermore, there are several types of formula milks that are available such as first milk, second milk, and follow-on milk (UNICEF, 2015). '*First infant formula*' is usually described as being suitable for new born babies because it is easier to digest as it is composed of the whey of cow's milk (NHS Choices, 2014a). '*Second milk*' is casein based formula which is thought to take longer for a baby to digest as they are based on the curd of cow's milk. '*Follow-on formulas*' are marketed only for babies over six months. These are sometimes mixed with cereals so they are more filling. Formulas vary in their nutritive value, calorie components, taste, digestion and cost but unlike breast-milk, they do not have any immunological protection against viruses and bacteria (Martin et al., 2016). Formulas are strictly regulated and must follow governing body guidelines to ensure that they are safe. For example, all of the ingredients must be able to be maintained throughout the shelf life of the product (Martin et al., 2016). As infant formula has become a normal alternative to breast-feeding, the quality and safety is continually being monitored worldwide (Boué, Cummins, Guillou, Antignac, Bizec et al, 2016).

Equipment used to prepare formula needs to be sterilised to reduce the risk of infection (NHS\_Choices, 2014b). Problems can occur from contamination caused by poor hygiene from the preparation, expressing or storing of milk (Boué et al, 2016) and microbiologists have advised that problems occurring from improper preparation of formula have found to be common and special care should be given to reduce the risk of this happening (Gribble & Hausman, 2012). For instance, under-dilution of infant formula can cause hypernatraemic dehydration, and over-dilution can cause water intoxication (Gribble & Hausman, 2012).

### ***2.2.3 Mixed-Feeding***

Mixed feeding is the combination of breast-feeding and bottle feeding. Mixed feeding can be a good option for some women as it enables them to have the benefits of breast-feeding but also be away from their infant. For example, if they need to go to work or if they would like a break from breast-feeding they can supplement some feeds with formula (Taveras, Li, Grummer-Strawn, Richardson, Marshall, et al., 2004). It has been

stated the majority of infants in developed countries are mixed fed by the age of three months (O'Sullivan, Farver, & Smilowitz, 2015). Although rates of mixed feeding appear to be high in developed countries, the literature surrounding the topic is limited and complicated as there is no consistent definition of the terminology and the majority of studies look at the effects of exclusive breast-feeding compared to exclusive formula feeding (O'Sullivan et al., 2015). Nevertheless, research shows that the protection breast-milk offers works in a dose-response manner (Scariati, Grummer-Strawn, & Fein, 1997). For instance, the more breast-milk an infant receives, the less likely they are to develop ear infections or diarrhoea (Scariati et al., 1997). The longer term outcomes of mixed feeding are less clear. There is some evidence to suggest that limiting the amount of formula an infant has may be protective against obesity later in life (Rossiter, Colapinto, Khan et al., 2015). Overall, the evidence suggests that supplementing some feeds with formula does not interfere with the protection breast milk, however the more breast-milk an infant receives in the first six months of life, the better (Taveras et al., 2004).

#### ***2.2.4 Breast-Feeding Health Benefits***

As previously mentioned, breast-feeding has some extensive and durable effects on an infant's health and development (Quigley, Carson, Sacker & Kelly, 2016). Specifically there is evidence that exclusively breastfed babies are at a lower risk of diarrhoea, constipation, gastroenteritis, obesity, respiratory infections, sudden infant death syndrome (SIDS), Type 1 and Type 2 diabetes, allergies such as asthma, and eczema (Kramer & Kakuma, 2009). As a consequence of these positive health outcomes, recent epidemiological research has shown that breast-fed infants are less likely to need to require medical attention. Furthermore, it has been found that increasing breast-feeding could prevent 823,000 deaths a year worldwide in children under five years old (Victora et al., 2016). It has also been found that children who are breast-fed for longer periods of time rather than shorter periods of time, or not at all, have positive health outcomes that are sustained later in life (Victora et al., 2016). This is believed to be due to the vital nutrients found in breast milk which limit infant programming of metabolic diseases later in life (Martin et al., 2016).

Evidence suggests breast-feeding has a positive effect on cognitive development. A lot of the research in this area is based on observational studies. However, a randomised trial including 13,889 children at follow-up showed that prolonged and exclusive breast-

feeding led to improved cognitive development at six and a half years of age (Kramer, Aboud, & Mirnova, 2008). In accordance with this, a recent systematic review of 17 studies found that being breast-fed compared to formula-fed was associated with improved performance in intelligence tests (Horta, Loret de Mola, & Victora, 2015). Across the literature advantages in Intelligence Quotient (IQ) scores tend to be small (3-4 points), however they are consistent across studies (Jacobson, Carter, & Jacobson, 2014).

It is well documented that there are health benefits for mothers from breast-feeding, such as a reduction in ovarian and breast cancer risk (Lancet, 2016). Furthermore, levels of protection can increase along with duration of breast-feeding (Zhou, Chen, Li, Huang, Lan et al., 2015; Luan, Wu, Gong, Vogtmann, Wang et al., 2013). Recent epidemiological studies have found that 20,000 deaths from breast cancer annually could be prevented from breast-feeding worldwide (Victora et al., 2016). This research also highlighted that mothers who breast-feed also have a reduced risk of osteoporosis and hip fractures later in life, and that there is an association between prolonged breastfeeding and prevention of Type 2 diabetes and postmenopausal risk factors for cardiovascular disease (Victora et al., 2016). In addition, the production of prolactin and oxytocin during breast-feeding contributes to lowering of maternal stress which has been related to prevention against maternal postpartum depression (Chung, Raman, Chew, et al., 2007).

### ***2.2.5 Economic and Environmental Factors***

Breast-feeding is free and has extensive economic benefits. Failure to breast-feed worldwide has been shown to account for economic losses of around \$302 billion a year or 0.49% of gross national income (Rollins et al., 2016). This figure is based on reduced direct treatment cost associated with lower child morbidity, and the economic scale of cognitive benefits associated with breast-feeding. For instance, higher IQ scores are associated with a 12% increase in hourly earnings in high income countries (Rollins et al., 2016). This figure is conservative as it does not include the impact of breast-feeding on women's cancers, as well as other savings such as the manufacturing, transportation, and storage of formula (McFadden, Mason, Baker, Begin, Dykes, et al., 2016).

On a national level, United Nations International Children's Emergency Fund ([UNICEF], 2012b) published a report showing how increasing rates of breast-feeding

could save the NHS millions of pounds due improving health outcomes and reducing hospital admissions and general practitioner (GP) consultations. The report showed that for five common childhood illnesses and the cost of treatment and hospitalisation, just moderate increases in breast-feeding would account for saving of around £40 million to the NHS a year (UNICEF, 2012b). Therefore, they suggest if breast-feeding rates increased dramatically, the savings could be considerably higher. For example, if women who were breast-feeding one week post-partum were supported to continue to breast-feed until four months, a minimum of £11 million annually would be saved due to the reduction in childhood illnesses (Pokhrel, Quigley, Fox-Rushby, McCormick, Williams et al., 2014).

Aside from the savings that could be made related to improving health from breast-feeding, there is the direct cost of formula or breast-milk substitutes for families. It has been found that the savings per household from replacing formula feeding with breast-feeding would be at least £500 a year (Patient, 2016). Between 2003 and 2013 infant formula sales rapidly grew from \$22.4 billion in 2003 to over \$58 billion in 2013 globally (Holla-Bhar, Iellamo, Gupta, Smith, & Dadhich, 2015). Infant formula industry profit is predicted to reach US \$70-6 billion by 2019 (McFadden et al., 2016) as the amount of people choosing to formula feed is predicted to rise (Dadhich, Smith, Iellamo, & Suleiman, 2015), and subsequently the costs across these households. Furthermore, the environmental impact of formula-feeding is considerable. As a naturally produced product, breast-feeding has no bi-products, unlike breast-milk substitutes (Rollins et al., 2016; Dadhich et al., 2015). For example, in the USA alone it has been found that 550 million cans are used annually to package breast milk substitutes (Rollins et al., 2016). With the breast-milk substitute industry continuing to increase, more needs to be done to raise public awareness of the economic and environmental factors associated with infant feeding choices.

### ***2.2.6 Breast-Feeding Rates***

Exclusive breastfeeding is recommended by current UK guidance, the NHS and the World Health Organisation (WHO), for the first six months of a baby's life (NHS Choices, 2016a; WHO, 2003). It is recommended that breast-feeding should then be continued, along with appropriate complementary foods, up to two years of age or as long as the mother and infant desire. According to UNICEF rates of breast-feeding in the UK are among the lowest in the world (UNICEF, 2012b; Oakley, Renfrew,

Kurinczuk & Quigley, 2013). Compared to our European counterparts, exclusive rates of breast-feeding are also considerably low and duration is particularly poor (Oakley et al., 2013). Breast-feeding rates are measured by the total number of 0-5 month old infants exclusively fed breast milk on the previous day, divided by the total number of infants of that age and multiplied by 100. WHO and UNICEF jointly collect data on infant and child feeding and pool the information from national surveys (WHO, 2010). However, in the last 20 years, the number of women initiating breast-feeding in the UK has risen (UNICEF, 2012b). In 1990 62% of women started to breast-feed, compared to 81% in 2010 (Pokhrel et al., 2014). This increase is likely to be due to developments in public and health policy, wider awareness of the benefits of breast-feeding and better support (UNICEF, 2012a). A huge amount of money has been invested into national and local strategy and campaigns (UNICEF, 2012b). For example, the Baby Friendly Initiative, The Public Health Outcomes Framework 2016, Public Health England's Health Matters, The Healthy Childhood Programme, NICE guidelines, The Early Years Outcomes Framework 2015, just to name a few. These are all at the forefront of British policy making and have helped to increase breast-feeding initiation rates however, they are still low, and duration rates are even lower (Bartington, Griffiths, Tate, Dezateux, & Millennium Cohort Study Child Health Group, 2006).

The latest UK breast-feeding statistics published in November 2012 by the NHS Information Centre statistics show that 83% of women started to breastfeed in England, 74% in Scotland, 71% in Wales, 64% in Northern Ireland. By week six exclusive breast-feeding rates were 24% in England, 22% in Scotland, 17% in Wales, and 13% in Northern Ireland. At three months exclusive breast-feeding across the UK was 17%, but by six months it had fallen to only 1% (Health and Social Care Information Centre, 2012). The sharp decline in breast-feeding in the early days and weeks post-partum is a trend that has been consistent since 1975, when national surveys began (Health and Social Care Information Centre, 2012). As stated, breast-feeding rates in the UK are some of the lowest in Europe and Worldwide (Dyson Renfrew, McFadden, McCormick, Herbert et al., 2006; Earle, 2002). Furthermore, it is known that most women who discontinue breast-feeding in the early days do so because of challenges, not because they want to (Pokhrel et al., 2014). More specifically it has been found that 90 percent of women who discontinue breast-feeding within the first six weeks do so before they wanted to (Renfrew, Pokhrel, Quigley, McCormick, Fox-Rushby et al., 2012a).

Understanding what determines women's breast-feeding intentions and behaviours is essential for the provision of appropriate support.

### ***2.2.7 Breast-Feeding Determinants***

There are many determinants that influence women's intentions to breast-feed and breast-feeding behaviours (Bowman, 2013). It has been found that these determinants are embedded in a mixture of social, cultural, psychological, and biological factors (Meedy, Fahy, & Kable, 2010; Renfrew, McCormick, Wade, Quinn, & Dowswell, 2012b; Swanson & Power, 2005). Breast-feeding determinants are often highly interrelated. Although they are interrelated, they will be discussed individually below.

#### ***2.2.7.1 Socio-Demographic Factors***

Research has demonstrated that socio-demographic factors are strongly associated with breast-feeding choices (McInnes, Hoddinott, Britten, Darwent, & Craig, 2001). For example, research has found that babies that are breast-fed for a period of time adequate to benefit from the highest health gain, up to six months (Leung & Sauve, 2005), tend to be from higher socioeconomic status families, have mothers who are older and married, or are from minority ethnic background families (Meedy et al., 2010). Mothers are less likely to breast-feed if they are younger, less educated and from a lower socioeconomic background (McFadden & Toole, 2006; Renfrew et al., 2012b). Therefore, educational level is believed to influence breast-feeding because higher educated parents are thought to be more likely to research information about infant feeding and be more informed about the benefits of breast-feeding (Heck, Braveman, Cubbin, Chávez, Kiely et al., 2006). There has been little change in the social differences that influence breast-feeding over the last 25 years, making breast-feeding a contributor to health inequality (Dyson et al., 2005).

#### ***2.2.7.2 Cultural Norms***

Cultural norms influence breast-feeding intentions and behaviours. For example, in countries where breast-feeding is not normative behaviour, women find it particularly challenging to breast-feed (Renfrew et al., 2012b). The Western culture often portrays breasts as sexual objects and their biological and nurturing function is downplayed and therefore the sexuality of breasts has led to some women feeling uncomfortable about feeding in public and the need to conceal themselves (Office of the Surgeon General, 2011). In contrast to this, in countries where breast-feeding is normative behaviour,

women feel more supported (Clifford & McIntyre, 2008). For example, in rural Thailand, strong family support and traditional practices such as breast-feeding are seen as very important. Consequently women who have had no experience of breast-feeding are encouraged and supported to successfully breast-feed (Clifford & McIntyre, 2008). Maternal ethnicity is also a strong determinant of breast-feeding with white mothers being less likely to breast-feed than mothers from ethnic minority groups in the UK (Griffiths et al., 2005). A large national UK study found that black African, black Caribbean, Bangladeshi, Pakistani and Indian mothers were more likely to initiate breast-feeding compared to white mothers (Kelly, Watt & Nazroo, 2006). Further, the Millennium Cohort Study; a longitudinal survey of almost 19,000 babies in the UK, provided evidence that minority ethnic women were more likely to initiate breast-feeding as well as to have maintained breast-feeding at four months (Griffiths & Tate, 2007). This is believed to be due to breast-feeding practices and attitudes that are embedded within cultural expectations (Tully & Ball, 2013) as white women who have partners who are of a different ethnic group are more likely to breast-feed and continue to do so (Dyson et al., 2005). White single mothers have also been shown to be more likely to breast-feed if they live in an area that has predominantly ethnic community (Dyson et al., 2005). Therefore ethnicity can positively influence breastfeeding.

### ***2.2.7.3 Birth Experience and Breast-Feeding***

A mother's birth experience can influence breast-feeding. For example, trauma caused from birth experiences, such as a stressful labour and pain, has been identified as a risk factor for delayed lactation. One study found that traumatic experiences had one of two strikingly different effects in that women would either be less likely to breast-feed, or otherwise their experiences facilitated breast-feeding as they felt impelled to persevere (Beck & Watson, 2008). However, most research has shown that women who have undergone trauma such as an emergency caesarean are less likely to initiate breast-feeding than women who have given birth vaginally (Prior, Santhakumaran, Gale, Philipps, Modi & Hyde, 2012). In support of this a large meta-analysis of over half a million women from 31 countries revealed that caesarean delivery negatively impacts breast-feeding due to delayed onset of lactation. Moreover, there is a positive association between birth centre delivery and initiation of breast-feeding (Meedya et al., 2010). Regardless of delivery all mothers are able to breast-feed and should be supported to do so if this is what they would like to do (Prior et al., 2012).

Post-delivery care routines can also have an impact of breast-feeding. The first few hours post-delivery are critical to establish mother-infant interaction, and early infant sucking and timing of first feed are key determinants of successful breast-feeding (Prior et al., 2008). Therefore, hospital routines and practices that interrupt women holding their babies and bonding may reduce early breast-feeding (Prior et al., 2008). For example, a UK study including 923 parents found that 40% of mothers waited more than an hour before babies were able to be breast-fed. The same study found one third of babies were given supplementary feeds, which have been found to negatively impact breast-feeding (Wright, Parkinson & Scott, 2006). In the UK the majority of women give birth in a hospital, and evidence shows that women's experiences of hospital care post birth are generally poor, which has important implications for breast-feeding support (Beake, Rose, Bick, Weavers & Wray, 2010).

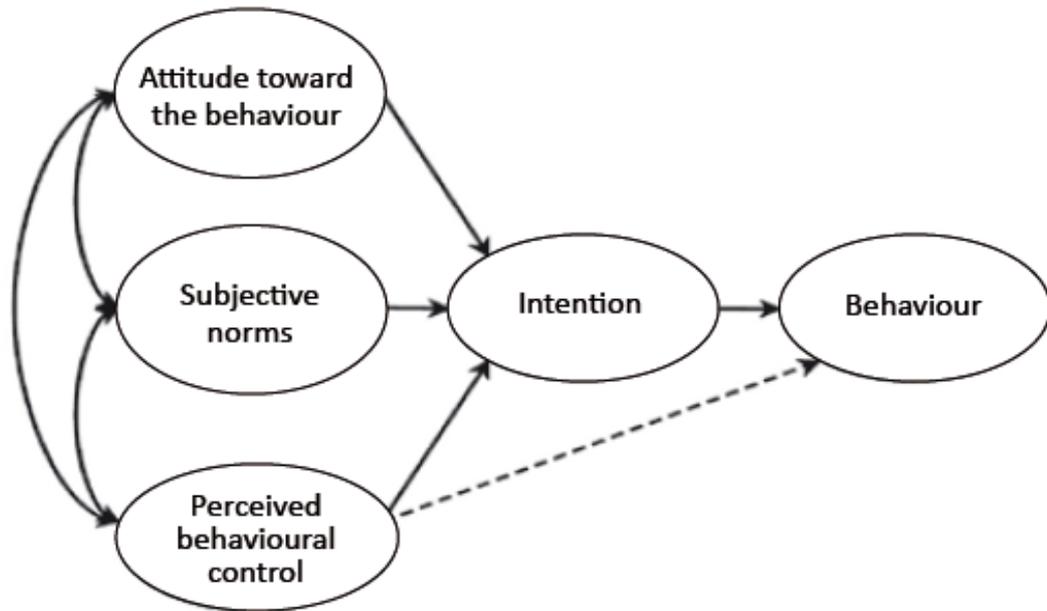
#### ***2.2.7.4 Physical Difficulties***

Physical difficulties are also closely related with early cessation of breast-feeding (Wright et al., 2006). It is very rare that someone has a true biological inability to breast-feed (Brown, 2014a). However, physical difficulties are common and are one of the main reasons cited for women discontinuing breast-feeding (Scott & Colin, 2002). The main physical problems encountered by women include nipple pain and latch problems with the incidence of nipple pain been reported at between 34-96% (Brown, 2014a; Brown, Raynor & Lee, 2011; Abou-Dakn, Fluhr, Gensch, & Wöckel, 2010). A lot of women experience painful cracks and fissures which are usually a result of a baby's 'poor' sucking technique and latch (Livingstone, Willis & Berkowitz, 1996; WHO, 2000). However, positioning the baby so that the latch or suction to the breast is 'good' will help to limit negative pressure that gives way to cracked nipples and consequently pain.

#### ***2.2.7.5 Psychological Factors***

It is not just physical problems (perceived or otherwise) that affect breast-feeding initiation and duration but psychological factors have also been shown to play a part. It has been found that breast-feeding intentions, confidence, self-efficacy, and anxiety are all influential factors (O'Brien, Buikstra & Hegney, 2008). The intention to breast-feed has been shown to be a strong predictor of breast-feeding initiation (Scott, Aitkin, Binns, & Aroni, 1999). This is consistent with the Theory of Planned Behaviour (TPB,

Ajzen & Fishbein, 1991, Figure 1), which works on the premise that the best way to target behaviour is to measure behavioural intentions (Giles, Connor, McClenahan, Mallett, Stewart-Knox et al., 2007).



*Figure 1: Theory of Planned Behaviour (Ajzen & Fishbein, 1991)*

Four variables, namely: attitudes, subjective norms, perceived control and self-efficacy are said to influence intentions, which in turn determine behaviour. Positive maternal attitudes about the benefits of breast-feeding have been found to increase intentions to breast-feed and the likelihood of breast-feeding initiation (Hauff, Leonard & Rasmussen, 2014). Although intention to breast-feed is a strong predictor of initiation; there is a discrepancy between intentions to breast-feed and duration (Williamson, Leeming, Lyttle, & Johnson, 2012). Breast-feeding is a dynamic process and unforeseen factors, such as pain, may influence breast-feeding practice (Odom, Li, Scanlon, Perrine, & Grummer-Strawn, 2013). For instance, one study measured mother's intentions to breast-feed prenatally and found that, of the mothers who intended to breast-feed for at least two months, 14% had ceased by six weeks (Odom et al., 2013). Problems encountered with breast-feeding post birth and expectations not being met interfered with mothers' intended duration. More research is needed to understand this further.

Studies exploring influences on breast-feeding cessation (even when breast-feeding was reported to be important to the mother) found that self-efficacy and confidence were very influential. Self-efficacy is the belief or confidence in one's capabilities to execute

a specific task (Stajkovic & Luthans, 1998), and confidence is the belief in the ability to do something arising from an appreciation of one's abilities (Colman, 2006). Self-efficacy has a central role in breast-feeding as women with high self-efficacy believe in their ability to breast-feed and have the confidence to challenge the views of people who suggest or oppose breast-feeding (Brown, 2014b). High self-efficacy might explain why women who have had previous breast-feeding experience are more likely to breast-feed, because they have successfully breast-fed in the past and positively overcome difficulties (McInnes et al., 2001). However, confidence is very important in breast-feeding especially when faced with challenges or criticisms of others (Avery, Zimmermann, Underwood, & Magnus, 2009). For example, a large study of 1163 breast-feeding women found that breast-feeding discontinuation was associated with lack of confidence in the ability to breast-feed (Taveras, Capra, Braveman, Jensvold, Escobar et al., 2003). Similarly, low confidence has been linked to use of formula, particularly if women have low confidence in their milk supply or have anxieties that the baby is gaining weight too slowly (Stajkovic & Luthans, 1998).

Perceived insufficient milk supply is one of the most common reasons for stopping breast-feeding (Kent, Hepworth, Sherriff, Cox, Mitoulas et al., 2013). It is hard to know how much milk a breast-fed infant has had as there is great variation in feeding frequency and consumption is not directly time related or otherwise capable of measurement. This uncertainty may lead to the belief that the infant is not receiving sufficient nutrition, especially where comparisons with bottle feeding quantities are made. However, using infant weight gain as a marker of sufficient nutrition, evidence shows that fewer than 5% of mothers of exclusively breastfed infants are actually unable to produce enough milk in infants up to four months (Brown, Dodds, Legge, Bryanton, & Semenic, 2014b). A qualitative study exploring reasons for ceasing breast-feeding found that a lack of maternal confidence in providing adequate quantities or quality of milk often leads to breast-feeding cessation (Li, Fein, Chen, & Grummer-Strawn, 2008). In line with this, quantitative research has shown that a perceived insufficient milk supply is one of the most common problems associated with stopping breast-feeding and results in around 35% of all breast-feeding women deciding to introduce formula or wean early (Gatti, 2008).

Breast-feeding can contribute to a women's sense of identity as a mother. Where breast-feeding expectations are not met, this may lead to negative self-attitudes. Often breast-

feeding is portrayed as being natural and instinctive (Williamson et al., 2012), and as a result, women who find breast-feeding to be surprisingly difficult may find it damaging to their '*sense of worth*'. Women can feel like they have failed if they experience breast-feeding difficulties and this makes them in turn anxious (Williamson et al., 2012). A meta-synthesis that analysed seven studies from Australia, Ireland, UK and Sweden explored a total of 883 mothers' breastfeeding practices found that women felt there were expectations as a mother that breast-feeding was natural and that the female body is built to feed a baby. As such, if problems were encountered they felt like they had failed or been unsuccessful (Larsen, Hall, & Aagaard, 2008). Societal perceptions that breast-feeding is a natural trait may be counterproductive as it can put pressure on women. Therefore, if women are not prepared if breast-feeding does not meet their expectations, their confidence can be shattered (Larsen et al., 2008). The first systematic review to look at mothers' experiences of bottle-feeding found that mothers who bottle-fed had negative emotions of guilt, anger, uncertainty and a sense of failure. Mothers who bottle-fed were very informed about the benefits of breast-feeding but found the pressure too much (Lakshman, Ogilvie, & Ong, 2009).

Embarrassment has been found to influence use of formula and discontinuation of breast-feeding (Brown, 2014a) as it has been found that women who feel embarrassed to breast-feed in public have a shorter breast-feeding duration (Forster & McLachlan, 2010). For example, embarrassment about feeding in public places or feeling excluded from social interactions has been shown to make women feel reluctant to breast-feed and choosing to bottle feed, or to even give up breast-feeding altogether (Office of the Surgeon General, 2011). According to Sayers (2014), up to 69% of women worry about being judged if they feed in public, and 80% are too embarrassed to actually feed in public. Younger mothers have also been shown to be less likely to initiate breast-feeding and have a shorter breast-feeding duration partly due to embarrassment (Brown et al., 2011). Western society has typically seen breast-feeding as something that is private, making it difficult for some women to breast-feed, especially if they experience difficulties (Williamson et al., 2012).

#### ***2.2.7.6 Social Support***

Social support is predictive of breast-feeding initiation and duration. Women who were not breast-fed themselves are less likely to breast-feed making it an intergenerational problem as women often follow the pattern of their own mothers (UNICEF, 2012b).

Furthermore, women who breast-fed are able to pass on their practical knowledge of breast-feeding to their daughters which encourages confidence and normalises breast-feeding (Grassley & Eschiti, 2008). It has been found that women often rely on their family members rather than healthcare professionals for breast-feeding advice when facing problems (Clifford & McIntyre, 2008). A Scottish study found maternal support was hugely influential on breast-feeding commitment in that even if a woman was keen to breast-feed, if her mother had a lack of empathy, she felt undermined in early attempts to breast-feed (Clifford & McIntyre, 2008). In addition, if mothers themselves had been unable to breast-feed, or were embarrassed about it, they may be more likely to put pressure on daughters, albeit well meaning, to formula feed (Clifford & McIntyre, 2008). Conversely, grandmothers who had breast-fed communicated the importance and value of breast-feeding to their daughters (Grassley & Eschiti, 2008).

Women who have partners who are supportive of breast-feeding are more likely to initiate and continue to breast-feed (Brown & Davies, 2014c). Therefore, paternal support has been found to increase maternal feelings of confidence and competence in relation to breast-feeding and in the face of breast-feeding challenges (Brown & Davies, 2014c). Positive and active partner support such as verbal encouragement and helping with domestic chores or bringing the baby to the mother to be breast-fed has been shown to support breast-feeding maintenance (Mannion, Hobbs, McDonald, & Tough, 2013; Brown & Davies, 2014c).

Women who have friends who breast-feed have also been found to be more likely to choose to breast-feed and to breast-feed more successfully (Office of the Surgeon General, 2011). For example, women who have seen friends or family members breast-feeding successfully perceive breast-feeding as a positive experience and are consequently more confident and dedicated to do it themselves (McInnes, Hoddinott, Britten, Darwent, & Craig, 2013). On the contrary, negative attitudes from family and friends have been shown to be a barrier to breast-feeding (Office of the Surgeon General, 2011). Clearly, given their influence, understanding positive and negative exposures to breast-feeding are important.

#### ***2.2.7.7 Healthcare Professional Support***

It is not just informal social and familial support that can influence breast-feeding behaviour as good quality professional support and guidance has also been shown to be

an important determinant of breast-feeding success (Brown & Davies, 2014c). Research has found that women are more likely to continue to breast-feed despite experiencing problems if they receive good support from healthcare professionals (Blixt, Mårtensson, & Ekström, 2014). One perspective is that breast-feeding is not instinctive but is a learned behaviour and good support and advice is paramount to success (Wells, 2006). Good professional support has been shown to increase women's self-efficacy to breast-feed (Blixt et al., 2014). Furthermore, good healthcare professional hospital advice and support post-delivery is important. In particular, enabling skin-to-skin contact early on and feeding as soon after delivery as possible is a key determinant of successful breast-feeding. Not receiving this clinical practice from healthcare professionals during this time can have a negative impact on breast-feeding (Blixt et al., 2014). Hospital staff giving babies occasional bottle feeds is a further negative determinant of breast-feeding as it may impact onset of a woman's milk supply and has been linked to feelings of depression (Astbury, Brown, Lumley, & Small, 1994; Blixt et al., 2014). The way women are spoken to about breast-feeding has also been shown to be important (Beake et al., 2010). However, women often report feeling like healthcare professionals are too busy to offer the necessary support and reassurance (Hong, Callister, & Schwartz, 2003). This is especially as contradictory healthcare professional advice has been found to have a negative impact on breast-feeding (Yngve & Sjöström, 2001). For example, healthcare professional's advice regarding length and time of feeds, supplementing with formula, on demand feeding, latch issues, milk supply, and infant weight gain is often contradictory (Blixt et al., 2014). Research has found that healthcare professionals who are under time pressures or lack evidence-based knowledge have difficulty providing good support to women. Women have been found to be frustrated and confused when they received conflicting healthcare professional advice (Blixt et al., 2014). Wambach (2005), who conducted a review of 20 years of breast-feeding practice, concluded that healthcare professionals need more training regarding lactation and breast-feeding.

## **2.3 Mastitis**

### ***2.3.1 Mastitis Overview***

Mastitis is a common condition that has been estimated to affect up to 33% of breast-feeding women (Kaufmann & Foxman, 1991; Cusack & Brennan, 2011; Contreras & Rodriguez, 2011; WHO, 2000). Symptoms typically begin with hardness, redness and swelling in a wedge section of one breast, a warm and tender breast, feeling unwell and

a fever of 39-40 degrees Celsius. Mastitis symptoms may appear as a distinct lump that is painful to touch, or a larger sore area. However, it is inflammation of the breast that is usually very painful, accompanied by a burning pain that is continuous or more severe when feeding (NHS Choices, 2016b). Nipple discharge (which can be white or blood-stained) can sometimes occur and flu like symptoms are common, including a fever, muscle pain, aches, headaches, chills, and feeling low and tired (Patient, 2015a; NHS Choices, 2016b).

There are two types of mastitis; non-infectious mastitis and infectious mastitis. Non-infectious mastitis is when the breast tissue becomes red, swollen and hot whereas infectious mastitis is the same but with the addition of infection in the breast tissue. Non-infectious mastitis can lead to infectious mastitis if it is not treated quickly (Patient, 2015b). More severe cases of mastitis can lead to breast abscess, septicaemia, and hospitalisation (Amir et al., 2007; Barbosa-Cesnik et al., 2003). Although mastitis usually lasts from two to three days, it can last for 14 days or more, depending on the type (Crepinsek, Crowe, Michener, & Smart, 2010). It is most common within the first three months postpartum (WHO, 2000) with the majority of reports indicating that 74%-95% of incidences occur within this time frame however, it can occur during any stage of lactation (WHO, 2000; NHS Choices, 2016b). Very occasionally it can develop at weaning (Michie, Lockie, & Lynn, 2003). Mastitis at any stage can be very difficult because of the demands of motherhood whilst experiencing excruciating pain and negative symptoms such as a fever and inflammation (Kvist, Hall-Lord, & Larsson, 2007). Although the incidence of mastitis has risen, due to an increased reported incidence of breast-feeding initiation, the literature in the field is minimal (Lawrence, 2002; Khanal et al., 2015). Over the last 20 years, few reports have been published about mastitis. Early literature stated that mastitis stemmed from staphylococcal outbreaks in hospitals in the 1960s. Since then many cases have been diagnosed over the phone and consequently there is a lack of diagnostic findings. Inconclusive evidence about the causes and successful management continue to be a problem (Lawrence, 2002; Cusack and Brennan, 2011).

### ***2.3.2 Mastitis Causes***

Mastitis has several identified and several hypothesised causes (Vogel, Hutchison, & Mitchell, 1999; Foxman, D'Arcy, Gillespie, Bobo, & Schwartz, 2002). One of the leading identified causes is a build-up of milk within the breast, known as milk stasis

(WHO, 2000). Milk stasis occurs when milk in the breast becomes stagnant, providing a medium for bacterial growth. This can be a result of inefficient removal of milk from the breast. For example, if breasts become engorged from an infant not feeding as frequently or as much, or if an infant does not feed properly due to ineffective sucking or a *'poor latch'*. Therefore, milk stasis can lead to a blocked milk duct, leading to the localised tenderness of mastitis (Spencer, 2008). Overabundant milk supply can also cause milk stasis (Vogel et al., 1999). An under-production of milk supply is widely acknowledged, yet it has been found that an over-production or overabundant milk supply can also be a problem and increase the risk of mastitis (van Veldhuizen-Staas, 2007). Women who have an overabundant milk supply will feel like their breasts are full and will often leak milk, and infants may appear to gulp when feeding leading to colicky symptoms and sub-optimal feeding techniques. This may happen because an infant is not able to latch properly due to the milk flow being too much, and this in turn may cause trauma to a mother's nipple and problems in the baby. Overabundant milk supply is often undiagnosed and more research is necessary to understand the relationship with mastitis (van Veldhuizen-Staas, 2007).

Another of the recognised leading causes of mastitis is nipple cracks or fissures (Spencer, 2008). Cracked nipples can lead to tissue breakdown which provide an entry for bacteria (Abou-Dakn et al., 2010). Cracked nipples or fissures can easily get worse, especially when a baby is feeding regularly as there is little opportunity for them to heal. One of the largest formal studies of mastitis contributing to the literature is a large cohort study of almost 1,000 women in the USA. Foxman et al., (2002) found that of the 9.5 percent of the women in the study who experienced mastitis, more than a third of them had cracked nipples and sores in the first week post-partum. Pain caused from sore nipples and nipple trauma from breast-feeding has been shown to inhibit the *'let-down reflex'*. This may in turn cause a build-up of milk leading to mastitis (Abou-Dakn et al., 2010). Sore nipples may also result in women avoiding breast-feeding, which then can lead to engorgement, milk stasis and mastitis.

There are several other factors have been proposed to increase the risk of mastitis. For example, stress and fatigue are regularly highlighted as factors that predispose women to mastitis (Spencer, 2008). This can happen in one of two ways (Ueda, Yokoyama, Irahara, & Aono, 1994). Firstly, inhibition of prolactin and oxytocin caused by stress may suppress lactation (Groer, Davis & Hemphill, 2002) and affect milk ejection,

interfering with lactation (Lau, 2001). Secondly, stress and fatigue may inhibit a mother's immune system, making her more susceptible to infection and vulnerable to mastitis (Kaufmann and Foxman, 1991). Sleep deprivation is a common occurrence among new mothers and it therefore not surprising stress and fatigue are interlinked with mastitis (Foxman et al, 2002). Wearing nipple shields, breast pads, or tight clothing over the breast has all been linked to mastitis (Spencer, 2008). Nipples may become irritated from trapped moisture, for instance from plastic backed breast pads, and bacteria may develop (Spencer, 2008). Other proposed risk factors include blocked ducts, cleft lip or palate and tongue tie in the infant and poor maternal nutrition (Spencer, 2008). Blocked ducts can stop milk draining from the breast properly and lead to milk stasis and mastitis and infant mouth abnormalities such as tongue tie can result in nipple trauma (Spencer, 2008). Maternal health is under-researched and it is possible that there are links between mastitis and a weakened immune system due to malnutrition (Kaufmann & Foxman, 1991; Foxman, Schwartz & Looman, 1994).

### ***2.3.3 Recurrent Mastitis***

Women who have previously experienced mastitis are more likely to develop it again (Kinlay, O'Connell & Kinlay, 2001). This may be in one infant, or in successive infants (Michie et al., 2003). A large cohort study conducted in the USA by Lawrence (2002) including almost 1,000 women found that the strongest risk factor for developing mastitis was a history of it with a previous infant. They found that women who had a history of mastitis and used a manual breast pump in the same week were most likely to get it. More recently it has been acknowledged there is a lack of understanding of maternal anatomy, breast-feeding techniques and colonisation of pathogens in relation to why some women are more prone to recurrent mastitis than others (Lawrence, 2008). One explanation is that inappropriately or inadequately treating patients may predispose them to mastitis. Therefore, patients that are not properly treated in the first instance may develop recurrent mastitis as well as chronic mastitis that could last months (Lawrence & Lawrence, 2010).

### ***2.3.4 Mastitis Treatment***

Mastitis must be treated promptly and adequately and most cases are treated by a clinician (Spencer, 2008). However, self-treated cases are not recorded as the symptoms for mastitis range from inflammation of the breast to breast abscesses or occasionally

septicaemia, treatment consensus therefore differ (Kvist, Larsson, Hall-Lord, Steen, & Schalén, 2008). Clinicians usually diagnose mastitis by examination, rather than conducting a milk culture. A milk culture would show whether or not there was a bacterial infection, but, as milk itself is not sterile, milk cultures are seldom conducted as it is difficult to distinguish the bacteria associated with mastitis from normal bacterial colonisation (Spencer, 2008; Michie et al., 2003). They are however conducted in very severe cases of infection or when a patient is hospitalised (Spencer, 2008). The most standard treatments for mastitis in the UK include self-care treatments or/and antibiotics. The NICE (2016) first line management for mastitis in primary care where referral is not necessary, include reassurance, continued breast-feeding, over the counter painkillers such as paracetamol and ibuprofen, management of predisposing factors such as nipple damage, warm compression and massage, breast-feeding advice and antibiotics. Continued breast-feeding from both sides, including the infected side is recommended. If treated properly, normal breast-feeding can resume and it is important that women understand this (NICE, 2016). Continued breast-feeding is fundamental as it will allow the milk to drain from the breast (NHS Choices, 2016c). Breast milk may taste different when a woman has mastitis because there is increased sodium content. This may cause some infants to be put off the milk, and in such cases the milk can be expressed via a pump and discarded (Spencer, 2008). Breast-feeding may be painful as the breast may be inflamed and sore so expressing using a pump is recommended in these cases and over the counter pain killers are recommended to help cope with pain and discomfort (NICE, 2016). Warm compression and massage can be used to relieve pain and help milk flow. Furthermore, support with breast-feeding technique can help to effectively manage mastitis (Cusack & Brennan, 2011). There are also a range of herbal therapies available, although there is a lack of scientific research to show whether or not they are effective (Michie et al., 2003).

Involvement of a breast-feeding specialist may be recommended as they can identify breast-feeding problems such as a poor latch and can help to treat the underlying cause of mastitis, and prevent recurrent cases (NICE, 2016). Antibiotics are often required to treat mastitis (NHS Choices, 2016c; Spencer, 2008). As a culture would not have been obtained, it cannot be certain which infecting organism caused the mastitis (Spencer, 2008). However, the most common organism is *Staphylococcus aureus* and there are antibiotics that can be used to commonly treat this, such as dicloxacillin (Spencer,

2008). Courses of antibiotics usually last between 10 to 14 days. A systematic review examining antibiotics for mastitis in breast-feeding women found that higher use of antibiotics compared to no antibiotics would result in more rapid symptom relief (Jahanfar et al., 2013). Other research shows that if initial cases of mastitis are not treated adequately, patients may require more antibiotics that would not have been required initially (Lawrence & Lawrence, 2010). It is important that initial cases of mastitis are therefore treated properly, to ensure symptom relief and prevent recurrent cases. NICE (2016) recommends that several actions should be taken if patients have recurrent mastitis. These include explaining to the patient that a good breast-feeding technique is necessary. For example, it is recommended that women start to breast-feed subsequent children within an hour of birth to avoid mastitis recurrence, to avoid a dummy, and to exclusively breast-feed for 4-6 months. They also recommend being aware of certain things such as milk stasis and what to do to prevent symptoms developing into mastitis. Thorough hand washing and other hygiene measures are also recommended to reduce the incidence of recurrence (NICE, 2016) and other research has highlighted that improved management of nipple damage could prevent the risk of women developing mastitis (Amir et al., 2007; Livingstone, Willis, & Berkowitz, 1996). Overall there is a lack of research into prevention for mastitis and most of the literature focuses on treatment (Spencer, 2008).

The WHO (2000) stated that women often get conflicting advice from healthcare professionals regarding treatment for mastitis. Often they are advised to stop breast-feeding or given no guidance either way. For example, a Canadian study that included 227 breast-feeding women found that non-pharmacological treatment options were rarely advised by healthcare professionals for those who had experienced mastitis (Livingstone et al., 1996). A longitudinal study of 420 breast-feeding women conducted in Glasgow found that a significant number of women were advised to stop breast-feeding altogether when they had mastitis (Scott et al., 2008). Moreover, many were prescribed inappropriate antibiotics. According to the NHS, healthcare professionals often see mastitis as being synonymous with infection and therefore may advise women to unnecessarily stop breastfeeding (NHS Choices, 2016c). This can leave women confused and anxious and unwilling to continue breast-feeding. Another possible explanation is that prescribing any pharmacological treatment for breast-feeding women is complex due to concerns about drug toxicity for the infant (Jayawickrama, Amir, &

Pirotta, 2010). Contrary to this, a study investigating healthcare professionals found that general practitioners found it straight forward to prescribe pharmacological treatments for conditions such as mastitis as they were so common and straightforward, but difficult for conditions that were more complex such as depression (Jayawickrama et al., 2010). However, there is no recent research exploring women's experiences in the UK with regard to what healthcare professional advice and support they received and how this impacted on their breast-feeding practice.

### ***2.3.5 Psychological Impact of Mastitis***

The period following a baby is a time of great change and many women feel tired physically and mentally (Haran, Van Driel, Mitchell, & Brodribb, 2014). Experiencing mastitis during this time can be very debilitating as women are providing maternal care while often feeling very unwell (Kvist et al., 2007). Research has found that mastitis frequently results in women feeling very emotional and distressed (Amir et al., 2007; Barbosa-Cesnik et al., 2003). It has been shown to be associated with depression, anxiety, and helplessness (Lumley & Amir, 2006). Mastitis symptoms have been associated with feelings of negativity and uncertainty with regard to continuing or discontinuing breast-feeding (Lumley & Amir, 2006, Cusack & Brennan, 2011). A prospective cohort study of 379 women found that women who experience pain, milk stasis, mastitis, and cracked nipples have higher stress levels than women who do not have these problems and are more likely to stop breast-feeding sooner (Abou-Dakn et al., 2010). It has been cited that a quarter of mothers say that mastitis is the reason they stop breast-feeding (Michie et al., 2003). Women who had planned on breast-feeding for longer may feel emotionally distressed if they feel they cannot continue (Patient, 2015b). Conversely, a Swedish study has found that women who have inflammatory symptoms while breast-feeding felt their psychological well-being was, on the whole, good (Kvist et al., 2007). This may be explained by evidence that shows that breast-feeding is protective of negative moods and stress. However, those with recurrent symptoms who had managed the symptoms themselves rated their psychological well-being as lower than those without symptoms (Kvist et al., 2007). More research is needed to understand the psychological factors of mastitis.

It is imperative to understand the experiences of women and their decisions to continue or discontinue breast-feeding. The majority of women who suffer from mastitis do so within the first three months post-partum, and this often leads to a cessation of breast-

feeding, which in turn influences recommended guidelines (NHS Choices, 2016a; WHO, 2003). Understanding the advice and support women received when they had mastitis is invaluable as it could potentially affect their breast-feeding practices. Further understanding of these things could lead to better advice and support which could enable women to continue to breast-feed when they have experienced mastitis, if this is what they would like and are able to do.

## **2.4 Rationale for the Present Study**

There are currently no studies in the UK that have explored women's experiences of breast-feeding as well as mastitis and the formal and informal support they received. The aim of this study is to explore women's experiences of breast-feeding, mastitis, the advice and support they received when they had mastitis, and how this impacted on their decision to continue or discontinue breast-feeding. It is hoped that by doing so better support can be provided to women to help them to continue to breast-feed, if this is what they would like to and are able to do.

# **Methodology**

## **3.1 Overview**

This study adopted a qualitative methodology of the grounded theory. It was chosen to explore and generate an understanding on women's experiences of breast-feeding and mastitis, the support they received and impact this had on their breast-feeding practices. Other methodologies could have been used, such as thematic analysis, however as the topic had not been explored before it was believed to be the most appropriate methodology for this study. The following section aims to outline the study design and the rationale for using this theory; the methodology that was applied; a description of the participants, and any ethical issues that arose.

## **3.2 Design**

As mentioned, a qualitative methodology using constructivist grounded theory was adopted for the purpose of the study. Qualitative researchers are interested in people's experiences and how they make sense of the world (Willig, 2001). The qualitative method investigates what happened and how it felt, and what happened next (Willig, 2001). Grounded theory is a methodology that comes under the experimental approach which was developed by Glaser and Strauss (1967). The grounded theory process is

dynamic by nature and a theory is generated from examining patterns of behaviour (Strauss & Corbin, 1990). The data collected guides the sampling procedure and hypotheses are formulated and tested to form a theory. Consequently, the grounded theory process is not linear; it is iterative (Dempster, 2011). It consists of a cycle of induction and deduction whereby data is collected and constantly compared informing the guidance of further data collection (Strauss and Corbin, 1990, Miles & Huberman, 1994). Data is then collected until theoretical saturation is reached, hence until no new or relevant data emerges (Strauss & Corbin, 1998). Charmaz (2008) developed grounded theory further by proposing a constructivist approach. This version of grounded theory aims to understand participants' experiences whilst conserving the complexity of social life and taking into account the researcher's prior knowledge and theoretical preconceptions. More specifically, the constructionist approach makes several assumptions which include (Charmaz, 2008):

1. Reality is multiple, processual, and constructed—but constructed under particular conditions (Charmaz, 2008, p402).
2. The research takes into account the researcher's and participant's personalities.
3. The data are a product of the process rather than purely observed objects of it. The constructivist approach recognises that inherently researchers are part of the research situation and have an influence on perspectives and interactions. This is continuously reflected on.
4. The research process is developed from interaction.

This study adopted a constructivist grounded theory approach to the qualitative research. Under this approach the aim of the research was to develop an understanding of the participant's experiences from their perspective. This was done via understanding the participant's thoughts, feelings, perceptions, and behaviours (Dempster, 2011). As the constructivist grounded theory is a popular methodology for research that is relatively new or under-researched (Strauss & Corbin, 1998), it was considered as the most appropriate method for this study as women's experiences of breast-feeding and in particular mastitis and the support they received has not been widely explored.

### **3.3 Inclusion/Exclusion Criteria**

Only female adults (over the age of 18) were included in the study. Participants were not excluded on the basis of race, ethnicity or other demographic variables. Originally,

participants were only included if they had mastitis within the past eight months. However, there was a large response from women who had mastitis longer than eight months ago who wanted to participate and share their experiences. An amendment to the City University Ethics Board was therefore submitted and approved, and women were included if they had experienced mastitis in the past 18 months (see evidence folder). Having talked to a lot of women about their experiences of mastitis, it was felt that experiencing mastitis was something they would remember beyond eight months. Autobiographical memories are formed and retrieved depending on the experience and the priority given to them by the working self. Therefore it is likely that mastitis was something women would remember clearly as it would have contained episodic detail and self-relevant information which would enable people to reflect on past personal experiences that had been important to them (Hauer, 2008). Individuals were excluded if they had cognitive deficits or emotional/psychological problems, and/or difficulties in adequate understanding of English.

### **3.4 Ethical Issues**

Ethical approval from City University London Ethics Committee was gained. All participants were treated according to the code of ethics of the British Psychological Society (BPS) ethical guidelines (2009).

### **3.5 Participants**

Sixteen women were included in the study. The average age was 33.5 years, with a range between 30-39 years. The majority of the women were white British. All of the participants had a university degree, and the majority had higher degrees. All of the participants were either married or in a domestic partnership. They had between one and three children.

### **3.6 Sampling**

Purposeful criterion sampling was used to recruit participants. A flyer was posted on the National Childbirth Trust (NCT) Facebook Central and West London websites. The NCT is the UK's largest charity for parents. The websites the flyer was posted on has over 5,000 members. The study aimed to include up to 25 participants, however 16 were included as saturation was reached. Therefore 64% of the proposed sample was included. If saturation had not been reached, the full sample would have been recruited as there were still a lot of women who wanted to be included in the study. The NCT

Facebook websites are available to thousands of women across Britain, however as women have to pay to attend NCT courses, it is recognised this may have influenced the sample as they may have been more likely to be of a higher socioeconomic background. Snowball sampling was also utilised. Snowball sampling has been described as a procedure the researcher uses to recruit participants through the contact information provided by other informants (Noy, 2008). Snowball sampling has been described as a way of accessing groups of people that can deliver unique knowledge as they are often willing to meet and speak openly to the researcher.

Participants were able to contact the researcher via email or telephone if they were interested in participating. Once initial contact was made, the researcher explained the purpose and potential benefit of the study, no monetary incentives were offered.

### **3.7 Materials**

The materials required for the study consisted of a flyer, Dictaphone, a demographic questionnaire, an information sheet, a consent form, a semi-structured interview guide, a notepad and pen for note taking notes, and a debriefing form. A flyer (Appendix 1) providing brief information about the research and contact details of the researcher was used to recruit participants via the websites mentioned.

A participant information sheet (Appendix 2) was devised that described a brief purpose of the study, the right to withdraw, information about the storage and anonymity of the data collected, and the risks and benefits of participating. It also included the researcher's details and the university supervisor's details as well as the ethics committee review details, in line with City University's ethical requirements.

A standard consent form (Appendix 3) was used to ensure the participants understood the overall aims of the research and to gain participant consent. Demographics and other relevant information were gathered via a short questionnaire (Appendix 4) prior to the interviews. These included the variables age, relationship status, qualifications, occupation, ethnicity, London borough, and number of children. The demographic questionnaire consisted of seven questions in total. Two screening questions were asked to identify anyone with postnatal depression. If participants answered yes to either question, they were referred to a mental health charity or to their general practitioner. Details of a pre and post-natal depression support organisation were also available at the interview. If participants answered yes to one or more of the screening questions then

the interviewer explained that some sensitive issues may come up and would see if they were able to continue or not.

A semi-structured interview guide (Appendix 5) was developed by the researcher that explored the main themes that would be discussed in order to address the aims of the study. The interview guide was developed by researching the topic and it was structured around main themes that influenced the topic. The main themes included in the interview guide were: women's experiences of breast-feeding and having mastitis; what support (informal or formal support) was available to them, and how this impacted on their decision to continue or discontinue breastfeeding. The original interview guide consisted of 20 open ended questions. For example, '*What has been your experience of breast-feeding*' and '*what did you know about mastitis before you had it?*' All of the 16 women were asked these questions, however additional questions were asked as data was collected to the later participants depending on the findings of the research. For example, it was clear that there was a consistent theme that women were reluctant to use antibiotics when they had mastitis, and a question addressing this theme was added into the interview guide in interview four. Appendix six shows a list of the additional questions that were added as the data progressed.

Lastly, a debriefing form (Appendix 7) was made available to each of the participants. This thanked the participants and outlined the aims of the research in more detail.

### **3.8 Procedure**

After initial contact was made over email or telephone, potential participants that met the inclusion criteria were identified. Dates and venues that were convenient for the participant were arranged for the interviews to take place. It was important that the interviews were convenient to the participants because all of them had at least one baby or child. Due to this, most of the interviews took place at the participant's homes so that they were able to tend to their infants if they needed to. If women needed to stop the interview at any time to look after their infant, it was clear from the outset that this would not be a problem. This openness and flexibility created a trusted and safe environment for women to talk. Some women organised a time to meet when their infant(s) were sleeping, and some met without their infants, and preferred to do so in a public place, such as a quiet coffee shop.

All of the interviews were face-to-face. After meeting and introductions being made, an information sheet was given to the participants. This noted that the interview would not take more than one hour. The length of the interviews varied, with a range between 20 minutes and 45 minutes. Consent was sought and gained. Following this the demographic form was completed. All of the interviews were recorded via a Dictaphone so that they would be able to be transcribed. As previously mentioned two screening questions were asked that ensured participants did not have post-natal depression but no-one was excluded on this basis. One participant had experienced antenatal depression, but had been seen by her general practitioner and did not currently have post-natal depression. The interviews then commenced and conversation was free flowing with additional questions being asked in line with the participant's responses. After the interviews the participants were thanked and given a debrief form that explained in more detail the aims of the study and overview of the topic.

### **3.9 Data Collection and Theory Building**

The researcher transcribed all of the interviews after each interview. This ensured that constant comparative analysis could be conducted. The participants were coded (i.e. p1, p2, p3), to ensure they were anonymous and the data was confidential.

#### **3.9.1 Coding Techniques**

Several coding techniques are employed in grounded theory and applied to this study (Dempster, 2011). These are outlined below:

- Open sampling and coding
- Focused and axial coding
- Selective coding

Open sampling and coding is also known as line by line coding. It involves the researcher immersing themselves in the data and analysing almost every line of the interview transcript into themes (Walker & Myrick, 2006). This is a very meticulous process and the themes that emerge are closely linked to the interview context (Strauss & Corbin, 1998). The researcher reads the sentences and writes down initial thoughts, associations and responses. The themes or categories that emerge are low level descriptive titles (Willig, 2001). An example of the open coding is found in Appendix eight. Focused coding is the second technique used in grounded theory. Categories and themes that emerged from the open coding are scanned for relationships and meanings

so that a higher level analysis with more abstract categories is formed. The most informative codes that represent the data are then formed as the purpose of axial coding is to make connections between categories and subcategories (Walker & Myrick, 2006). The third and final coding technique is selective coding. An overarching category is formed that contributes to the theory. This demonstrates saturation and the core category which is central to grounded theory (Dempster, 2011, Glaser & Strauss, 1967). The researcher continued collecting and analysing data until no new themes emerged. Data saturation was reached at the sixteenth interview.

### **3.9.2 Memo Writing and Reflexivity**

Memo writing is a core component of grounded theory (Glaser & Holton, 2004). Memo writing is a continual process that consists of writing down the researcher's thinking and theoretical notes about the data (Glaser & Holton, 2004). Memo writing is important as it helps to conceptualise ideas, connections between categories, and contributes towards the formation of theories (Glaser & Holton, 2004).

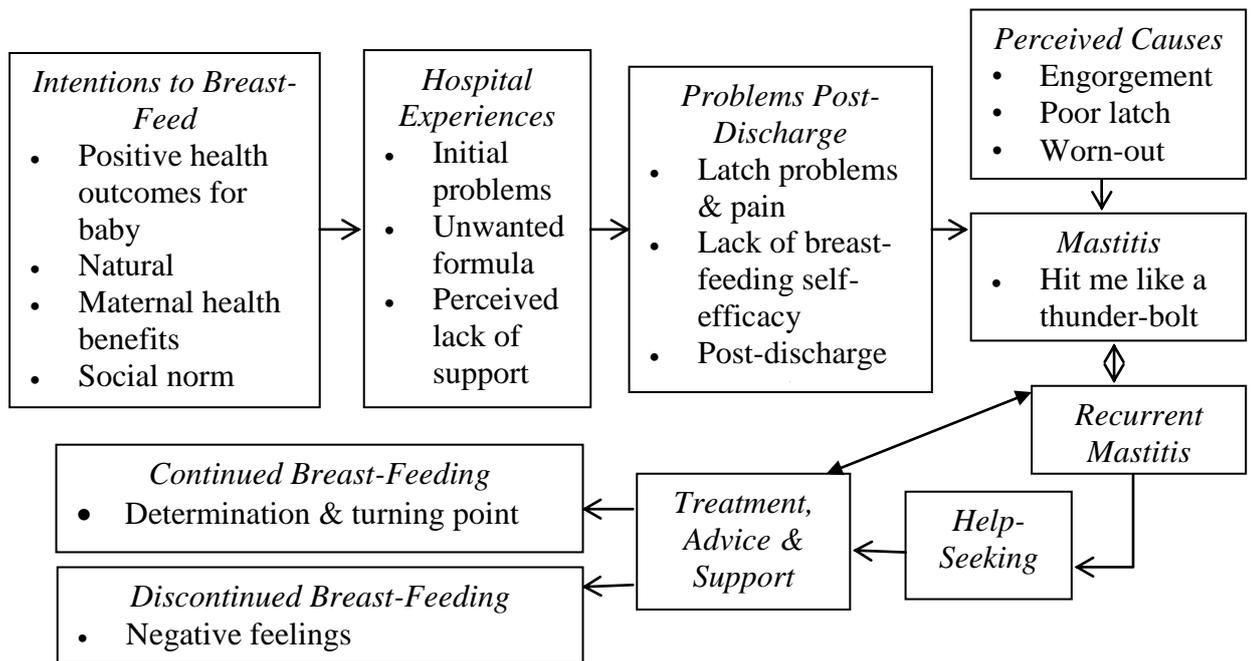
Reflexivity is also important as it allows conscious awareness of the self during the research, and reflecting on this (McGhee, Marland, & Atkinson, 2007). As the study was something the researcher had personally experienced this was an important part of the process of analysis. Thus, due to the researcher experiencing mastitis, it was not possible to remain completely unbiased, however the researcher continually reflected and evaluated the impact her own experiences and thoughts had on the study to help to minimise these. Thus, it is acknowledged that the biases were inherent, as also recognised in the constructivist approach to grounded theory.

## **Results**

### **4.1 Overview**

This section presents the main findings resulting from the grounded theory analysis of the data. A model was developed from the data, *'The Breast-Feeding Journey Precipitating Mastitis, Women's Mastitis Experiences and Breast-Feeding Outcomes'*. The model which is shown below gives an overview of the main themes, and how they are linked to one another. It describes the main factors women experienced before they got mastitis, the interaction of factors women experienced when they had mastitis and

the impact this had on them continuing or discontinuing breast-feeding and how they felt.



*Figure 2: The Breast-Feeding Journey Precipitating Mastitis, Women's Mastitis Experiences and Breast-Feeding Outcomes*

The model shows the main themes that influenced women's intentions to breast-feed before they had their babies, such as breast-feeding is a natural and healthy choice positively influencing women to breast-feed. It then shows the factors influencing women's experiences of breast-feeding. For instance their initial breast-feeding experiences and how they often felt there was a lack of support with breast-feeding from healthcare professionals which they believed instigated on-going problems. Factors experienced post-discharge affecting breast-feeding are then highlighted; such as pain due to babies not latching onto the breast which precipitated mastitis as their nipples became damaged. All of the women got mastitis, their perceptions of what caused it are shown (i.e. engorgement, poor latch and feeling worn-out), and their negative experiences of having mastitis. Help-seeking, treatment, advice and support factors are highlighted, and their breast-feeding outcomes, that is, whether they continued or discontinued to breast-feed and how this made them feel.

Table one below summarises the demographic information of the 16 participants. It includes the age, relationship status, level of qualification, ethnic group and number of children of the participants.

*Table 1: Summary of Participant Demographics*

Participant	Age	Relationship Status	Qualifications	Ethnic Group	Number of Children
1	30	Married	First degree	White British	One
2	35	Domestic partnership	First degree	White British	One
3	31	Married	Higher degree	White British	Two (twins)
4	33	Married	First degree	White British	Three
5	37	Married	Higher degree	White British	One
6	30	Domestic partnership	Higher degree	White British	One
7	39	Married	Higher degree	White British	Two
8	31	Married	Higher degree	Asian/British	Two
9	36	Married	First degree	White /French	Two
10	32	Married	Higher degree	White British	One
11	31	Married	First degree	White British	One
12	31	Married	First degree	White British	Two
13	36	Married	Higher degree	White Irish	Three
14	33	Married	Higher degree	White British	One
15	37	Married	Higher degree	White British	Three
16	35	Married	First degree	White Canadian	One

The participants' occupations and boroughs have not been included in the table in order to maintain anonymity. All of the participants lived in the Greater London area.

Table two below gives an overview of each of the participant experiences. It describes how long they had symptoms, who they sought help from and who diagnosed their mastitis, the treatment they received, and the outcome.

*Table 2: Overview of Participant Experiences*

Participant	How long they had symptoms	Who they sought help from and who diagnosed it	Treatment	Outcome
1	Realised straight away she had mastitis.	Called an NHS breast-feeding consultant who	Kept breast-feeding through it and used cabbages and	Did not get it again and continued to breast-feed.

		diagnosed it over the phone.	paracetamol.	
2	Delayed seeking help as she did not realise what it was. Then she googled it and sought help.	GP.	Antibiotics and self-care treatments.	Had it recurrently for eight months, then hired a private breast-feeding consultant who changed her feeding positioning and she never had it again and continued to breast-feed.
3	Delayed seeking help overnight and symptoms got worse (two full days and one night).	Had rung the midwifery help line but could not get through to the right person. Then rang a private GP who diagnosed it at a home visit.	Prescribed antibiotics but delayed taking them until she sought help from a family member who advised her to take them, and she did.	Did not get it again and continued to breast-feed.
4	Didn't know how long she had it as she didn't know what it was.	Was at a routine check-up at the GP and he diagnosed it. When it got worse a friend advised her to go to the hospital.	Took antibiotics and kept expressing and it got so bad that an abscess formed and opened up.  Admitted herself to hospital.	Had to stop due to the drugs and bandaging. Then had it recurrently with a subsequent child. Health visitor advised her to stop straight away. Therefore, she discontinued breast-feeding.
5	Knew something wasn't right for a few days but then woke up with a fever and sought help.	Went to the GP in the morning.	Excellent advice and antibiotics.	Had mastitis 10 days later and sought help more quickly and more antibiotics and continued to breast-feed.
6	Woke up feeling ill. Had a fever and delayed all day until she googled it	GP diagnosed it over the phone and	Antibiotics.	Felt better very quickly and didn't get it again. Continued to breast-feed.

	and realised what it was. In the evening her partner came home and rang the GP.	husband picked up antibiotics.		
7	Woke up feeling awful. It was Sunday so rang the hospital who advised her to come in. Could not get to the hospital as there was a bike race on and felt dreadful all day. Once the race finished that evening went in.	Hospital.	She was given antibiotics intravenously as she had a very bad infection (diagnosed via a blood test). She spent four days in the hospital.	She saw over 15 NHS professionals about her problems but then paid privately to see a lactation consultant who helped her with the latch and then felt it was resolved. She continued to breast-feed.
8	Felt dreadful and was out at a friend's so went home. Had a bath and went to bed. In the morning she felt so ill she went to the GP.	The GP advised her to go straight to the hospital. She was admitted overnight.	The hospital put her on a drip. She went home the next day but still felt ill so was readmitted to the hospital for two nights. She was given a pill to stop her lactating.	She discontinued breast-feeding. She then had it again with her second child but knew from before what it was and was able to treat it herself.
9	She felt unwell and quickly saw a GP.  She felt ill from May to June.	Misdiagnosed with thrush. She was put on antibiotics for thrush but she still felt unwell and she saw a health visitor who said to see a GP.	She then saw a different GP who prescribed her antibiotics for the mastitis. She still felt ill and was prescribed a third set of antibiotics.	She saw a private health consultant who used pressure points to drain her blockage and cut her babies tongue tie. She then felt better about breast-feeding and continued to breast-feed.
10	She had issues for weeks. She got mastitis and within an hour and a half felt like she had the	She rang the GP and was prescribed antibiotics over the	Antibiotics.	An initial NHS consultant advised her to stop breast-feeding, but then a second NHS consultant helped her

	flu and felt awful so sought help.	phone. Her husband picked them up.		with her latch and she felt she had solved the issues and continued to breast-feed.
11	She didn't know she had mastitis.	A health visitor was at her home and advised her to go to the GP.	She had three consecutive courses of antibiotics prescribed by the GP.	She felt like it took two weeks to clear up. An NHS health visitor helped her to gain confidence with her latch and she continued.
12	Felt so sore that she couldn't wear a bra so went to see her mum who said it didn't sound right. The next day she had a fever and sought help	She went to the GP first thing in the morning	The GP prescribed her antibiotics and within two days she felt better	She had mastitis four times and had antibiotics every time she got it. The GP gave her two prescriptions so she could just take them if she got it again. She continued to breast-feed.
13	She had symptoms at two pm and went to the hospital at four pm. She was seen by the doctor at nine pm.	Was told to stay in hospital on intravenous antibiotics overnight but would not as she had small children.	She was given antibiotics.	She then saw a specialist as she felt problems were persisting. She then got mastitis again. She went to the hospital at eight am and was given antibiotics and a pill to stop her lactating and was discharged at twelve pm. She discontinued breast-feeding and she then had it again with her next child.
14	Felt run down and ill during the day. She woke in the middle of the night feeling terrible. She went back to sleep and in the morning felt awful so her husband didn't go to work and took her to the GP.	GP.	She took antibiotics straight away and felt better by the evening.	She then got it again while she was abroad and she didn't seek help for two days and tried to self-treat. She then was prescribed antibiotics by a GP but the antibiotics were not effective and she felt very ill. She rang a helpline and they told her to take double doses of antibiotics which helped her but she then stopped breast-feeding as she was worried it would recur.
15	Had terrible pain from the outset in hospital. She	Her husband is a doctor and he	She delayed taking them for a few	She then had it again the following week. She went to the GP and was

	couldn't recall when mastitis came on as it was all so painful anyway. She had shooting pain and a fever within 20 minutes.	prescribed her antibiotics.	hours to see if it would clear with self-remedies such as massage but it didn't so she took the antibiotics for a week.	prescribed two weeks of antibiotics and it cleared. She then had it a third time and saw a GP and had more antibiotics but this time she stopped breast-feeding and she was scared it would keep recurring.
16	Felt ill during the day and went home and to bed and used massage and compression and breast-fed.	She self-diagnosed using information from the internet.	She felt bad all night and the next day but after that she felt better.	She then had it again. This time she could not get rid of it herself so she saw the GP and took antibiotics. She then got it a third time but managed to clear it herself using breast-feeding and massage and continued breast-feeding.

A detailed account of the main themes that emerged from the data will now be provided to show how the model was developed.

## 4.2 Intention to Breast-Feed

All of the women in the study intended to breast-feed before they had their babies. Some women were very keen to breast-feed whereas others said they intended to and wanted to but would see how it went. There were a number of reasons women intended to breast-feed, which will now be explained in more detail including the words of participants.

### 4.2.1 Positive Health Outcomes for Baby

Positive health outcomes for a baby were the main reasons women intended to breast-feed. The most commonly discussed health outcome influencing women to intend to breast-feed was the antibodies babies receive from breast-milk. Women said breast-feeding was the healthiest option and that it was better for their baby to be breast-fed rather than formula-fed. The following quote demonstrates that women saw breast-feeding as the best option:

*“Because I think it is the best start in life you could possibly have, and you know, I wanted him to be healthy, and I believe that is the way to do it by breast-feeding them”* (mother of two, aged 36).

Some of the participants were able to recite a list of specific positive health outcomes related to breast-feeding, such as a reduced risk of asthma and eczema. As demonstrated:

*“The whole long list of nutrients and all sorts of immunisation that you get in there. Things like how information how breast-fed babies are less likely to get asthma and eczema and things like that, ear infections, all sorts of health issues. That was the main reason for me wanting to do it”* (mother of one, aged 37).

When discussing health outcomes the focus tended to be on the overall health benefit for a baby (i.e. it is better for the baby’s health) and short-term outcomes (i.e. reduced risk of infections), rather than long-term outcomes (i.e. reduced risk of diabetes later in life).

#### **4.2.2 Natural**

Another common reason women intended to breast-feed was that it is natural and perceived as being a central part of motherhood. This is demonstrated in the following quote:

*“I think to me it seemed like a central part of motherhood and it is something since I was a child that I have envisaged I would do. You know how little girls hold there dolls up because they have seen people breast-feed, they associate it completely with motherhood and it seemed like an utterly natural thing to do, and I think I am probably the kind of person who errs towards doing things in the natural way to the extent possible, and of course I knew about all of the health advantages and so on but that was all sort of part and parcel really”* (mother of two, aged 39).

Women’s bodies’ being physically designed to breast-feed was also discussed. The quote below shows this:

*“I kind of feel that if we hadn’t breast-fed then we would have died out historically, like evolution, so I must be able to do it in some way”* (mother of one, aged 30).

Therefore breast-feeding was perceived as being a central part of motherhood, and the most natural thing to do, which positively influenced them to intend to breast-feed.

#### **4.2.3 Maternal Health Benefits**

Another factor influencing women to intend to breast-feed was maternal health benefits. For example, they knew there was a reduced risk of developing cancers (i.e. breast cancer), and for weight loss reasons. This quote describes one woman’s intentions:

*“And also I believe it is good for me, it helps me lose weight and I think it is good also to prevent from breast cancer and cancers, so for me there was no question really, it was a good thing all round”* (mother of two, aged 36).

A lot of women knew about that overall it was good for them to breast-feed, and some knew in detail why (i.e. such as specific cancers).

#### **4.2.4 Social Norm**

Women who had family members or friends who breast-fed were positively influenced to intend to breast-feed. As seen in these two quotes:

*“I think because one that is all I’d known, my sister had had children and she’d breast-fed both of them until they were two, all the health benefits for the baby, for me it was just that is the right thing to do”* (mother of one, aged 33).

And:

*“I knew my mum had breast-fed me and my sister breast-fed her kids so it was the obvious thing to do”* (mother of two, aged 31).

Women discussed being breast-fed themselves or exposed to sisters and friends who had breast-fed which made it seem like the obvious choice for them and the normal thing to do.

#### **4.2.5 Convenience of Breast-Feeding**

A further reason women intended to breast-feed was that from a practical perspective breast-feeding was perceived as being a lot easier than bottle-feeding. Ease of not

having to sterilise bottles, prepare formula, and the convenience of being able to breast-feed on demand when outside the home was consistently discussed. The following quote is an example of this:

*“From a practical level I thought it sounded a lot easier. You know, just being able to go out and about and you could be anywhere and not have to sterilize bottles”* (mother of one, aged 37).

#### **4.2.6 Cost**

The cost of formula was regularly highlighted as a negative factor that deterred women from intending to use it. This is shown in the following quote:

*“There is obviously a cost factor to it as well”* (mother of one, aged 31).

Another mother stated:

*“..not have to buy the milk which is an expense as well”* (mother of one, aged 37).

Formula was perceived as being expensive, but moreover it was seen as a cost that could be avoided as breast-feeding is free. The majority of the participants had a breast-feeding timespan in mind that they intended to reach. In the main this was six months, two women said they intended to breast-feed for at least three months, and two said up to a year. For the majority, six months was seen as a good amount of time to breast-feed as it was enough time for the infant to receive health benefits and a lot of the women also knew that six months was the recommended NHS timeframe. For some this goal was not reached, but for the majority it was surpassed. Women then had their babies and their actual breast-feeding and mastitis experiences were discussed. This will now be looked at in sequential order.

### **4.3 Hospital Experiences**

#### **4.3.1 Initial Problems**

There were some initial problems that women experienced once they had their babies that had a negative impact on breast-feeding. Some of the women experienced a difficult delivery and this was perceived as having a negative impact on breast-feeding from the outset. For example, one woman said she had a very sleepy baby due to a long and traumatic birth and the baby would consequently not feed. Another woman

described having problems with breast-feeding because she could not hold her baby's head as it was bruised from the use of forceps'. The following quote shows this:

*"I think it was a long labour and he'd done a lot of work, so he was really exhausted and just wanted to sleep and lethargic...they said because he was delivered by forceps his head was sore, he actually had bruises on his head. So because he didn't want me to hold his head and you have to actually hold their head quite firmly to position them and he just used to cry and scream"* (mother of one, aged 37).

A further issue perceived as having a negative impact on breast-feeding was infant health issues (i.e. being born prematurely or with jaundice). These babies were less likely to breast-feed as well at the beginning as those who were full-term or did not have any health issues. Mothers found this difficult and had not foreseen these problems and felt that they contributed to complications with breast-feeding from the very beginning.

Separation from babies sometimes due to health issues or hospital routine practices was also highlighted as a factor that negatively influenced initial breast-feeding. Separation post-delivery meant that some women were not able to have the amount of physical contact with their babies that they would have liked, as seen in the following quote:

*"Yeah it was horrible. So when he was born we both had an infection so they took him away for I don't know how many hours, maybe four or five hours to do tests and everything. We both had a thing in our hand with antibiotics and a drip and I think because when I was separated from him I didn't get that skin-to-skin or anything and from the start the breast-feeding was just not working"* (mother of two, aged 31).

This was an emotional subject and being able to have initial skin-to-skin contact was seen as a key determinant in initial breast-feeding success.

A lot of women encountered problems with babies not latching onto the breast well while they were still in the hospital. Poor latches resulted in women having nipple damage, experiencing pain, and feeling exhausted and emotional. A quote by mother of one aged 32 (who was talking about her third child and had previous breast-feeding experience), shows her experience of latch problems in the hospital:

*“I was in agony in the hospital already with the breast-feeding. For whatever reason her latch was appalling and I kept trying and I knew what I should do, I knew perfectly well what I should do and I kept trying to sort it out and it seemed ok but within 24 hours I had like ridiculous cracked nipples and it was unbelievably painful and every time she sucked it was like someone was stabbing me.”*

This quote shows the extent of the nipple damage. It also shows that some of the women in the study had successfully breast-fed before; however then experienced difficulties with second or third born infants which had been unexpected. Conversely, some women found breast-feeding easier with subsequent infants, as seen in the following quote by participant eight who had a lot of difficulties breast-feeding her first child but not her second:

*“Like you know right after she was born she just latched on straight away. I haven’t had any issues so I haven’t had to give her any formula”* (mother of two, aged 31).

This issue around breast-feeding difficulties and birth order was explored as the research progressed.

#### ***4.3.2 Unwanted Formula in Hospital***

Another issue experienced by women while they were still in the hospital was the introduction of formula. Some women felt like they had been encouraged to give their babies formula which had been a huge disappointment to them and perceived as an issue that contributed to breast-feeding problems. Often women described feeling overwhelmed and confused by the healthcare professional advice and there was incompatibility between what they wanted to do, which was to breast-feed, and what was done, which was to give their baby formula. The women that discussed this were usually first time mothers. The following quote shows one participant’s experience:

*“They were really keen on giving him formula, some of them were really keen on giving him formula and some were fine with me not. I felt pressure from some of them to, and I didn’t really want to, I had one midwife in particular who came in who, she took him and she fed him and I didn’t want her to”* (mother of two, aged 31).

There was conflicting advice about giving formula. Participant two who was a mother of one aged 35 felt there was a lot of pressure to breast-feed, however hospital healthcare professionals were telling her to bottle-feed using formula which she found difficult:

*“I did NCT classes and one of the sessions was a breast-feeding session but they won’t talk about bottles at all. It might be a matter of policy which is then very difficult if you are in the hospital and the doctors are telling you if you can’t breast-feed then you have to just feed him out of a bottle or he will get dehydrated.”*

Participants talked about babies being ‘taken away’ and fed formula, as seen in this quote:

*“So they kind of convinced me to give him formula but then she gave it to him and I didn’t really like that, I wanted to feed him, I just felt like she was some woman that liked kids and feeding babies and she took my baby and fed him and I was like ‘he is my baby’, if he had to be fed formula then I wanted to do it, I didn’t want someone else to come in and do it” (mother of two, aged 31).*

Consistently women discussed feeling disempowered and helpless when faced with the decision to use formula. Some of the women felt that when healthcare professionals gave their baby formula was the beginning of breast-feeding problems, as described by participant eight, mother of two aged 31:

*“..and they were like ‘do you want me to give him a bottle?’ and said ‘you need to feed the baby’ and they said he is so big and his blood sugar is low so I just said ok ‘just give him a bottle’ and they gave him a whole bottle...I didn’t realise until later but that was too much cos it would stretch his stomach out and it would end up being more cranky when he was feeding because he wasn’t having enough breast milk. So that sort of, I think, was the start of our problems.”*

### **4.3.3 Perceived Lack of Hospital Support**

There was a perceived lack of support with breast-feeding while women were still in the hospital. This is seen in the following quote:

*“I didn’t have much support in the hospital with breast-feeding and they would do things that I actually don’t think are right”* (mother of three, aged 33).

There was a general feeling that if there had been more support with breast-feeding formula-feeding in the early stages may have been avoided. This is demonstrated in the following participant:

*“Nobody helped at all and on the ward, I don’t know if this was again it was because it was the weekend, but I was struggling and their answer was to take her and give her a bottle which they did a couple of times”* (mother of one, aged 32).

Women felt like hospital staff, such as midwives, were very busy. For example, participant eleven, mother of one aged 31, described how she felt like healthcare professionals had to prioritise babies who had more serious issues:

*“You know there was a baby in our room who had jaundice so I think they prioritised that, and I think he was kind of feeding but I did get mastitis within the first seven days at home so I probably think there was a latching issue. In some respects he was going well but in others it wasn’t going so well.”*

Some women did receive practical advice and support with breast-feeding but felt like there was a lack of empathy. The following quote demonstrates this:

*“So the midwives they did try to teach me how to latch him on but they were so forceful about it. I remember one lady, I was crying and she was like ‘what’s wrong’ and I said ‘I just can’t get him to feed’ and she was like ‘ok wait until he is screaming, like screaming and crying and when his mouth is open really wide then ram him on your breast’. I was like, this can’t be the way to breast-feed, I was like ‘this is not how I imagined it’. I imagined it to be really relaxing and peaceful and a bonding experience, not like both of us crying. So it was so stressful”* (mother of two, aged 31).

Hitherto breast-feeding had not always happened as easily as women had expected it to. Continually women described how they had thought breast-feeding would be a natural and lovely experience, however when they encountered problems early on it had taken them by surprise and left them feeling very upset and stressed. In hindsight, women

thought that having additional support with breast-feeding problems may have helped them overcome some of these early issues. Women were then discharged home, sometimes feeling like they had not accomplished breast-feeding or with persistent problems.

#### **4.4 Problems Post-Discharge**

##### **4.4.1 Latch Problems and Pain**

A lot of women in the study experienced physical and emotional difficulties with breast-feeding once they returned home, in the early weeks post-discharge. Women consistently talked about having very bad nipple damage and experiencing a lot of pain, predominantly due to their babies having a poor latch. Nipple damage was discussed in detail, including bleeding nipples, scabs, blood stained milk, and terrible pain. As per the following quotes:

*“With my daughter I had just excruciating pain and nearly every mother you talk to talks about how painful breast-feeding is at the beginning. I am pretty confident in hindsight that this was on a completely different level. The usual bleeding and scabs and bruising all the way around the nipple, with both of them, and everyone said it wouldn’t happen again with number two, but it did and it was probably worse”* (mother of two, aged 39).

Another mother stated:

*“My nipples were in a terrible state, I was crying every time”* (mother of one, aged 32).

Lastly, participant four, a mother of three, aged 33, described the issues she had with her baby latching:

*“He had problems latching and was a really hungry baby from the beginning. He demanded a lot of boob, I had two days where he didn’t leave my boob which I know is normal but he hadn’t latched on properly so my boobs had got all hard and bleeding and pussy and painful”* (mother of three, aged 33).

Women felt like they lost a lot of confidence due to problems and experiencing so much pain. Three of the women in the study felt the pain was so much that they stopped

breast-feeding and exclusively expressed and fed their babies breast-milk out of a bottle for their entire breast-feeding duration.

#### **4.4.2 Lack of Breast-Feeding Self-Efficacy**

Some women experienced a lack of breast-feeding self-efficacy due to feeling like they could not do it properly. The following quotes show how women felt like they were not proficient at breast-feeding, yet when they felt like they had got better at it, they gained self-efficacy:

*“At the beginning when I hadn’t quite got the hang of the technique, it took me a good six weeks to kind of get her in the right position, and it was then I got comfortable doing it outside. Before that I didn’t feel comfortable doing it outside my house or someone else’s house because I basically had to have my boob out”* (mother of one, aged 32).

Another mother stated:

*“I didn’t really know that you only get a tiny amount in the first few days and it is normal for your milk not to come in for four or five days. I know that now, at the time I was thinking what am I doing wrong. That was quite stressful”* (mother of two, aged 31).

And:

*“I went and spoke to this midwife who was fabulous; she was so great, because I kind of lost my confidence a little bit”* (mother of three, aged 36).

Women felt pressure to breast-feed which impacted them psychologically as they felt like they were failing when they experienced problems. Often they questioned whether they could continue. Consistent reference was made to ‘*the breast is best*’ campaign and perceived societal expectations. Participant 10, a mother of one, aged 32 stated:

*“I just think there needs to be more support for women because it is all very well to preach the ‘breast is best’ but if women want to breast-feed it can make you feel quite inadequate so there has to be that support.”*

#### **4.4.3 Post-Discharge Support**

The support the women in the study received from healthcare professionals post-discharge (health visitors and midwives) was mixed. Some received excellent advice

and emotional support whereas others desired a lot more support. Support was deemed most helpful when it included both practical and emotional support. A lot of women talked about a significant person, like a health visitor, that really supported or championed them. Without this person they said they would have definitely given-up breast-feeding. This is illustrated in the following quote:

*“I think I had lost confidence with breast-feeding because of everything that had happened, but XX (husband) rung her one day and said ‘oh XX (participant) isn’t coping very well’ and she actually came over to see me within half-an-hour and really helped and she was sort of on call for me over two weeks and if I wanted to ring her she would come. She just kept popping by and saying ‘is everything ok’ and was really supportive”*  
(mother of one, aged 31).

Participant six, a mother of one, aged 30, also discussed her experience of having a very supportive healthcare professional:

*“Do you know I had a fantastic service at the children’s centre, the postnatal class? I think it was six weeks. She is like an old school health visitor that runs it. She was fantastic... She was just really reassuring; it was like seeing a mum. She just had seen everything and there was a couple of other girls as well that were there that had problems with breast-feeding and various things.”*

Women were resourceful and utilised several avenues of support if they felt they were not getting the right support, as seen by the following quote:

*“I had a lot of difficulty at first but because I was so determined I just got on with it and got the support, I had a lot of support and advice from various sources”* (mother of one, aged 37).

For some women they sought help from NHS, but for others they had sought help privately. The women in the study were assertive and financially secure. If they felt like they had not received enough support then they paid to see someone else (i.e. a lactation consultant).

Some women felt there was a lack of empathy from healthcare professionals. For example, women were often anxious that their babies were not gaining weight from breast-feeding, as previously seen in the hospital, and this contributed to them doubting

whether or not they could breast-feed. This participant discussed her experience around this issue:

*“Then you have all the anxiety and the problems and pressure because she wasn’t putting on weight properly and you then worry about topping them up and all the health visitors are being utterly insensitive”* (mother of two, aged 37).

There was a consistent request for more practical support around breast-feeding technique. A lot of women persevered with problems until they saw a different healthcare professional and were given different advice, as described by participant 10, a mother of one, aged 32:

*“Because the woman that came around initially basically didn’t bother to show me properly because she said I basically wasn’t going to be able to do it, so it wasn’t until six weeks I asked for help again. I thought I’m just going to have to feed her like this and then this woman at six weeks showed me how to do it.”*

Having someone who was able to provide good practical support was discussed as being really important. Other women desired more help generally with breast-feeding. As seen in participant 13, a mother of three, aged 36:

*“I wish there was more support because I think if people had a number to call and someone who would come to the house and talk to you it would be so much nicer, and someone with some softness about them.”*

Some women gained comfort from talking to friends or other women who had also experienced problems. A quote from participant 12 demonstrates how difficult she found breast-feeding to be and that she didn’t realise it would be normal to experience problems until she talked to other women:

*“It was a total shock, I felt like why doesn’t anyone ever talk about it being this hard, why does it seem like it should be natural when actually it is really hard and the more people I spoke to everyone else or most people seemed to be experiencing something similar to me. So everyone seemed to be finding it hard, it is only when you start talking to people at the same stage as you that you realise that it is normal so to begin with when you are at home, I guess you don’t see people struggling”* (mother of two, aged 31).

Therefore, some women had excellent advice and support from healthcare professionals or sought reassurance from other women who were breast-feeding. However, there was a consistent need for more emotional and practical support from healthcare professionals.

Up until now women's breast-feeding journeys precipitating mastitis have been discussed. All of the women then got mastitis, usually within the first three months post-partum. Over half the women in the study had recurrent episodes of mastitis, with the same infant, or subsequent infants. Women's mastitis experiences and outcomes will now be discussed.

## **4.5 Mastitis**

### ***4.5.1 Hit me Like a Thunderbolt***

Mastitis symptoms very quickly and suddenly progressed. Although some women did not realise what it was at first, they knew something was wrong straight away. Women talked in detail about what happened when they first experienced mastitis. The following quote gives one example:

*“We were driving back and I started feeling kind of fluey, and I thought that I was coming down with a cold. Then in the middle of the night I was shaking, I was shivering all night and I was thinking something was really wrong and then at about five in the morning I woke my husband up and was like ‘I am dying!’ so yeah, I have never felt that bad in my life. I am pretty tolerate to pain and illness and I don’t get ill that often so I think that’s why it came and struck me like a thunder-bolt. And that’s the thing, it progresses so quickly”* (mother of one, aged 33).

A further quote demonstrating how women were initially affected by mastitis came from participant four, a mother of three, aged 33:

*“I had the fever just awful, like a flu, really ill. But when you are a first time mum and with twins you kind of just put it down to the fact that you are knackered and that you don’t know what you are doing anyway, and you feel slightly emotional and neurotic and everything else anyway. It was only when I had seen the GP and they said ‘oh that sounds like mastitis’ that it was making more sense. I was very tired. I remember feeling horrifically tired. I couldn’t get out of bed, that’s why it was a bit like flu. You know,*

*when you can't lift your head off the pillow tired. Emotionally, I think I was just fed-up. I wanted to stop, but felt guilty for stopping”.*

Psychologically women found having mastitis very upsetting. It affected them at a time when they were already tired and worn-out. This quote demonstrates one woman's emotional experience of mastitis:

*“It was awful and I did feel very emotional throughout the whole thing. Obviously you have the hormones and it was like being on a rollercoaster, I was very exhausted and in pain and emotionally bad, and it was something else on top of hormones, and the lack of sleep. It was quite stressful you want to make sure you are doing whatever you can to try and get better”*  
(mother of two, aged 36).

All of the women talked about feeling very emotional. It was described as being the lowest point of child-birth and breast-feeding experiences. Several women described mastitis as being *‘worse than child birth’* and feeling like they were *‘dying’*. This seen in participant 14:

*“I thought I was on my way-out. It's weird cos I don't think you can die from mastitis but that is how you. I never felt anything like it!”* (Mother of one, aged 33).

Women also often described mastitis contributing to them feeling like a failure. This was described by participant 11 in the following quote:

*I don't know if it was the mastitis or because you get the hormonal thing at seven to ten days but I had the blues, I definitely got baby blues but I don't know whether it was linked to mastitis. I think part of it was that it was linked to feeling like a failure because I had got this mastitis. You know, the clouds part after a week or two and you are like well you start feeling better. Part of it is that it is your first one and you just want everything to be perfect”* (mother of one, aged 31).

A further difficulty women found about having mastitis was trying to look after their babies during such a debilitating experience. They felt like all they needed to do was focus on recovering but could not, as stated:

*“It is like the most insane experience of your life. Usually when you are ill you just go and sleep don’t you, but you still have to look after the babies”*  
(mother of twins, aged 31).

A further quote illustrating this:

*“I just started feeling like I had a fever and I had to leave early and go home and by the time I got home the fever was just so bad. I went to take a cold bath and it just didn’t work and I was just shaking and shivering and I couldn’t even feed my son, I just felt like I wanted to die, it was just horrible”* (mother of two, aged 31).

All of the participants had flu symptoms, a red lump, found it painful to feed, had a sore breast, felt emotional, worn-out and exhausted. Most of them had mastitis that lasted a few days, whereas a few had it for longer, and/or recurrently. A quarter of the women from the study were admitted to hospital from mastitis.

#### **4.6 Mastitis Perceived Causes**

There were several perceived causes for getting mastitis. Predominantly it was linked to engorgement from overabundant milk supply, poor latch, expressing, undiagnosed tongue tie, or generally being ‘worn-out’.

##### **4.6.1 Engorgement**

For a lot of women mastitis was thought to be brought on by engorgement. For example, they said their babies suddenly slept through the night which caused their breasts to become engorged. Expressing was also constantly discussed as a potential reason for engorgement. Women thought that expressing had interfered with milk their supply and led to an oversupply of milk and therefore engorgement. The following quotes show participant’s experiences of expressing:

*“To be honest I tried to express quite early on and that was a massive mistake. My mum was encouraging me to do that because she was desperate to give her a bottle so I expressed after like six days and that made me massively engorged. So that was uncomfortable, and I just seem to leak all the time, it just sort of feels quite unglamorous! It felt like sore nipples as well and then the mastitis as well”* (mother of one, aged 30).

A further two quotes support this:

*“My breasts were very very engorged so I was getting up in the night to express my breast but it was the wrong thing to do because I should have just been expressing a little bit by hand rather than pumping because it was stimulating my milk in the night. I think it was exactly at that time, and I woke up one day, and I was trying not to express but I was getting engorged and wearing things that were too tight for me and then it just flared up within a few days”* (mother of one, aged 37).

And lastly:

*“I think it is because I expressed. I shouldn’t have expressed. I used an electric pump”* (mother of one, aged 30).

A quote by participant eight, a mother of two, aged 31, shows that the doctors believed her mastitis had been caused by expressing:

*“I was just devastated because they told me it was better you know if you don’t breast-feed, your mastitis is so bad it could possibly be an abscess so you know they did like a scan, they took a sample out from a lump or something and it turned out it wasn’t an abscess it was just really severe and they said that because I was expressing so much that my nipples were so damaged to stop”*.

The majority of women also discussed having an overabundant milk supply which they believed had led to engorgement and subsequently mastitis. Women described how they had so much milk that it was dripping from their breasts. The following quote shows one women’s experience of overabundant milk supply:

*“I was like a cow; I produced three litres of milk a day, right! So I express it and freeze a litre and a half and the baby would normally use a litre and a half, so half and half, so I had to use the pump quite a bit. It has happened every time; I just have so much milk. It is just ridiculous. Especially in the first few weeks before it starts to reduce, I just have to get that out because I am in so much pain”* (mother of three, aged 36).

#### **4.6.2 Poor Latch**

Most women in the study had very sore and damaged nipples which they believed were caused from a poor latch and led to mastitis. As shown by a mother of one, aged 31:

*“Also though I don’t know enough about mastitis, and I think for my situation it happened because the latch was bad and my breasts weren’t emptying and there actually needs to be more support for women from the moment you have your child in hospital, because if I hadn’t got mastitis I don’t think anyone would have checked-up on me and come and visited me at home sort of thing”.*

Several women believed that their babies had been born with tongue-tie which had in turn had led to latch problems. Participant eight explains her experience of this:

*“I always wanted to do it (breast-feeding) you know, I thought it would be a lot easier than it actually is. I had like real issues with my son especially, he just couldn’t latch on. I think maybe he had tongue-tie and I just didn’t realise so I started expressing”* (mother of two, aged 31).

Some women were able to have tongue-ties diagnosed and cut but the majority did not have them diagnosed for some time. Women with latch problems wondered if their nipples had become so sore and damaged that they were open to infection and consequently developed mastitis.

#### **4.6.3 Worn-Out**

Lastly, women felt that being worn-out from a lack of sleep and having a young baby was related to getting mastitis. For example, participant six, a mother of one, aged 30, reported:

*“Worn-out! I think I kind of struggled to sleep when she was sleeping, and I didn’t get the rest I needed anyway. I was pretty (much) a wreck by about week six”.*

Women felt physically exhausted, alongside breast-feeding problems and being hormonal they believed it had led them to getting mastitis.

#### **4.7 Recurrent Mastitis**

Out of the 16 women in the study, 11 had recurrent mastitis. Some of the women had it several times with the same infant, whereas others had it with subsequent infants. The first time women experienced mastitis was usually the worst, for instance:

*“The first time I had it that was the worst because I didn’t know the symptoms so it took me a while to know I had it. After that I knew I had it so it was easier”* (mother of two, aged 31).

The first time was usually described as being the worst because they did not know what mastitis was and it progressed quickly. Subsequent episodes were less severe because they knew the symptoms and therefore as soon as they felt them they were able to treat them. This is shown in the quote below:

*“I felt like I was more prepared. When I started feeling a little bit feverish this time I knew it could happen so I kept breast-feeding her like constantly and I think it cleared it up before it developed into full blown mastitis”*  
(mother of two, aged 31).

Therefore, in the main women felt like having knowledge of mastitis and knowing how to treat it quickly was important to stop it from progressing. There were a few women however that found recurrent episodes of mastitis to be more difficult, and this was predominantly because they had to look after their subsequent children. Women who had recurrent mastitis felt scared that they would keep getting it.

#### **4.8 Help-Seeking**

Women who realised they had mastitis and sought help quickly usually had less severe mastitis outcomes than women who delayed seeking-help or who did not realise they had mastitis. There were women who realised they had mastitis but something got in the way of them seeking-help (i.e. they felt dreadful and went to bed and rang for help once they had woken-up). Usually their symptoms had already progressed by the time they sought help. There were some women who did not realise that they had mastitis. Although they realised something was amiss (i.e. they thought they had the flu), they did not seek-help until their symptoms were a lot worse. There were three main help-seeking pathways identified:

1. Pathway 1: Women quickly realised they had mastitis; they sought healthcare professional support and were then treated quickly.
2. Pathway 2: Women quickly realised they had mastitis; they then had issues seeking-help or delayed seeking-help, they then sought help when their symptoms had progressed.

3. Pathway 3: Women did not realise that they had mastitis (although they felt something was wrong i.e. they thought had the flu). Their symptoms progressed and they then sought healthcare professional support.

The diagram below gives an overview of the three different help-seeking pathways.

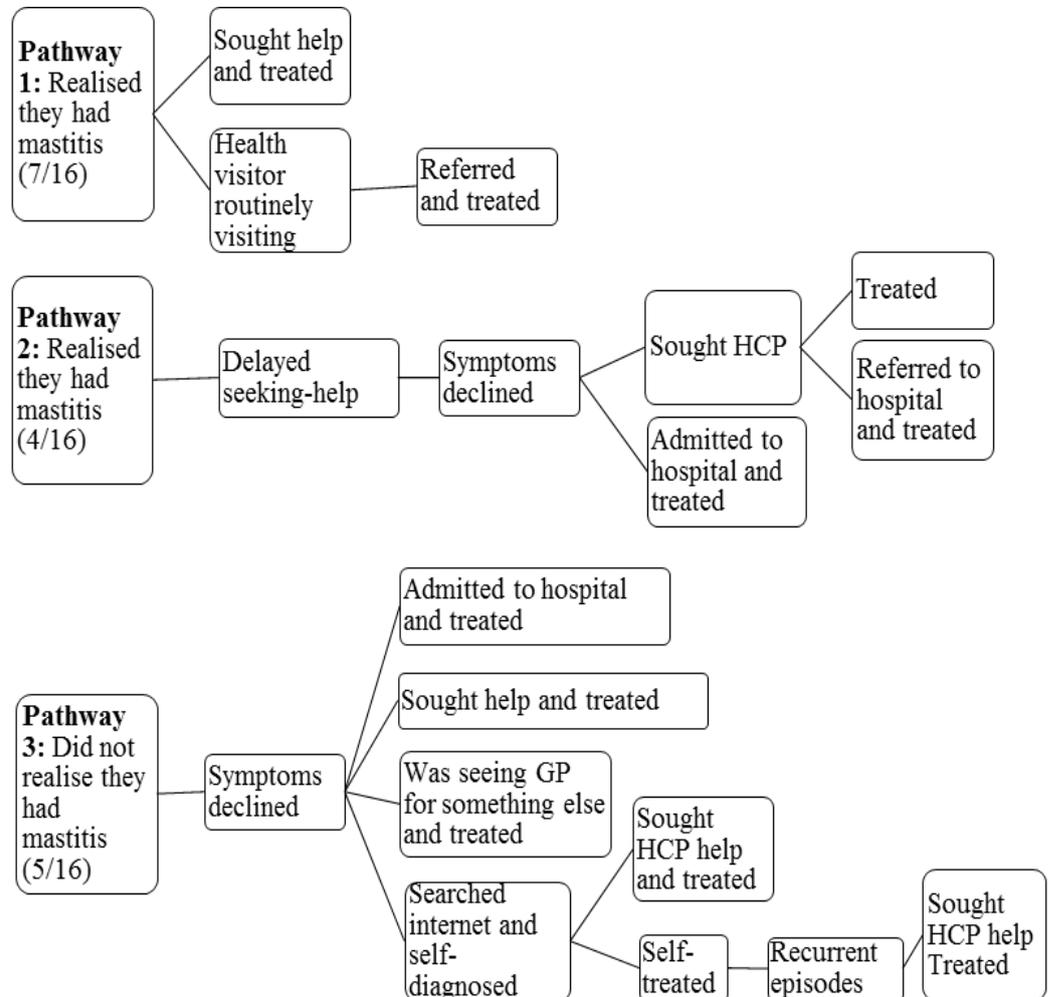


Figure 3: Help-Seeking Pathways

The three pathways will be discussed in more detail below.

#### 4.8.1 Pathway 1

Women in the first pathway used the internet in the first instance to self-diagnose. They googled symptoms or went to mothering websites such as netmums.com or kellymom.com to find out what the matter was. These mothering websites include information in a forum type layout where women can chat to each other or search for topics such as mastitis. The following two quotes show women’s first responses to their symptoms:

*“The first thing I did was google it, and basically it seemed like antibiotics was what you needed to do to get rid of it” (mother of one, aged 30).*

She added:

*“I looked at a breast-feeding website called kellymom.com. It has a load of information on it around all different aspects of breast-feeding, so I looked on there” (mother of one, aged 30).*

These women who realised quickly that they had mastitis had often previously read about it or heard of someone they knew having it. They therefore recognised the symptoms (i.e. a red patch on the breast, tenderness and fever) and knew they had mastitis. This is demonstrated in the following quote:

*“Yeah it was a proper big red lump and I figured this looks like an infection and then when I got the fever just because I have never experienced a fever like that before, where I am in bed covered with blankets and my whole body is shaking, that has never happened before and I remember I must have heard someone else talking about it and I remember thinking this is definitely it” (mother of three, aged 37).*

Therefore having knowledge about what it was or hearing of friends or family members who had had mastitis enabled women to recognise symptoms quickly and seek-help. Once women had self-diagnosed using the internet they usually then contacted their general practitioner. Access to the general practitioner was an important factor in how women felt. Most women were able to be fast-tracked and this was a relief, as demonstrated in the following quote:

*“It is difficult to get an appointment on the same day, but when I described it they said we will get you an appointment that day. That made me feel better that you could get advice quickly and be seen to and if you needed antibiotics they were available quickly” (mother of one, aged 37).*

Women who were able to be seen quickly often felt better sooner, emotionally and physically. Although some practices had fast-track systems in place for problems with infants, they did not have them for problems with mothers. The following quote shows the issue that arose from this:

*“Certainly for the GP it feels like they prioritise anything to do with a baby but for the mum less so, which is a bit strange because if mum is unwell it impacts her ability to look after the baby and I was lucky that she was an absolute angel the whole time I was napping. But if she wasn’t, there is certainly no way I’d feel like I was able to look after her properly”* (mother of one, aged 30).

A few of the women were able to explain what had happened to their general practitioner over the phone and they wrote prescriptions that were available to be picked-up from reception without being seen. These women had husbands who were able to pick-up the prescriptions for them, as seen in the following quote:

*“I don’t think I could have left the house. It literally knocked me sideways. It was like the worst flu I’ve had, but I also got incredibly weepy. That was the first time, I’d coped with everything and I hadn’t really been upset until that point, and then I just couldn’t stop crying for about three days. It was horrendous....so I called the GP who didn’t have any appointments so tried to ask for some (antibiotics) over the phone and I had to battle for them a bit. He was like ‘have you had it before?’ and I was like ‘no, it’s my first baby, I’ve never breast-fed before’ and then my husband went and picked up the antibiotics and then I felt so much better”* (mother of one, aged 32).

Of the women who were able to get a prescription over the phone, they said they had to be very assertive. They said they had felt so unwell they did not feel that they were able to physically go to the surgery. These women all had support at home, such as a partner who was on paternity leave or a partner who had taken time off work to support them. In these instances their partners went to the surgery and picked up the prescriptions and antibiotics. These women often started medical treatment more quickly than some of the other women who had to actually go to the general practice themselves. A couple of women asked for prescriptions over the phone but were told they had to go into the practice. They found this very difficult due to feeling so unwell and emotional, and sometimes had their baby/babies with them. Participant 12 reported:

*“When I went to see the GP I couldn’t even tell the receptionist what or even ask her to see a doctor because I was crying so much and I think they*

*were like (whispers) oh no what is wrong with her”*(mother of two, aged 31).

Participant 14, a mother of one, aged 33, was not able to get a prescription over the phone, and explained her experience of having to go to the practice:

*“I basically said ‘I can’t move’ because I was feeling so unwell and they said I had to go in. I went and had to wait for about an hour and a half in the waiting room and I was just shivering and shaking and I know I am making it sound very dramatic but it was actually very bad, it was just awful, and it was August so it was really hot outside but umm I had this temperature and I was just shivering”* (mother of one, aged 33).

Some women were not able to get appointments quickly at the general practitioner. Participant one stated:

*“So I phoned them and this was beginning of December and they were like phone back at 8.30 tomorrow but it is highly unlikely you will get an appointment as we are really busy. So I was like ‘oh that’s really helpful’. It just reconfirmed why I don’t go to the GP very often”* (mother of one, aged 30).

In this case the participant rang a breast-feeding consultant who advised her over the phone. She had knowledge of local resources that were available was therefore able to seek alternative help. Aside from ringing the general practitioner, a few women rang family members first. Family members usually advised women to then ring their general practitioner. For example, one woman rang her mother who told her to ring the general practitioner immediately. Other healthcare professionals that were contacted in the first instance included an obstetrician, midwife, health visitor, and a breast-feeding consultant. One woman had a health visitor due for a routine appointment so she waited to show her the symptoms when she arrived. In this instance the health visitor diagnosed her and referred her immediately to the general practice. All of the women in pathway one realised quickly they had mastitis sought appropriate medical help and were then treated before their symptoms had progressed too much.

#### **4.8.2 Pathway 2**

There were some women who knew that they had mastitis, from self-diagnosing using information on the internet, but then delayed or had an issue seeking-help. It was only

when their symptoms progressed that they sought healthcare professional help again, often from a different avenue than they had first tried. For example, one participant rang the maternity helpline number she had been given when she had been discharged from the hospital. She kept being put through to different people so she eventually gave-up. This quote shows this:

*“I think that first night when I had the fever I called the twenty-four-hours out of office line on the maternity pack, and I called that and I couldn’t get through to the right people and they kept saying this is not the right number and kept putting me through and so I gave-up”* (mother of twins, aged 31).

Thus, she initially rang for help, could not get through, and then went to bed as she felt awful. By the next day she felt so unwell that she rang a private general practitioner who visited her at home.

Another woman knew she had mastitis, from using the internet to self-diagnose, rang the hospital (it was a Sunday so she knew the general practice was shut), and the hospital told her to come to come in straight away because she had such a high temperature. However, she was unable to get to the hospital as there was a bike race on and the roads to the hospital were blocked. That evening she was able to be driven to the hospital as the bike race had finished and she was admitted for several days.

Two other women in this pathway realised they had mastitis, from searching their symptoms on the internet, but as it was the evening and they felt so unwell they decided to go to bed and to go to the general practice in the morning. One of these women went to her general practice in the morning and was referred and admitted to hospital straight away. She also was kept in hospital for several days as her mastitis had progressed. The other woman managed to see the general practitioner and be treated. In summary, women in this pathway delayed seeking-help, due to feeling so unwell and going to bed or having an issue seeking-help, and their symptoms declined considerably sometimes resulting in them being admitted to hospital.

### **4.8.3 Pathway 3**

There were women in the study who did not seek-help straight away because they did not realise that they had mastitis. They all said they felt unwell but they thought they had the flu, or a virus, or that they were still exhausted from child-birth or breast-

feeding related issues. A quote by participant two explains why she did not realise she had mastitis and delayed seeking-help:

*“Well I didn’t do anything for ages because I didn’t know or recognise what it was, especially as breast-feeding was already painful so I thought it was just part of the process. I thought I was just getting used to it and I didn’t realise there was anything to be done. I think it must have been looking online and I put the symptoms together and thought that maybe this is what it is or could be. I then went to the GP”* (mother of one, aged 35).

Participant four, a mother of three, aged 33, did not realise she had mastitis for some time. She knew something was very wrong but delayed seeking medical help and it progressed into an abscess. She had to be admitted to hospital, as described in the following quote:

*“Yeah I got an abscess in my breast due to it and it became all infected, and the tissue had opened up... the abscess was getting worse and worse, it was just underneath my nipple, just where the machine latched on and so it got worse and worse and worse and I remember one day expressing, this is graphic, but milk came out of my nipple and also of the wound underneath. And then I thought, ‘that’s not looking good!’ I then went to the hospital.”*

She had not heard of mastitis and did not realise she needed medical help until her condition was severe. She said she had been speaking to a friend who advised her to go to the hospital and she was admitted. She felt so strongly that she wanted to breast-feed that she delayed until she could not physically continue. Another participant did not realise she had mastitis as she thought she had a virus. She then realised she had mastitis due to googling specific symptoms and self-diagnosed. Luckily her condition had not declined too much and she was able to use self-care treatments such as massage, paracetamol and breast-feeding. However, she did experience recurrent episodes of mastitis and was prescribed antibiotics for these.

Overall the women in pathway three did not realise quickly that they had mastitis and needed medical help or hospitalisation as their symptoms had progressed.

#### **4.9 Mastitis Treatment, Advice and Support**

The different treatments, advice and support women received will now be discussed.

#### 4.9.1 Treatment

Once healthcare professional help was sought, the majority of women were prescribed antibiotics. Most of the women who took antibiotics started to feel better very quickly, as seen in participant 14:

*“We then went to see the doctor and she prescribed antibiotics which I took straight away and then I’d say almost by the end of that day as I’d had two or three doses by that time, I was already starting to feel better”* (mother of one, aged 33).

This quote is in accordance with the previous quote:

*“I was in a lot of pain. I had a fever. That kind of flu feeling. Each time I got onto the antibiotics I felt a lot better very quickly. It did work”* (mother of one, aged 35).

Women felt antibiotics were effective at treating mastitis and eased the pain and symptoms very quickly. There was however a consistent theme that arose over the course of the research that the women were reluctant about taking antibiotics whilst breast-feeding. The following quote describes one women’s reluctance to take antibiotics:

*“So he gave me the antibiotics and I didn’t take them and this was when I started the conversation with my husband’s cousin about taking them or not. She said I was ill and was making sure I was ok and was telling me I had to take them and was telling me I had to take them”* (mother of twins, aged 33).

Women were worried about the potential negative affect antibiotics could have on their baby’s digestive system. In particular they discussed feeling concerned about taking antibiotics due the impact on the ‘gut’ or ‘tummy upsets’. Women in some cases, as in the example above, delayed taking antibiotics until they felt they ‘had to’ as the mastitis had progressed and they didn’t feel there was another choice. Women were then worried after taking antibiotics about the impact they had actually had on their baby’s tummy, as explained by participant 10:

*“Well I did (take the antibiotics) but she got diarrhoea fairly instantly and had it... that was when everything kind of starting going wrong with her*

*tummy, it was after I started taking antibiotics. She pretty much had diarrhoea for two weeks after I started taking them but I knew or it seemed that was the only way it would go” (mother of one, aged 32).*

Several women believed that taking antibiotics and breast-feeding had given their babies diarrhoea. Some thought that antibiotics had brought on intolerances such as dairy intolerance or lasting problems. Although there was a reluctance to take antibiotics, most weighed-up the pros and cons of taking them and decided to do so. Some considered taking antibiotics and stopping breast-feeding to avoid any negative impact of antibiotics on the baby, as shown in this quote:

*“I guess to me the breast-feeding was more important and carrying on breast-feeding, I had to kind of weigh the pros and cons and to me the benefit of breast-feeding weighed greater than having a little bit of antibiotics” (mother of two, aged 36).*

A couple of women had to take repeat antibiotics as the original antibiotics that had been prescribed had not treated the mastitis or they experienced recurrent episodes. This was the case for participant 11:

*“I think they usually give you a seven day course, and so they had given me a seven day course and then it happened again. I think they said they would wait after seven days to see if it had cleared and it hadn’t. Basically it never cleared and it came back” (mother of one, aged 31).*

Some participants felt that antibiotics alongside latch advice would have been helpful to treat the source of the problem; this was the case for participant nine (mother of two, aged 36):

*“The antibiotic was really helping a little bit but it wasn’t sorting out the problem which was the feeding, creating the blockage really, well he was not feeding properly because he couldn’t latch to my breast properly”.*

Some women were given antibiotics as well as self-care advice. For example, participant five was given very good advice and treatment from her general practitioner which included advice to continue to breast-feed:

*“He said lots of hot flannels, which I did I literally lay there with a hot flannel on it. He gave me some antibiotics. He said to rest and to keep*

*feeding from that side and to massage towards the nipple while you are feeding even as well. He also said about look at different positioning's for feeding and to get where the baby's chin was to massage the part that was sore. I did actually change the latch and did more of a rugby ball to get more of a chin on the part that was really hard and inflamed. Maybe that helped as it was painful but it was almost a pleasurable pain cos you feel it is doing something” (mother of one, aged 37).*

A few women were able to treat the mastitis with over-the-counter medicines such as Paracetamol and Ibuprofen, and self-care remedies. For example, one woman was given advice over the phone and was able to treat it herself following the advice of the healthcare professional. After initially failing to get an appointment at the general practice, she rang a breast-feeding consultant. When she explained her symptoms she was advised to continue to breast-feed and take over-the-counter medicines, use massage and cabbage leaves. Women who were able to treat mastitis themselves at home were usually in the early stages of mastitis and their symptoms were not severe.

#### **4.9.2 Advice**

Some of the advice women received was excellent, whereas a lot of women felt like they needed more advice. As seen in the quote earlier, some women had very good advice from healthcare professionals. A few women felt there was an issue around conflicting advice which they found difficult. This is described by participant nine (mother of who, aged 36):

*“I did have lots of different bits of advice and nobody would agree with each other either and also there are no notes, you know when you go and see a health visitor there are no notes to follow you, nothing that follows you”.*

Participant two also found receiving conflicting advice difficult, and did not know whose advice was right:

*“Well they were all very nice but it is a different one every time and they all have slightly different views on things, so I know it must be very difficult to organise it but if there was any way you could get the same person that would be a massive difference. Otherwise you get all this conflicting*

*information and no idea; especially with your first one you just have no idea what to listen to” (mother of one, aged 35).*

Another issue was that a small number of women felt like the pain was persistent, as seen in the following quote by a mother of three, aged 33:

*“It didn’t really matter what they looked like, they looked horrific, my left nipple was the worst, it looked raw like, and it looked like it was pulsating. But I remember thinking, if the pain could go I could carry on but then you can’t take Ibuprofen or anything, they recommended then not to because I was breast-feeding, so I was told not to. The only thing I could take was Paracetamol, which was just doing nothing. So I just felt really fed-up with the constant pain.”*

Therefore more advice to relieve symptoms and more consistent advice was desired. There was different advice around continuation of breast-feeding when women had mastitis. Some women were advised to keep breast-feeding to help clear the mastitis, some were advised to stop due to mastitis, and others were not advised either way or had mixed advice from different healthcare professionals. Table three gives a summary of the advice women received with regard to continuation of breast-feeding when they had mastitis.

*Table 3: Breast-Feeding Advice for Mastitis*

	<b>Breast-Feeding Advice</b>	<b>Continued or Stopped Breast-Feeding</b>
1	No advice either way	Continued
2	Advised to keep breast-feeding	Continued
3	Advised to stop	Continued
4	Advised to stop	Stopped
5	Advised to keep breast-feeding	Continued
6	Advised to keep breast-feeding	Continued
7	Advised to stop	Continued
8	Advised to stop	Stopped
9	Advised to keep breast-feeding	Continued
10	Mixed, stop and keep going	Continued
11	Advised to keep breast-feeding	Continued
12	Advised to keep breast-feeding	Continued

13	Mixed advice	Stopped (had frozen breast-milk)
14	No advice either way	Stopped
15	No advice either way	Stopped
16	No advice either way	Continued

The table above shows several things. Firstly, women who were advised to keep breast-feeding all did. The following quotes show the advice given with regard to breast-feeding and how this encouraged women to continue:

*“They said to go on unless its absolute agony. They said you won’t pass anything on to the baby and it will help the mastitis as it will help unblock the duct”* (mother of one, aged 35).

Another mother stated:

*“Well I remember them saying cabbage leaves, hot in the shower to massage the breasts, and things like that, but the main thing was to keep feeding. Keep feeing as much as you can to unblock everything”* (mother of one, aged 31).

One participant explained that knowing that breast-feeding was part of the treatment process encouraged her to continue:

*“If someone had said if you stop breast-feeding this will end I probably would have stopped because it was that awful but because some of the treatment was to continue feeding then made sure I continued. It was so awful that had that not been part of the healing process I would have stopped”* (mother of one, aged 32).

Therefore, being advised to continue to breast-feed resulted in continuation of feeding.

The table also shows that where women were advised by healthcare professionals to stop breast-feeding, some did and some did not. There are several quotes below that describe why women were advised to stop breast-feeding due to having mastitis:

*“He actually said I shouldn’t feed from the infected breast but I ignored that because of what I’d read on the internet and I fed them (twins). I read that it is fine to, and I don’t know, I used my own knowledge as a scientist about what I could read and what I could judge for myself and I didn’t see*

*that it would be a problem to give them that milk. And they were fine in the end” (mother of twins, aged 31).*

In this case the general practitioner advised against breast-feeding because the milk might have been infected but the participant used her judgement to keep going. Another participant was advised by hospital healthcare professionals to stop breast-feeding so that her breasts could heal and then potentially she could re-try to breast-feed once mastitis had been treated. Her experience is described below:

*“When they said ‘I recommend you stop breast-feeding’ I remember thinking because they told me that for this to heal that they would have to completely dry-up and then I’d have to try to re-lactate again so it would be like starting from scratch. They’d have to wait for the infection to completely clear and they’d wait for my milk to dry-up and then I’d have to see if it would start up again. That’s what they told me” (mother of two, aged 31).*

This participant did stop breast-feeding and did not breast-feed her baby again. Other healthcare professionals advised women to discontinue breast-feeding due to difficulties with latch and struggling emotionally. This was seen in participant four:

*“She had said ‘you are clearly not doing well, is this something you want to put yourself through?’ It got to the point that I was resenting him (baby), I didn’t enjoy him and I thought ‘god he is my last one and I thought I don’t want to do that.’ It was the health visitor that kind of at that point said stop” (mother of three, aged 33).*

This participant did stop breast-feeding. Another participant was advised to stop from a healthcare professional but sought a second opinion:

*“So I think on day four the breast-feeding specialist came from XX (hospital) and she said that she was tongue-tied and therefore I wouldn’t be able to breast-feed her, that was her answer. So I then called, I called a girl who had done the breast-feeding class at XX (different hospital) who had been really good” (mother of one, aged 32).*

This participant continued to breast-feed. Therefore, although some women were advised to stop breast-feeding due to having mastitis, they continued to breast-feed. They researched treatments on the internet or sought second opinions and came to the

decision themselves to keep breast-feeding. Some women received advice from family and friends to discontinue breast-feeding. This was the case for participant nine:

*“I was in so much pain for two and a half months so it did impact my breast-feeding but I think sheer determination got me through, the will to breast-feed and wanting to breast-feed my children because actually a lot of my friends said to me ‘just give him the bottle’ and I had loads of friends who said that to me, I even had relatives that said it to me ‘just go onto the bottle, why are you doing this to yourself’, I think you know that a lot of people think that if you have mastitis just stop breast-feeding. I knew, luckily I knew from the first time around that there is light at the end of the tunnel”* (mother of two, aged 36).

Lastly the table shows that where no advice given or mixed advice was given, it resulted in half the women stopping breast-feeding and half the women continuing. As seen previously, women did their own research and made a decision based on what they had read and knew.

Women consistently discussed wanting to know how to stop mastitis from recurring. A lot of women felt that although they had treated mastitis, they did not fully understand how to stop it happening again and this would have been useful. The following quote shows this:

*“No one really said anything about how to stop it happening again. Maybe there is nothing you can do but if there is anything that would reduce your chance then it would be useful to know that”* (mother of one, aged 35).

Therefore, improved advice about reducing the risk of recurrent mastitis was desired.

### **4.9.3 Support**

In some instances, mainly in those who were admitted to hospital from severe cases of mastitis, women felt like there was a lack of empathy and emotional support from healthcare professionals. Women described feeling very emotional and low due to having mastitis and felt like they needed more support from healthcare professionals. The following quote from participant eight, a mother of two, aged 31, demonstrates her experience of this:

*“The only time I felt that the specialists were all there and paying attention was when they came in all at once, and there happened to be ten of them and they were all men, it was really bizarre and they said ‘show me’ and I had to take off my shirt and I felt a little bit humiliated. They did their job well but it was sensitive and I don’t know if I was just hormonal because I was in tears. It was the first time I’d been separated from my son in four or five months.”*

Another participant reported:

*“I remember lying in the bed shivering and just being so ill from the flu feeling and I don’t think the nurses or midwives got how bad I felt. I was in tears a lot of the time and I don’t think they understood that was after I’d gone through two weeks of absolute hell and I had a tiny baby next to me and all those things, I don’t think there was a level of understanding of emotionally how bad it was. Maybe these are busy people are they have sicker people to look after and I am expecting too much. I felt the people who were caring for me in the middle of the night waking me up to give me medicine or coming in and I was shivering and sobbing, I felt they didn’t really understand and I perhaps needed someone to give me a hug and tell me they knew it was really tough” (mother of two, aged 39).*

A further quote below demonstrates how participants would have benefited from more emotional support:

*“That is the other thing they just kept saying ‘are you sure you have the latch, is he latching on properly, are you doing it right’. Actually that made me doubt myself and I thought ‘maybe I am doing something wrong’ and it is really tough, at one point I had a break-down and was thinking oh my god I am a failure, I can’t do this, what am I doing wrong’. You know ‘why is this still hurting, what am I not doing right” (mother of two, aged 36).*

More emotional support was needed to help women cope and improve their breast-feeding self-efficacy. As seen before, some of the women tried several avenues to get support if they felt like they were not receiving the right help. For example, participant two went to the internet, and then sought an independent consultant.

*“Babycentre.co.uk, umm and then when I was having a lot of trouble with it being painful I did in the end see a breast-feeding consultant independently. I had seen all the health visitors and I’d seen the breast-feeding women who did the breast-feeding session at NCT and nothing was helping basically, so I just thought at a last stitch attempt I will spill out £150 and have somebody come to the house and try and help”* (mother of one, aged 35).

This participant had experienced problems for eight months (including recurrent mastitis), and only after paying to see the consultant did her breast-feeding become a pain free experience.

The majority of participants received very good informal support, primarily from their families. For example, participant eight received practical support from her husband when she was in hospital and felt she needed help to ease the pain and engorgement from mastitis and he brought her in a breast pump:

*“It was actually it was quite lonely. They put me in a private room after a while and I remember thinking ‘ok what do I do next’. I had to call my husband to bring in my breast pump cos I was so engorged that I needed it”* (mother of two, aged 31).

Other participants described how supportive their family had been:

*“Definitely family were amazing, my husband and mum were amazing and they were just getting everything I needed and looking after her all the time and I just fed her and that was basically it. I think I was in bed for three days and felt awful for about a week”* (mother of two, aged 36).

Having informal support facilitated coping. All of the women were asked what support or advice they thought would be beneficial for women when they have mastitis. The majority of women said being more informed about mastitis before starting to breast-feed so that women could recognise the symptoms and get help and treatment quickly. A lot of women said organisations such as NCT that provide antenatal and breast-feeding courses are well placed to provide this information in a balanced way, as not to put women off breast-feeding.

## 4.10 Continued Breast-Feeding

### 4.10.1 Determination and Turning Point

Consistently women discussed being determined to continue breast-feeding. They said that all of the struggles and problems they experienced from breast-feeding and mastitis had made them feel more determined to persevere. The following quote by participant seven shows this:

*“It probably made me more dedicated to breast-feed and more keen to carry on as long as possible. I probably would have carried on anyway but I’d fought so hard, and it may not have been the mastitis it may have been the pain I had before but it is all wrapped into one thing. I fought long and hard and I was determined I wasn’t going to not breast-feed. So once I could do it and it became easy and lovely I appreciated it even more and carried on”* (mother of two, aged 39).

Two participants described feeling militant in the face of breast-feeding problems:

*“The mastitis and allergies and thrush were all around the same time. I had a bit of a hard time and by that point I was so like military that I was not going to stop, I wouldn’t stop”* (mother of one, aged 30).

Another participant reported:

*“After I had her I was militantly trying to breast-feed her because I struggled in the first couple of weeks and didn’t really want to give her the formula”* (mother of one, aged 32).

A quote by participant five shows her determination and breast-feeding journey:

*“I’ve really really enjoyed it overall but it wasn’t easy at first by a long way. I had a lot of difficulty at first but because I was so determined I just got on with it and got the support, I had a lot of support and advice from various sources. I feel I had a bit of a rollercoaster experience but overall I thought it was wonderful”* (mother of one, aged 37).

Although breast-feeding for the majority of participants included ups and downs and at times the women questioned whether or not they could continue, they felt like they reached a point where they ‘turned a corner’ and it suddenly became a lot easier. This

theme emerged as the data was collected and was added into the interview guide. The following quotes describe this 'turning point' women experienced:

*"It meant a lot to me at the beginning, it was really hard but I thought it is important to me to carry on. Someone said it does get easier and I just thought I will try and keep going and then eventually got easier and I was so glad I did. I turned a corner"* (mother of two, aged 31).

And:

*"I always thought that maybe tomorrow will be better. I found it very difficult to say 'right I'm not going to do this' and I thought surely this will have to improve at some point and by then I'd read a lot online and a lot of people had said they if you have trouble with breast-feeding then you do turn a corner at some point so I kept thinking maybe that is going to happen"* (mother of one, aged 35).

One woman compared her experience of breast-feeding to giving birth. She explained that there is a time limit to the pain experienced from giving birth, whereas with breast-feeding it is more ongoing:

*"At least with the birth you knew it was going to be over, tomorrow it will be over, but I think with breast-feeding it took a while for it to be enjoyable"* (mother of one, aged 30).

The experience of breast-feeding was discussed as being different from what women expected. It was for almost all of the participants it was a lot more difficult than they thought it would be, however became much more important than they could have ever perceived it to be. Participant three reflected on her breast-feeding experience:

*"I think it's more beautiful than I ever thought it would be. I think before your breasts are something, like I don't know, just something on your body, it's not connected to anyone or anything, but they have become something very different, something really amazing. You can produce milk to sustain another person's life"* (mother of twins, aged 31).

Breast-feeding often exceeded expectations. The following quotes also show this:

*“I don’t think I realised how important it was until he was born, but I desperately wanted to make it work when he was born”* (mother of one, aged 35).

Another mother stated:

*“As a whole having completed it something very positive but I had real horrors at the beginning with both of them, but my feeling of coming out the other side with both of them is that it is the most wonderful thing and I would do it all over again”* (mother of two, aged 39).

One of the reasons breast-feeding became more important was due to the closeness and bond they felt with their baby. The following quote shows this:

*“I think also I think most importantly it is the close bond you have with your child. It is a really lovely experience. I felt really linked with my children from breast-feeding”* (mother of two, aged 36).

Participant two explained her journey and the difficulties she experienced for a long time, and the corner she felt she turned and importance of bonding with her baby:

*“Because it wasn’t pain free for about eight months. It kind of got better during that period but for the first six months it was pretty much agony every time he started. It would get less painful once he got going but it really was a lot of pain, but once we got through that, the kind of eight months, the last four months I really really enjoyed. It was lovely and easy and bonding, a nice cuddle and all that. If it had been like that the whole 12 months then it would have been lovely. But I am glad we had that four months anyway!”* (Mother of one, aged 35)

## **4.11 Discontinued Breast-Feeding**

### **4.11.1 Negative Feelings**

The women that discontinued breast-feeding felt disappointed to have stopped. It was not something they had wanted to do, but due to getting mastitis, continued problems or the threat and fear of recurrent mastitis they felt they could not go on. Participant fifteen described her fear about getting recurrent mastitis for a fourth time which prompted her to discontinue breast-feeding:

*“It was a nightmare and at that point I was already thinking I can’t go a fourth time and I had already started slowly graduating to bottles because I thought I’m going to have to come off it. I didn’t want to do it quickly, at all speedily as obviously that can cause it to build-up again but I couldn’t do a fourth go so that was what prompted me to stop”* (mother of three, aged 37).

Other feelings women experienced when they had to stop included devastation and guilt, as shown in the following quote:

*“I was devastated when I had to stop. Yeah I just felt like at the time, especially with my first kid, I just felt like kind of like I was a bit let down. You know, like ‘oh no he’s not going to have my antibodies, he was get sick, he will just have formula’ I was just let down”* (mother of two, aged 31).

Women therefore had concerns about the negative health implications of not breast-feeding.

One woman described feeling selfish for stopping:

*“I never felt anything like it (mastitis). After that I think my view changed towards breast-feeding and I think I was just a bit like this is just a bit too much of a hassle, selfishly, then I started giving her formula and the breast-feeding stopped pretty quickly after that. I felt very guilty about it”* (mother of one, aged 33).

All the women in the study were very determined to breast-feed, including those who discontinued. In some instances they felt so determined to breast-feed that they continued as long as possible even though they had awful symptoms. They all felt passionately about breast-feeding but the women who discontinued had such bad mastitis or were so afraid that it would keep happening and they had other children to look after that they felt they could not go on with it. Women who discontinued experienced negative emotions, as breast-feeding had been something that was important to them.

#### **4.12 Reflective Practice**

Throughout this study I reflected on my own experiences and the influence they may have had on the design, data collection, and analysis. This was particularly important as the topic was something that I had personally experienced. I experienced mastitis and

was given incorrect healthcare professional advice to discontinue breast-feeding and this led me to research the topic. I found that mastitis and incorrect healthcare advice had been reported in the literature, however I was surprised by the lack of research into mastitis in general and in particular the literature regarding advice and support for mastitis, despite it being a common problem. This compelled me to conduct this study.

As previously highlighted, the sample was predominantly white British with a high level of education. The sample was recruited from NCT websites. I attended an NCT course which would have influenced me to recruit the sample from here. This may have led to a biased sample because people have to pay to attend the courses. However, I chose to recruit from these websites because the courses are open to anyone and there are discounts available to people who cannot afford the fees, and the NCT is the largest breast-feeding organisation in the UK. Although the sample was biased, researching this cohort of women uncovered some interesting findings. A lot of research into breast-feeding looks at women who are least likely to initiate breast-feeding and the sample in this study were the cohort most likely to initiate breast-feeding. Although they were most likely to initiate breast-feeding the findings showed these women needed more support to help them continue as this is what they would have liked to have done, which would in turn increase duration rates in line with the NHS guidelines.

I was very careful to try to minimise the impact my own experiences had on the data collection by continuously reflecting and remaining as unbiased as possible. However, some women asked me if I had had mastitis and if I had breast-fed. I did tell them that I had and I think this helped to form a trust and open conversation as they knew I had empathy for what they had experienced and understood how important it was to them. I really enjoyed conducting the interviews and was thankful to the women for their time and openness. Due to this I am very keen to publish my findings.

## **Discussion**

### **5.1 Overview**

The aim of this study was to explore women's experiences of breast-feeding and mastitis; the advice and support they received when they had it, and how this impacted on their decision to continue or discontinue breast-feeding. The evidence is well established that breast-feeding is beneficial for infants and mothers (Victoria et al., 2016). However, despite this knowledge and the national drive to promote it, rates

beyond six weeks are very low in the UK (Health and Social Care Information Centre, 2012). Mastitis has been reported to be one of the most common conditions breast-feeding women experience and a significant factor associated with discontinuation (Amir et al., 2007; Cleminson et al., 2015). This study has shown that there were clear factors that precipitated mastitis. With the right support these could have been treated or minimised and consequently reduced the risk of mastitis and improved breast-feeding experiences. Mastitis was a very bad experience for women, sometimes leading to them discontinuing breast-feeding even when they would have liked to have continued.

## **5.2 Conclusions of the Research Undertaken**

A main theme of this study was breast-feeding intentions. All the women in the study were well informed and educated about some of the positive aspects of breast-feeding and initiated breast-feeding. This finding is in line with existing research that has shown that intention to breast-feed is a strong predictor of breast-feeding initiation (Scott et al., 1999). However, the current research also showed that there was less known about the longer-term health benefits and bonding elements associated with breast-feeding that had an influence on their intentions. Highlighting these factors to prenatal women may increase their intentions to breast-feed. Furthermore, the current study found that although all the women intended to breast-feed and initiated breast-feeding, some then discontinued. Previous research has found that problems encountered post-birth can interfere with breast-feeding intentions (Odom et al., 2013). In accordance with this the current study found that post-birth problems such as mastitis led to breast-feeding discontinuation.

One of the most important findings reported in this study was that women often experienced problems early on that had a negative impact on breast-feeding. For example, initial problems surrounding babies' deliveries and health, such as not getting enough skin-to-skin contact or having a difficult delivery, were believed to initiate problems with breast-feeding. This has been found in existing literature in that traumatic childbirth and the first few hours post-delivery are important in establishing mother-infant interaction and successful breast-feeding (Beck & Watson, 2008; Prior et al., 2008) and emphasises the need for women to be able to hold their babies soon after delivery and to feel emotionally and physically supported. Further initial problems specifically with breast-feeding while women were still in the hospital were common. For example, women experienced latch difficulties, nipple damage, and pain. These

problems were often unexpected and resulted in them feeling upset and questioning why breast-feeding was not happening as naturally as they had expected it to. Previous research has shown that breast-feeding contributes to a mother's sense of identity and when breast-feeding expectations are not met; their sense of worth is damaged as they feel like they have failed (Williamson et al., 2012; Larsen et al., 2008). This was definitely the case in the present study. Women had expected breast-feeding to be natural and a lot easier than it was. When they encountered problems they felt stressed and upset. Women need to be prepared for problems that could potentially occur so that if they do, their expectations are not shattered.

The introduction of formula in hospitals was perceived to negatively impact breast-feeding. Women felt upset and emotional when their babies were given formula as it was something that they did not want to happen. Other related studies have shown that hospital staff giving babies supplementary feeds negatively impacts breast-feeding, has been linked to feelings of depression, and cessation of breast-feeding (Wright et al., 2006; Blixt et al., 2014; Astbury et al., 1994, Yngve & Sjöström, 2001). Women in this study felt a lack of control and inclusion in the decision making around this issue. Moreover, they felt confused by the healthcare professional advice and sometimes pressurised to feed their babies formula. Contradictory healthcare professional advice has been shown to have a negative impact on breast-feeding (Yngve & Sjöström, 2001). This emphasises the need for good communication and consistent healthcare professional support and advice. For example, if formula does need to be given to babies it is important to make sure parents understand why and that they are included in the decision making process. If formula is not completely necessary, it is equally important that parents feel it is their decision whether or not the baby has it and that they are supported to breast-feed (practically and emotionally), if this is what they choose to do. Existing literature has shown that improved healthcare professional communication and empathy empowers patients and positively influences patient satisfaction and coping (Asnani, 2009).

A lot of the women in the study did not receive the level of emotional and practical support from healthcare professionals while they were in hospital that they would have liked. Women discussed needing more practical support but also more emotional support during a time when they felt sensitive and vulnerable. They described feeling like healthcare professionals were too busy to help. These findings are consistent with

existing research that has shown that women's experiences of hospital care post-birth in the UK are generally poor (Beake et al., 2010). A lot of the initial breast-feeding problems women experienced may have been minimised with improved support. Specific support around latch problems, breast-feeding technique, and general discussion about the emotional impact of breast-feeding would have been beneficial. Maternity wards are notoriously busy and providing one-to-one care in this environment may be difficult. However, research has shown that healthcare professionals who have advanced training regarding lactation and breast-feeding are able to pass on their positive skills and attitudes pre and post birth to mothers (Wambach, 2005; Blixt et al., 2014). Providing good healthcare professional support early on that prepares and treats women for initial breast-feeding problems could reduce the need for healthcare professional resources later on when problems persist or get worse.

The current study found that women experienced a lot of problems post-discharge. Some of these problems persisted from the hospital, whereas others developed once women were discharged. The most common problems were latch problems, pain and extensive nipple damage. There was a mixture of healthcare professional support post-discharge for these problems. Some women had excellent healthcare professional support; often stating that they had a trusted healthcare professional they could rely on that really championed them. These women felt mostly supported, but the best support included both emotional and practical advice. Support lacking one of these elements was deemed less helpful. Women were very determined to breast-feed and sought help from a number of resources when they felt like their problems were not being addressed. They often paid to see private breast-feeding consultants and were in a position to do so. Women who are less determined or who have fewer resources may not be as able to seek additional support. This confirms the need for well-trained healthcare professionals who can provide support for women experiencing problems.

Self-efficacy played a central role in women believing in their ability to breast-feed. Research has found that self-efficacy is associated with continuation of breast-feeding (Brown, 2014b; Stajkovic & Luthans, 1998) and that women who have breast-fed before have been shown to be more likely to breast-feed as they know how to do it and have overcome difficulties (McInnes, Stone, & Love, 2001). The current study found that breast-feeding in public was difficult and embarrassing until women felt like they had become proficient at it. However, unlike previous literature, this study found that

regardless of whether women had breast-fed before when faced with breast-feeding problems (especially mastitis) they were as likely to discontinue. This demonstrates that all mothers who experience problems, regardless of whether they have breast-fed or not before, need support to improve their self-efficacy and so they feel they are able to continue to breast-feed if this is what they would like and able to do.

There was a perceived pressure to breast-feed. The findings from this study showed that the pressure women felt to breast-feed contributed to them feeling stressed and compelled to keep going. Research around this topic has found that women that breast-feed perceive more social pressure than those who bottle-feed (Swanson & Power, 2005). Furthermore, if women feel pressured by healthcare professionals to breast-feed but their family and friends are unsupportive of breast-feeding, they are more likely to discontinue (Cronin, 2003). The current findings showed that women felt a high level of social pressure to continue, as well as support from family and friends, and were therefore more likely to continue. However, women felt like healthcare professionals were not always supportive of breast-feeding (i.e. encouraging formula in the hospital and perceived lack of emotional support) which resulted in them feeling stressed as this was discordant with their social norms. The findings demonstrate three things. Firstly, national campaigns and societal pressure to breast-feed resulted in this demographic of women being more likely to continue. Secondly, women who are keen to breast-feed need to feel supported by healthcare professionals so that they do not feel conflicting feelings. Lastly, due to the high amount of pressure these women felt to breast-feed, when they were unable to continue they felt very guilty and upset.

Mastitis was a very bad experience for the majority of women, they found that it progressed quickly and the symptoms were very painful. It was often described as being the lowest point of their child-birth and breast-feeding experiences. Women discussed feeling extremely emotional and upset when they had it. These findings support the literature that has found that mastitis often results in women feeling emotional, distressed, anxious and helpless (Amir et al., 2007; Barbosa-Cesnik et al., 2003; Lumley & Amir, 2006). The main perceived causes of mastitis were engorgement, latch problems and being worn-out. These findings are consistent with the main identified and hypothesised causes of mastitis including milk stasis brought on by engorgement and an overabundant milk supply, cracked nipples, and stress and fatigue (WHO, 2000; Spencer, 2008; Vogel et al., 1999). Women frequently discussed their babies sleeping

for a longer than usual or expressing which led to engorgement and was perceived as interfering with their natural supply of milk.

Help-seeking behaviour was a main factor contributing to mastitis outcomes. Women who delayed help-seeking had worse outcomes than those who did not. Some women did not know that they had mastitis until their symptoms progressed, whilst others felt like they tried to get help unsuccessfully or delayed seeking-help because they felt so unwell and their symptoms progressed. Of these, a few were admitted to hospital as their condition had declined so much. Accessibility of healthcare professional support was an influential factor in health outcomes. Women that were able to get a general practitioner appointment quickly or were able to get a prescription without being seen found that their symptoms were treated faster than those who could not. It was a relief when general practices had fast-track systems in place. Conversely, women found it stressful when they could not be seen quickly. Those who did not physically have to go into the practice found this beneficial as they were feeling so unwell, especially if they had to take their baby with them. Some women tried other avenues to seek-help, such as midwifery services rather than their general practice. It is important that women know about mastitis symptoms and the need to seek-help quickly so that they can be treated as quickly as possible. In addition, knowing about what local resources are available (i.e. NHS or other breast-feeding specialists) is important.

Healthcare professionals have a significant role in providing clear treatment and advice that includes medical treatment, continued breast-feeding and self-care treatments, as stated in NICE's first line guidance for mastitis management in primary care (NICE, 2016). A proportion of the participants who sought help early were able to treat mastitis with self-care treatments such as continued breast-feeding and Paracetamol. However, the majority of women needed antibiotics, and once taken started to feel a lot better quickly. The best advice and treatment received was in line with NICE guidance yet, a lot of women felt like they would have liked more advice about self-care treatments and emotional support. There was a consistent theme surrounding concerns about taking antibiotics while breast-feeding in that they were worried about the impact taking antibiotics would have on their baby's stomach. Some women delayed taking antibiotics until they felt they really needed to. Ensuring women are well informed about the safety of antibiotics via patient-provider communication and providing information about

whether there is anything that can be done to reduce the negative side-effects of antibiotics (i.e. probiotics) is necessary. Further research exploring this is needed.

There was a perceived lack of support from healthcare professionals when women had mastitis. They felt like there was a lack of empathy during a time when they felt very upset and worn-out. Some women felt like they lost confidence because they felt like they were not able to breast-feed properly. A systematic review that included 31 studies exploring healthcare professional support interventions during pregnancy, at hospital, and the post-natal period found that mothers benefit from breast-feeding encouragement and support that increases their self-efficacy. In particular, it was found that it is important women were encouraged to feel empowered, capable and like good mothers. The review found that healthcare professionals need breast-feeding education to be able to provide good support (Hannula, Kaunonen, & Tarkka, 2008). There are no known interventions that specifically support women who have mastitis. More research is needed around this topic.

Women in the study predominantly had very good informal support, such as support from a husband or parent. Existing literature has found that informal support is fundamental in breast-feeding success. Studies have shown that women rely on family members rather than healthcare professionals for advice (Clifford & McIntyre, 2008), and those who have supportive friends and husbands are more likely to continue to breast-feed (Brown & Davies, 2014; Office of the Surgeon General, 2011). This study supports these findings in that the informal support women received was invaluable. For example, a lot of the women had a husband who took time off work when they had mastitis to support them or care for their infants and some did call friends and family if they wanted a second opinion or reassurance; however the current study found that women predominantly sought healthcare professional advice in the first instance. Women who do not have as much support may find it more difficult to cope when they have mastitis and be more likely to discontinue. The study also found that women often used the internet as a source of information and support. Research into the role of the internet for women experiencing breast-feeding problems such as mastitis should be considered.

The most common complication of mastitis reported in the literature is discontinuing breast-feeding (Spencer, 2008; Crepinsek et al., 2010). However, the current study found that most of the women who had mastitis continued to breast-feed, with women

stating that overcoming breast-feeding problems and sheer determination made breast-feeding all the more important to them. An Australian study explored characteristics of women that empower them to continue to breast-feed, despite experiencing extraordinary problems (including recurrent mastitis), included determination, flexibility, optimism and perseverance (Hegney, Fallon, & O'Brien, 2008). Interventions aimed at enhancing these characteristics may support breast-feeding continuation when women experience mastitis.

In the current study women consistently felt like there was a turning-point with breast-feeding when things became a lot easier. For some this was known about beforehand and was a goal they hoped they would reach, but for most it was something they only knew about from experiencing it. Reaching this turning point was strongly influenced by getting the right breast-feeding technique. Knowing there is a turning-point for a lot of women may help to encourage breast-feeding continuation in women who are experiencing difficulties. This needs to be explored.

One of the main reasons women discontinued breast-feeding was the fear of recurrent mastitis. Women who had recurrent mastitis had it in one infant, or in subsequent infants. Some did not know how to stop it happening or what caused it and others felt like they knew from past experience how to stop them progressing. For example, they continued breast-feeding and used massage to stop blockages and consequently stopped it progressing. Some women had several courses of antibiotics before they stopped getting it. Those who discontinued breast-feeding due to recurrent mastitis were unable to prevent it escalating and felt like it was something that would keep happening and they were afraid of. Some of these women had other children to look after and found it too debilitating to have mastitis and looking after their children. Healthcare professional advice needs to adhere to NICE (2016) guidance that states reducing mastitis recurrence via improved breast-feeding technique, not using a dummy, exclusive breast-feeding for four to six months, and techniques to avoid milk stasis. Training healthcare professionals in NICE guidance would be recommended as well as more research into understanding if there are preventative measures that can be taken that stop it escalating.

Women who discontinued breast-feeding felt negative about stopping as it had been something they had not wanted to do. Women described feeling guilty, devastated, disappointed, and selfish for stopping. These findings concur with existing literature that found that although women who bottle-fed were well informed about the benefits of

breast-feeding they found the pressure too much and had negative emotions of guilt, anger, uncertainty and a sense of failure (Lakshman, Ogilvie, & Ong, 2009). According to a UNICEF report, in the UK 90% of women who stop breast-feeding within the first six weeks do so before they would have liked to (Renfrew et al., 2012a). Therefore, there is a large cohort of women in the UK who discontinue breast-feeding before they want to, and with the right support they may be able to continue for a lot longer and have better breast-feeding experiences. Given initiation rates for breast-feeding have improved in the UK over the last 20 years but duration rates are particularly poor (Oakley et al., 2013; UNICEF, 2012), this highlights the need for better support for continuation.

Lastly, women were asked to reflect on their breast-feeding experiences. Overall it was described as being a journey, with lots of ups and downs. For those who were able to continue to breast-feed, they reflected on it as exceeding all their expectations. This was primarily due to the close bonding they had with their infants and for those who discontinued, they felt disappointed. Supporting women who intend to breast-feed achieve this goal will lead to improved health and psychological outcomes.

### **5.3 Limitations of the Study**

This study has raised important issues that are related to breast-feeding and mastitis. However, limitations exist relative to the sampling procedures and researcher bias. Firstly, the sample procedure involved recruiting breast-feeding women who had experienced mastitis from NCT Facebook Central and West London websites. Women often use these websites to support one another and the majority of the women who participated had bad experiences of mastitis. It is possible that women who had bad experiences were more likely to use these websites for support and information, and consequently more likely to participate. Thus, there is a risk of self-selection bias. The second issue relating to the sampling procedures was that women who attend NCT courses have to pay to go on them. There are two payment options, one is a reduced cost for people who have low incomes or who receive benefits and the second is the full price option. Therefore, it is probable that women and couples who attend NCT courses have more resources than those who could not afford to go on them. The NCT websites that were used to recruit participants are open to anyone, regardless of whether they have been on an NCT course or not. However, it is more likely women who knew about the courses and attended them will utilise the websites.

A further limitation of the present study relates to the recruitment of participants using snowball sampling. A lot of in-depth information was required to form the grounded theories and develop an overall view of women's experiences of breast-feeding and mastitis. Although it was not deliberate, women introduced other women to participate which resulted in snowball sampling. In one respect this is a way of accessing groups of people who are willing to participate and speak openly (Noy, 2008). However, this recruitment method can result in participants having similar behaviours and attitudes and the research may be prone to bias as the sample is not very diverse (Wilmot, 2009). The majority of the women in this study were white British, highly educated (most having a degree or higher degree), and relatively older mothers. These women represent the demographic of women more likely to breast-feed. Although this was a limitation, a lot of existing research has focused on women who are less likely to initiate breast-feeding; whereas this study has uncovered interesting findings that relate to those who have problems with duration when they intended to breast-feed.

The final limitation identified relates to researcher bias. It is inevitable that some degree of researcher bias occurs within qualitative research. This is highlighted in a constructivist grounded theory approach (Charmaz, 2008) and strategies were incorporated in the present study that aimed to minimise researcher bias (Noble & Smith, 2015). These included reflexivity and the reflection and triangulation. Reflexivity ensured that the researcher was aware of their own perspective and could reflect on this to remain as unbiased as possible. This was important as the topic was something experienced by the researcher as was disclosed by the researcher. However, it has been found that researchers can have an empathic understanding from their own experiences and knowledge which fosters engagement and may lead to a deeper understanding (Stiles, 1993). Triangulation was also used to validate the data by gaining the perspectives of different people, such as a health psychologist's. Triangulation adds credibility to research by providing different views on the same data (Al-Busaidi, 2008).

#### **5.4 Implications for Clinical Practice**

Women need to be prepared for problems that could potentially occur so that if they do, their expectations are not shattered. The provision of breast-feeding information pre-and-post birth which accurately reflects the breastfeeding experience may help set women's expectations. It is important this information is carefully relayed, as not to put women off breast-feeding. Understanding that breast-feeding is a skill that often

encompasses both ups and downs may reduce the pressure women put on themselves when they feel like they are failing because it is not going as well as they expected it to. Improved support, communication, and advice with breast-feeding while women are in hospitals and post-discharge would reduce the risk of problems occurring and persisting, and potentially reduce the risk of mastitis developing. There needs to be investment in breast-feeding training for healthcare professionals. During a time when NHS funding is scarce this is not easy, however investing to prevent problems will reduce the risk of greater expenditure later on when breast-feeding related problems escalate. Reductions in health problems and economic savings, such as a reduced rate of NHS hospital admissions and savings from manufacturing and transportation of formula (Rollins et al., 2016), could be made investing in training and interventions that support both continuation and initiation of breast-feeding.

Early diagnosis and treatment of mastitis is also very important. This confirms the need for accurate information for women, including mastitis related information, so that they are aware of symptoms and know what to do. Access to healthcare professional support is also very important so women can be treated quickly. Potentially, having a list of resources (i.e. local NHS breast-feeding services) that are available would be beneficial. Furthermore, good patient-provider communication is instrumental in improving breast-feeding experiences. Post-natal women may be worn-out and emotional and therefore need to be communicated to sensitively and empathically so they feel supported and that their needs are being met. This will help to treat problems effectively and prevent issues escalating. Training around this issue is recommended.

Healthcare professionals need to know and follow guidelines such as NICE when treating and advising women with mastitis and recurrent mastitis. This includes continuation of breast-feeding, ensuring symptoms are addressed with medical and self-care treatments, and that they feel emotionally supported. It is important women's concerns can be addressed, such as those surrounding taking antibiotics. It is also important that healthcare professionals give the right advice that is to continue to breast-feed which has been highlighted as an ongoing issue. Adhering to NICE guidelines will result in mothers receiving the right and consistent advice. Furthermore, it will result in more mothers continuing to breast-feed and having a better experience of breast-feeding, which in turn will increase the UK's breast-feeding duration rates which are among the lowest in the world (Health and Social Care Information Centre, 2012).

## 5.5 Future Research

This study did not explore healthcare professionals perceptions and experiences of breast-feeding and mastitis. Specifically understanding their knowledge of NICE guidelines and facilitators and barriers to implementing them would be useful. Gaining healthcare professional perspectives would lead to increased knowledge that could contribute towards improved support for women that could help them to continue to breast-feed if this is what they are willing and able to do. Conducting research in areas of low incidence of breast-feeding in the UK would give a very different perspective on the topic. Women in the current study all intended to breast-feed and fitted the demographic most likely to breast-feed. Gaining insight into women's perspectives who are less inclined or supported to breast-feed is important because when they face difficulties such as mastitis, they may feel less able to continue. Understanding the impact of ethnicity on mastitis and breast-feeding is also an area warranting further research. It is also important that women who cannot continue to breast-feed are supported emotionally. There will be cases where women cannot continue and their expectations are not met. These women often feel very negative about discontinuing and need support and research into how to cope with this is needed.

In addition, more research is needed to extend our knowledge of the impact of taking antibiotics for mastitis. This may uncover whether this is an influential factor in women discontinuing breast-feeding and how to overcome such worries. Lastly, there needs to be more information about recurrent mastitis. This is an area that is under-researched and could help to reduce the risk of women getting it over and over, and consequently discontinuing.

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## Appendix 1

### Study Flyer



### Exploring Women's Experiences of Mastitis

I am conducting a research study that is looking to explore women's experiences of mastitis. Up to 33% of breast-feeding mums get mastitis. It can be very painful and exhausting and can leave one feeling stressed and tired. I am interested to understand your individual experiences, and the support you felt you received.

- Have you had mastitis from breast-feeding within the last 8 months?
- Are you aged 18 or older?

If you answered yes to both the above questions and you are interested in talking about your experiences and helping to provide invaluable insight into the topic, please do not hesitate to contact me to discuss the project in more detail.

Thank you,  
Beatrice Chapman  
Email - [REDACTED]  
Tel - [REDACTED]

## Appendix 2



**CITY UNIVERSITY  
LONDON**

**School of Community and Health Sciences**

### **PARTICIPANT INFORMATION SHEET**

**Title of Project** Exploring women's experiences of mastitis and the impact of formal and informal support: a qualitative study.

(Project ID: )

#### **Introduction**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

**Researcher:** Beatrice Chapman

Department of Psychology,  
Whiskin Street,  
London,  
EC1R 0JD

Email: [REDACTED]

Tel: [REDACTED]

#### **Project Supervisors**

Dr Triece Turnbull  
Co-director of DPPsych in Health Psychology and Visiting Lecturer

Email: [REDACTED]

Tel: [REDACTED]

#### **What is the purpose of the study?**

The study is an exploratory piece of work which is seeking to explore women's experiences of mastitis. The study is also seeking to understand the support women received from health care professionals and other people such as family, and what impact this had on their breast-feeding practices.

No specific prior knowledge of the subject area is required or expected.



### **What are the Risks and Benefits?**

It is anticipated that there should be no risk involved to your well-being during or after completion of this study.

The benefits of this research are to provide some useful insight in relation to breast-feeding and the support women need when they have mastitis. Understanding how best to support women during mastitis is very important and will help them to make the most informed decisions that is right for them with regard to breast-feeding.

### **How do I take part?**

If you would like to take part, you will be asked a series of questions by the researcher (Beatrice Chapman). The questioning will be performed face-to-face at a time and place to suit you.

### **Can I Refuse or Withdraw?**

You may decide not to participate in this study. Alternatively, if you do decide to participate in this study you may withdraw at any time without penalty. In the event of withdrawal, all data pertaining to you will be destroyed.

### **How long will it take?**

The interview, should take no longer than one hour at the most. You can at any stage, have a break, stop the interview completely, or not answer any particular questions you are not happy to, without prejudice.

### **How will the answers be recorded?**

The interview will be recorded via a Dictaphone. This allows the researcher to go over the data thoroughly during the analysis stage.

### **How will the data be stored?**

If you consent to take part in this research, we will follow ethical and legal practice and all information about you will be handled in confidence. Your answers to the interview questions will be audio-recorded so that they can be listened to again for analysis but all data will be stored anonymously and no comment will ever be made attributable to you as an individual.

City University will overview the collection, storage and handling of the data, analysis and dissemination of results. Beatrice Chapman, will be responsible for security and access to the data. Only study investigators (named above) will have access to the data. The information collected during the study, with exception of your name, will be stored and analysed confidentially in a secure locked computer. No identifiers on the data held by computer will enable a third party to link the data to you. All data will be kept strictly confidential and secured under lock and key or behind secure firewalls electronically in City University. The data will be stored for 10 years after the study has been completed. The results of this study may be published within the psychology, medical, public health and social care literature, however, no personal details will be revealed. Copies of the publications will be available to you from the researchers. A report of the findings of the research will be sent to all interested participants in approximately 1 year from the start of the study.

### **Ethics Committee Review**

All proposals for research using human subjects are reviewed by an ethics committee before they can proceed. This proposal was reviewed and approved by the City University Ethics Committee (Reference Number: **xxxxxx**).

If you have any queries regarding the project, you can contact me, Beatrice Chapman on telephone number- **██████████**, or by email at **██████████**.  
You may keep this information sheet and will be given a copy of the consent form you sign when agreeing to take part in the study.

**Thank you for taking the time to consider taking part in this study. Your time and contribution are invaluable.**



CONSENT FORM

Title of Project Exploring women’s experiences of mastitis and the impact of formal and informal support: a qualitative study. (Project ID: )

Lead Researcher: Beatrice Chapman Research Co-ordinators: Dr Triece Turnbull

- 1 I confirm that I have read and understand the information sheet dated for the above study and have had the opportunity to ask questions.
2 I confirm that I have had sufficient time to consider whether or not to be included in the study.
3 I understand my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
4 I understand that what I say during the interview is to be recorded and to be electronically stored, in concordance with the Data Protection Act 1992.
5 I understand that my identity will remain anonymous throughout the study, and in any further reports that may consequently be written.
6 I agree to take part in the above study.

Name of Participant Signature Date

Name of Person taking consent Signature Date

Name of Investigator Signature Date

Participant Identification for trial:



## Appendix 4

### Demographic Questionnaire

1) What year were you born?

2) Which of the following best describes your current relationship status?

- a. Married
- b. In a domestic partnership or civil union
- c. Widowed
- d. Divorced
- e. Separated
- f. Single
- g. Other (please specify)

3) Which of the following qualifications do you have?

- a. No Qualifications
- b. O levels
- c. A levels
- d. First Degree
- e. Higher Degree

4) Please describe your occupation

5) What is your ethnic group? Choose one option that best describes your ethnic group or background

- a. White
  - 1. British (English/Scottish/N. Irish)
  - 2. Irish
  - 3. Gypsy or Irish Traveller
- b. Mixed/Multiple ethnic groups
  - i. 5. White and Black Caribbean
  - 6. White and Black African
  - 7. White and Asian
- c. Asian/Asian British
  - 9. Indian
  - 10. Pakistani
  - 11. Bangladeshi
  - 12. Chinese

- d. Black/ African/Caribbean/Black British
- e. 14. African  
15. Caribbean
- f. Other ethnic group (please describe)

- 6) What London or Greater London borough do you live in?

- 7) Was this your first child/children?

- a. Yes
- b. No

- i. How many children do you have?

## **Appendix 5**

### **Semi-Structured Interview Guide**

The research will involve semi-structured interviews with approximately 25 women who have had mastitis across central and west London. The interview schedule outlines the main themes that will be discussed. These main themes include: women's experiences of breast-feeding and having mastitis; what support (formal or informal support) was available to them and how this impacted on their decision to continue or discontinue breastfeeding.

#### **Screening Questions**

1. During the past month, have you often been bothered by feeling down, depressed or hopeless?
2. During the past month, have you often taken little or no pleasure in doing things that would normally make you happy?

#### **Opening Questions**

3. How old is your baby?
4. How did you feel about breast-feeding before you had your baby?
5. Why did you decide to breast-feed in the first place?
  - a. Probe: was it something that was important to you and why/why not?
6. How long had you thought you might like to breast-feed for before you started?
  - a. Probe: did this change once you started breast-feeding?
  - b. Probe: if so, why?
7. Are you breast-feeding now?
8. What has been your experience of breast-feeding?
  - a. Probe: was/has it been a positive experience, or something you felt you struggled with?
  - b. Probe: what have been/were some of the positive and negatives of breast-feeding for you?

#### **Mastitis**

9. What did you know about mastitis before you had it?

- a. Probe: did you know what it was?
  - b. Probe: did you know why it happens?
  - c. Probe: what did you know about the symptoms?
  - d. Probe: what did you know about how it is treated?
10. Did you know anyone that had had mastitis?
- a. Probe: what was their experience?
11. When did you have mastitis?
12. Could you explain your experience of having mastitis?
- a. Probe: how did you feel when you had it?
  - b. Probe: how did you feel physically?
  - c. Probe: how did you feel emotionally?
13. What did you do when you had it?
- a. Probe: how did you know what it was?
  - b. Probe: did you go to the GP, phone a friend, and/or search the internet?

### **Formal and Informal Support and Subsequent Breast-Feeding Decisions**

14. How was it diagnosed?
15. When you had mastitis who do you feel provided support to you and what impact did this have on how you felt?
- a. Probe: what support did healthcare professionals provide?
  - b. Probe: what support did family members provide?
  - c. Probe: what support did friends provide?
  - d. Probe: did you have any other support networks? (I.e. online forums)
16. What advice were you given with regard to continuing or discontinuing breast-feeding?
- a. Probe: what advice did the healthcare professionals give you?
  - b. Probe: was it clear?
17. Who gave you advice that you felt resonated the most with you?
18. Did you feel you were given the support that you needed?
19. Thinking now of your experience of mastitis, to what extent did mastitis impact on your breast-feeding, if at all?
- a. Probe: did you continue or discontinue breast-feeding?
  - b. Probe: how did you feel about this?
20. What support do you think would be beneficial when women have mastitis?

## **Appendix 6**

### **Interview Guide List of Additional Questions**

1. How did you feel about taking antibiotics?
2. How was breast-feeding at the beginning for you?
3. Did you experience any issues with breast-feeding while you were in the hospital?
  - a. If so, what were these?
4. Some women have said they felt like they turned a corner with breast-feeding. What has been your experience of this?
5. How were your experiences of mastitis different with different children? (For those who have multiple children)

## **Appendix 7**

### **Debrief Form**

#### **Exploring women's experiences of mastitis and the impact of formal and informal support: a qualitative study**

Thank you for taking part in this research project. This project aims to explore women's experiences of mastitis and the support and advice they received and the influence this had on continuing or discontinuing breast-feeding.

Mastitis is a condition that occurs in breast-feeding women. It is an inflammation of the breast that can be accompanied by infection and results in breast pain, swelling, warmth, redness and often fever and chills. It can leave women feeling exhausted and tired and in a lot of pain. It is caused by a build-up of milk within the breast associated with poor breast-feeding technique, stress, and incomplete emptying of the breast.

It has been estimated that up to 33% of women get mastitis. Mastitis must be treated promptly and adequately. The World Health Organisation state that women often get conflicting advice from healthcare professionals and often they are advised to stop breast-feeding or given no guidance either way. This can leave women confused and anxious and unsure to continue breast-feeding.

The aim of this study was to therefore understand women's experiences of mastitis and what support they felt they received.

The data that has being collected as a result of your participation will be held confidentially. If you feel that you would like to withdraw your data from the study, you may do so at any point and without explanation.

If you would like to discuss the project and the findings of the study in more detail, please do not hesitate to contact me.

Beatrice Chapman

Email - [REDACTED]

Tel - [REDACTED]

## Appendix 8

### Example of Open Coding

Interview Data (EXTRACT)	Open Coding
I – How old are your babies?	
P – They are five months now.	Five months old
I - How did you feel about breast-feeding before you had your babies?	
P – How did I feel about it? I really wanted to do it. I spose based on that it is the best for the child; I don't see the point in giving formula when you can create the milk yourself, for money purposes and bonding purposes. It is nice for them to be close to you. Even though I knew it was a possibility with twins I might not be able to breast-feed, cos there's two, I thought I'd try and see how it goes. But yeah, I was very determined to do it.	Very keen to breast-feed Best for child Natural Financially free Bonding Felt very determined Was realistic as had twins that might not be easy
I – How do you manage with twins?	
P – At the beginning it was insane! A lot of support from my husband because at the beginning a lot of the time I'd feed them together to save time. I'd have like a big pillow and have one on each side. Because it is so time consuming, you know yourself at the beginning it takes half an hour or twenty minutes each feed and then you start the next one and then you are starting the next one again. Now it is easy, they both eat within seven or eight minutes each quickly and then take a good feed, they are gaining weight, it is all good.	Difficult at the beginning Very supported from husband Time consuming Gets easier
I – Yeah they look like they are a good weight.	
P – I am aiming to get them to six months to wean them, when you start the food, but I will see with jobs etcetera, but I am determined to keep going as long as I can.	Will keep breast-feed until weaning Work might interfere Determination
I – Ok great, and you were saying it was something that was very important to you to be able to breast-feed, was this mainly due to the health benefits to them and the bonding .....	
P – Yeah the health benefits, the bonding, I spose and there is no reason not to, it is the natural thing to do.	Natural thing to do Bonding Health Obvious choice
I – And how long, before you had them, did you think you might breast-feed for?	
P – I spose I didn't have any expectations. It's hard before you have a child you don't know what you are in for, I think as long as possible, I didn't have a specific time, I think as long as possible, as long as I could.	No expectations of how long Not as expected Hoped to breast-feed as long as possible
I – Ok so see how it went?	

P – I didn't want to be a crazy like three, four years person like my husband's sister, I knew I didn't want to do that, but a reasonable amount of time.	Reasonable amount of time
I – And how did this change at all once you started?	
P – Yeah cos you realise how hard it is and the strain on your body, the calories I have to intake to sustain what is going out and the water.	Hard on own body Have to eat and drink a lot
I – Yeah it makes you thirsty all the time.	
P – Yes I must have a drink now (goes off to get water). Sorry what was the question again?	
I – Whether it had changed once you started?	
P – Yeah sometimes I feel like quitting, believe me. But no, I realise why I'm doing it and I want to. I spose they didn't really change. They changed a bit but I still committed to doing it.	Felt like quitting at times but the pros outweigh the cons Commitment
I – And there are good days and bad days.	
P – Yeah exactly.	
I – What has been your experience of breast-feeding? You were saying it's been challenging at times...	
P – I think it's more beautiful than I ever thought it would be. I think before your breasts are something , like I don't know, just something on your body, it's not connected to anyone or anything, but they have become something very different, something really amazing. You can produce milk to sustain another person's life.	Beautiful experience Female body and bonding Has loved experience To sustain another's life
I – And what would you say have been some of the negatives attached to it?	
P – I spose when I got an infection this was horrible. I spose my breasts have changed shape, definitely, for sure, I used to have no boobs whatsoever, so now they are really big and droopy. And they are never going to be the same, I know that. So that is quite negative. But I spose that is just society's negativity towards breasts....	Negatives – physical changes to breast Mastitis Societal pressure/perception of breasts
I – Yeah and if you think about what they have gone through...	
P – Yeah and that is actually what happens in life. My mum always had big droopy boobs, and that's probably because she fed us. You know, it is interesting.	Part of life Mother breast-fed
I – Thank god for bras!	
P – Yeah. (Both laughing). But negatives, hmm no I'd say there are probably more positives.	More positives definitely
I – Ok great it kind of all worked smoothly.	
P – Initially there was the pain with the latch, but only a few days.	Pain for a few days with latch
I – Now talking about mastitis, had you heard of it before you had it?	

P – Well, interesting... I'm not sure. Probably. I'm not sure you know. Had I heard of it? I would have definitely read about it. I would, I would have read about it for sure, but maybe not before I was pregnant. I would have heard about it before I had it. For sure.	Had heard of it
I – So did you know what it was?	
P – Yeah. Yeah cos I knew what was happening when I had it. So I did have knowledge about it.	Knew what it was Had knowledge
I – Ok, and so did you know about the symptoms, why people got it, treatment... ?	
P – Yeah I spose I did.	Had some knowledge
I – Did you know anyone else that had had it?	
P – Once I had it I knew people who had had it. I had a blocked duct before, and then a week or so after I then had mastitis. So the blocked duct I think I then started to speak to people because I knew I had to clear it otherwise I would get mastitis. And then I got mastitis.	Once had it heard people who had it Believed blocked duct caused it
I – From the blocked duct....	
P – No, from another thing, it was the other side. I got it because XX slept like five or six hours during the day one day and I left it, and he (other baby) was awake and I kept feeding him off the same breast to save this one for her (breast's milk), so I thought 'ok I want her to have a nice feed, I don't want him to drink all the milk. And then cos I left it too long, I then got a blockage. I think it was a classic mistake. Especially at the beginning, it is very different at the beginning, how the milk regulates itself.	Got it from build-up of milk from baby sleeping longer Interfered with natural regulation of milk

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## **SECTION C: PUBLICATIONS**

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# **A Qualitative Investigation into Healthcare Professional's Perceptions of Inappropriate Use of Accident and Emergency Services**

**Beatrice Chapman and Tiece Turnbull**

**British Journal of Nursing, 2016, Vol 25, No 8**

## **Abstract**

**Objective:** The aim of the study was to investigate healthcare professionals' perceptions of the inappropriate use of accident and emergency services.

**Method:** Qualitative methods were used to interview nine hospital staff as part of this exploratory study.

**Results:** Six main themes emerged from the data: (1) convenience, (2) lack of patient knowledge and help-seeking behaviour, (3) Lack of knowledge of local services amongst health and social care professionals, (4) long-term conditions, (5) parents with small children, and (6) the Nepalese community.

**Conclusion:** Further research is needed to understand what drives service-users behaviour to inappropriately use accident and emergency services for non-urgent treatment.

## **Keywords**

National Health Service, healthcare professionals, accident and emergency, treatment

## **Original paper**

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## **Implementation of Guidelines: An Online Survey for the Department of Health Respiratory Team**

Health care guidelines and tools exist to help professionals make optimal decisions about treatment or care for specific conditions and situations. They are usually written by experts in the field, such as National Institute for Health and Care Excellence (NICE), professional bodies, research charities or the Department of Health (DH). It is essential that guidelines are implemented properly to improve health care services, professional practice and above all patient outcomes. However, guidelines are not always implemented well and failure to do so can have negative consequences (Francke, Smit, de Veer, & Mistiaen, 2008). A wide variety of interventions and research have been conducted by health psychologists to improve health care services (Michie & Abraham, 2004). This includes research into implementation of guidelines, which is an interesting and growing area that health psychologists can work within. For example, health psychologists are well placed given their broad range of skills, such as consultancy, research, training, and clinical skills to work with organisations such as the department of health to understand whether the guidelines they develop are implemented at a local level.

Psychological theories such as the theory of planned behaviour ([TPB] Ajzen, 1991) can be used to understand factors that influence implementation of guidelines. Constructs of the TPB explain processes that govern people's decisions and behaviours (Michie & Abraham, 2004). For example implementation or lack of implementation of guidelines can be influenced by knowledge or awareness of a guideline, perceived behavioural control over using it such as having the resources (e.g. staff time) to implement it, and subjective norms such as organisational support for implementing it. For instance, an audit of NICE guidance found that guidelines were more likely to be adopted if there was strong professional support (Sheldon, Cullum, Dawson, Lankshear, Lowson, et al., 2004). Understanding these factors that influence intentions and behaviours will help to encourage positive behaviour change.

The department of health respiratory programme has been responsible for producing a suite of guidance, tools, and resources aimed at improving outcomes and services for people with respiratory disease. These include the Outcomes Strategy for chronic obstructive pulmonary disease (COPD) and asthma (DH, July 2011) and the Respiratory

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## **Making the Most of Our Unique Skill Set:**

### **Beatrice Chapman Talks to Health Psychologist Vanessa Bogle**

Dr Vanessa Bogle is an experienced health psychologist who has worked in a range of applied roles. She works on a part-time basis as a Senior Public Health Strategist within a Public Health Department located within a London-based local authority. She has over 13 years of NHS experience. She is also currently the Acting Programme Director of the Health Psychology Doctorate at City University London. In addition, she is a member of the Motivational Interviewing Network of Trainers (MINT) and regularly designs and delivers Motivational Interviewing and behaviour change skills training to a range of health professionals and students.

As a psychology doctoral student at City University London and a trainee health psychologist and research/project manager for a private healthcare company, I was particularly interested in the role of health psychologists in applied settings. So I wanted to ask Dr Bogle to share her thoughts on her varied career and experience.

*Tell me about your experience working as a public health strategist?*

Within my role as Senior Public Health Strategist I provide expert psychological advice and leadership on behaviour change interventions and training. Examples include the commissioning of behaviour change interventions, for example, social marketing, Health Trainer/Champion services and physical activity programmes, which often involve developing new service models. I am also responsible for the development of the infrastructure to support the delivery of the NHS Health Check programme, a national programme which aims to prevent cardiovascular disease (CVD) amongst people aged 40-74 years. My key areas of work include men's health, obesity, physical activity, cancer prevention and brief intervention training.

Health psychology is very much ingrained in the work of health trainers and the national core training was developed in collaboration with a team of health psychologists. Further examples of work include conducting an evaluation of the NHS Health Check programme and developing service models to increase physical activity levels amongst sedentary populations. On an on-going basis I deliver Motivational Interviewing training to a range of health care professionals to support the delivery of

the NHS Health Checks programme. Those eligible for a health check, irrespective of their risk of CVD, should receive a brief intervention to support health behaviour change. The training is designed to enhance the quality of the interventions delivered.

*You are saying this is very much a health psychology role, however your title at work is not Health Psychologist?*

Yes. Although my title does not reflect that I am a health psychologist, I use my skills and knowledge in applying health psychology theory and evidence to address major public health concerns, such as obesity and physical activity and to address health inequalities. This contributes towards changing and understanding health behaviours and in developing more effective interventions and services.

One of my key areas of work is physical activity. I sat on physical activity steering group where we were looking to develop a physical activity care pathway. The initiation and complexities of behaviour change was over-looked and simplified so with my health psychology expertise I was well placed to support this piece of work. I introduced motivational interviewing as an approach to facilitate behaviour change and as a result underpins the approach used within the physical activity care pathway, namely 'Let's Get Moving'. I delivered the motivational interviewing and physical activity promotion training for health care professionals for the London pilot, which supports health professionals to deliver physical activity brief interventions.

*Have you got any examples of any novel projects you have used your health promotion skills in?*

It is necessary to use targeted approaches in health promotion, as we know that one size does not fit all. There is the need to use theory and evidence-base when delivering health promotion. However, I strongly feel that we should be innovative and creative and think outside the box, particularly if we want to engage with clients who tend not to utilise health care services. For example, we know men use healthcare services less frequently than women and tend to present late with symptoms of ill-health, or when disease has progressed which can negatively influence health outcomes. Having reviewed the evidence for using the performing arts as a vehicle for health promotion, for the past few years I had been looking for an opportunity to use this approach. An opportunity arose in June 2013 in my role within public to address the men's health agenda. I developed an initiative aimed at black African Caribbean men aged 40+ living

in the deprived area of a London borough that was run during national Men's Health Week.

The rationale for targeting this population was that black men are 3 times more likely to develop prostate cancer, and due to ethnicity are at increased risk of developing certain long-term conditions, such as diabetes, stroke and hypertension. The event named the 'Men's Comedy Health Check' used comedy as the vehicle to raise awareness about serious health issues. The line-up included a BBC Radio London presenter (cancer survivor), a four-time Olympian, a prostate cancer specialist nurse from Prostate Cancer UK, and a range of stand-up comedians who were very credible with the target audience. A well-known DJ and some high profile singers also helped to attract the target audience. The aim was to raise difficult topics and to challenge hegemonic masculinity, for example, erectile dysfunction and linking it to health behaviours such as healthy eating, physical activity and drinking alcohol in excess. The use of comedy was effective in delivering these messages in a way that may be more challenging using a traditional approach such as leaflets. The event sold out and as a result additional seating was added which then sold out for a second time. It was a somewhat risky project as it was not scripted. I gave the cast key messages that I wanted to be communicated which they delivered 'free style'.

The feedback from the audience was extremely positive.

"The message needs to be sugar-coated otherwise men won't listen. The comedy provided the sugar".

"First and foremost it was comedy and entertainment throughout. The health message was loud and clear but you were not being preached to – the delivery was comfortable".

Due to the success of the first event I put on a further event independently in November (during 'Movember' month), which also sold out. The event was video recorded and was evaluated using three methods (1) direct observation, (2) questionnaires and (3) semi-structured interviews.

*Do you think there are many other health psychologists in roles such as yours?*

No. However, I believe that health psychologists are very well placed to offer skills to compliment and support public health, given that much morbidity and mortality associated with long-term conditions have a behavioural aetiology. It is important for

health psychologists to promote the discipline and our unique skill set so that potential employers understand what we do and what we have to offer.

*One of the things people might not realise, especially those who are looking for jobs in applied settings, is that you might need to look for jobs that are not necessarily advertised as Health Psychologist posts.*

Absolutely! I always encourage trainee health psychologists who are coming to the end of their training to look beyond the title because if they just search for jobs solely using the term 'health psychologist' they are few and far between and may be disappointed. Look at the job description/specification and if you meet the competencies apply for those roles. It is really about health psychologists broadening their minds and thinking about their skill set and competence and then looking for jobs. You might need to spell out to potential employers what you can bring that is over and above other applicants. Our skill set is unique!

*Do you think there is more that can be done to inform up-and-coming psychologists of the opportunities that are out there?*

A lot of health psychologists naturally enter into teaching and research positions, which is obviously important. However, I think it is also important to highlight applied areas that health psychologists can work in as there are many opportunities out there.

*How do you see health psychology developing in the next five to ten years?*

Given the rise in long-term conditions, I think there is a clear role for health psychologists. We need to raise our profile as we are well placed to address these issues. If we look at help-seeking behaviours and primary prevention, this is an important area in terms of helping people to stay well. Informing policy is also of crucial importance. Health psychologists need to have a voice and it is pleasing to see that we are making inroads within this area.

Unlike clinical psychology we have to self-fund our training, which may be a limiting factor, and in addition fees are on the increase. If we do more to raise the profile of health psychology and make organisations aware of our unique skill set, this could result in more organisations funding or part-funding trainee health psychologists.

*What advice would you give to someone who is looking to start a career in health psychology and would like to work in an applied setting?*

There are many opportunities within this field of psychology. Do not restrict yourself to looking for jobs within the NHS or those with a '*health psychologist*' title. Think broadly!

**The full text of this article has been removed for copyright reasons**

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**SECTION D: PROFESIONAL PRACTICE  
(COMPETENCIES)**

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**The Professional Practice Component of this thesis has been  
removed for confidentiality purposes.**

**It can be consulted by Psychology researchers on application at  
the Library of City, University of London.**

# Appendix 1

## Guidelines for Interviewing Patients

### Core Principles

- I. Market research (MR) respondents must provide voluntary, informed consent for data collection and use, based upon a clear understanding of the purpose of the data collection and the use(s) to which the data will be put.
- II. The rights of respondents are paramount, including rights to confidentiality, anonymity, and the right to withdraw at any stage.
- III. MR must be kept separate from any form of promotion. MR must not be a vehicle for disguised promotion.
- IV. Researchers must forward adverse events (that meet the reporting criteria) raised during the study to fulfil drug safety responsibilities, without compromising respondents' rights to anonymity and confidentiality.

### Definition

Market research attempts to generate understanding and knowledge about a market place and "*consumer*" behaviour within it, by gaining information (data) from specific samples of "*consumers*" and extrapolating results to the population as a whole. MR is scientifically conducted research where the identity of respondents, and all personal data they give to the researchers, are kept fully confidential, and cannot be disclosed or used, for any non-research purpose.

### Ethics

Only activities defined as research by the Research Governance Framework for Health and Social Care (RGF) should be presented and managed as research in the NHS. Other activities, whether MR, audit, or other types of activity outside this definition should not be managed as research and do not require NHS REC review and NHS permission for research (though they may require other types of NHS management and review).

Bona fide MR relating to market or consumer behaviour, of the sort that pharmaceutical companies routinely commission, whether involving healthcare professionals, patients,

carers, or members of the public, falls outside of the remit of the RGF. Accordingly, it does not require REC approval.

### **Vulnerable Adults**

Vulnerable respondents are those that could be more susceptible than normal to physical or mental stress induced by the research process. Patients may well be vulnerable respondents because of their age or physical or mental health. A vulnerable respondent could be e.g. someone who is HIV positive, has cancer, a psychiatric illness, or is physically handicapped.

No specific guidelines exist for interviewing vulnerable respondents, apart from children. However, MRS guidelines clearly state:

*“The researcher must take all reasonable precautions to ensure that respondents are in no way harmed or adversely affected as a result of their participation in a MR project.”*

A researcher’s responsibility is, at all times, to safeguard the well-being of the respondent.

### **The remit of an NHS REC**

Ethical advice from the appropriate NHS REC is required for any research proposal involving:

- **Patients and users of the NHS.** This includes all potential research
- **Participants recruited by virtue of the patient or user’s past or present**
- **Treatment by, or use of, the NHS.** It includes NHS patients treated under contracts with private sector institutions
- Individuals identified as potential research participants because of their status as relatives or carers of patients and users of the NHS, as defined above
- Access to data, organs or other bodily material of past and present NHS patients
- Fetal material and IVF involving NHS patients
- The recently dead in NHS premises
- **The use of, or potential access to, NHS premises or facilities**
- **NHS staff** – recruited as research participants by virtue of their professional role

## **Appendix 2**

### **List of CPD Activities**

- Evaluating real life interventions (University of Cambridge, Ely 2011)
- Neurology network meeting (London, September 2011)
- King's Fund Transforming Patient Experience Conference (London, November 2011)
- Patient Intelligence Panel Convention (London, November 2011)
- Meeting with Dr Bradley (Royal Holloway University, November 2011)
- Motivational interviewing training (2011)
- Cognitive Behavioural Therapy (CBT) Training (London, February 2012)
- Qualitative research methods training course – Carla Willig (May 2012)
- Nuts and Bolts of Clinical Commissioning Groups & Commissioning Support Units (May 2012)
- Tele-health meeting with Dr Hirani (London May 2012)
- Tele-health webinar - Developing and Supporting Telehealth in the NHS (June 2012)
- Systematic review library training with Antonella Yarnold (June 2012)
- Social marketing meeting (London, 2012)
- Public speaking training (Visions4health, July 2012)
- Webinar - How to understand Emotional Drivers through Market Research (January 2013)
- British Psychological Society Conference (Brighton, May 2017)

## Appendix 3

### Practice Log

Date	Role	Task and brief description	Outcome
Sept. 2011	Project Manager	<ul style="list-style-type: none"> <li>• Co-facilitation and organisation of the Neurology Network Meeting: A catalyst for service improvement for long term neurological conditions – a spotlight on epilepsy.               <ul style="list-style-type: none"> <li>○ Pre-research/development of pre-reading literature.</li> <li>○ Meeting was attended by some leading epilepsy specialists in London.</li> <li>○ Wrote the report and disseminated it to all the delegates.</li> </ul> </li> <li>• Weekly teleconferences</li> <li>• Weekly ‘In the news reports’</li> </ul>	<ul style="list-style-type: none"> <li>• There is a wealth of evidence that there is considerable variation in the provision of epilepsy services across England. The aim of the meeting was to collaborate and plan some actionable strategies that will help to raise the profile of neurology and epilepsy in the context of the NHS reforms.</li> <li>• Epilepsy services need to be designed so that patient’s quality of life is improved. This can be done by redesigning services and doesn’t necessarily mean spending lots of money.</li> <li>• Understanding patient’s perspective’s and how they are self-managing is vital and impacts their health, adherence and mental health.</li> <li>• The Protection Motivation Theory is relevant to understanding some elements of epilepsy patient’s behaviours. For example, the model can be used to predict whether patients will take their epilepsy medicine. I.e. the influence of self-efficacy could be a factor as well as severity.</li> </ul>
Oct. 2011	Consultant NHS Surrey	<ul style="list-style-type: none"> <li>• Working at Surrey NHS doing a one day a week secondment.               <ul style="list-style-type: none"> <li>○ The need to reduce inappropriate A&amp;E use has been highlighted.</li> <li>○ I have been working on literature searches to understand the topic and share with colleagues.</li> <li>○ Data found little indication of</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• I have been working to form relationships and understand who does what within NHS Surrey.</li> <li>• I have applied the Health Belief Model to my work so far. Demographic variables such as level of education, gender, ethnicity may all impact on use of urgent care. When someone is unwell they will weigh up their perceived susceptibility, the perceived severity and benefits and barriers which will influence behaviour.               <ul style="list-style-type: none"> <li>○ I.e. Do I have the skills to cope with this bad cold? How bad is this cold, will it get worse, if I go to A&amp;E will I be seen more</li> </ul> </li> </ul>

	<p>Research manager</p> <p>Trainee</p>	<p>‘who’ inappropriately uses A&amp;E.</p> <ul style="list-style-type: none"> <li>○ I am therefore designing a questionnaire and organising interviews, ethical approval and so on.</li> </ul> <ul style="list-style-type: none"> <li>● Patient experience – working with GlaxoSmithKline (GSK) looking at how patient experience influences outcomes in elderly people.</li> <li>● Weekly teleconferences</li> <li>● Weekly ‘In the news reports’</li> <li>● University workshop – supervising others</li> <li>● Supervision – Dr Claire Howard</li> </ul>	<p>quickly than at the GP, where can I get to most easily.</p> <ul style="list-style-type: none"> <li>● It is difficult to define patient experience and measure it. I.e. elderly people may have memory issues and it will depend on their condition and the severity.</li> <li>● We need to narrow down what we are looking at. You cannot just examine ‘patient experience in elderly people’ as this is too broad.</li> </ul>
Nov. 2011	Research and project manager	<ul style="list-style-type: none"> <li>● Attendance at the Patient Intelligence Panel Meeting in London. <ul style="list-style-type: none"> <li>○ The aim was to discuss incorporating the patient experience and perspective into research and economic modelling.</li> </ul> </li> <li>● Meeting with Dr Bradley (psychologist) at Royal Holloway University to discuss patient experience.</li> <li>● Kings Fund Patient Experience Conference.</li> </ul>	<ul style="list-style-type: none"> <li>● Shared decision making was highlighted. Shared decision making can have a huge impact on adherence.</li> <li>● I felt that the meeting and data presented was slightly biased. The company had a database of over 2000 patients. They use this platform to send out questionnaires to get information for the health sector. People attracted to such platforms will have an interest in doing this sort of thing and are more interested in their health.</li> <li>● She is an expert in the field. She has developed lots of patient experience measures for adults and children. She would like to work together to develop another measure.</li> <li>● Locus of control will influence adherence to doctors and nurses recommendations.</li> <li>● At the heart of everything is self-management in order to reduce costs to the NHS, and help people manage and</li> </ul>

	Trainee	<ul style="list-style-type: none"> <li>• Weekly teleconferences</li> <li>• Weekly ‘In the news reports’</li> <li>• Warner Chilcott project – GP guideline implementation research</li> <li>• University workshop – Consultancy</li> </ul>	<p>understand their own conditions.</p> <ul style="list-style-type: none"> <li>• Interesting practice examples we can use at work were given. Really interesting day discussing patients journeys through the NHS, how staff empowerment can positively influence patient experiences and the importance to see things from the patient’s perspective</li> </ul>
Dec. 2011	Surrey consultant	<ul style="list-style-type: none"> <li>• Using the work at NHS Surrey for my consultancy competency. <ul style="list-style-type: none"> <li>○ Ethics done</li> <li>○ Planned to do 10 interviews and am liaising with a hospital in Surrey</li> <li>○ Analysis will be thematic</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Communication to organise the project and planning of deadlines.</li> <li>• Organisation of meetings.</li> <li>• So far it is all going to plan.</li> </ul>
	Research manager	<ul style="list-style-type: none"> <li>• Patient experience work continues.</li> <li>• Weekly teleconferences</li> <li>• Weekly ‘In the news reports’</li> <li>• Proposal for Warner Chilcott on patient experience in patients with IBD, written and sent.</li> </ul>	<ul style="list-style-type: none"> <li>• Chrono’s disease and ulcerative colitis can be debilitating. Managing stress and adhering to medication can improve patient’s health and outcomes.</li> </ul>
	Trainee	<ul style="list-style-type: none"> <li>• University workshop – Professional skills</li> <li>• Supervision</li> </ul>	
Jan. 2012	Surrey consultant	<ul style="list-style-type: none"> <li>• 9 Surrey interviews were conducted. <ul style="list-style-type: none"> <li>○ Started to analyse data.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Nepalese community, parents with small children, alcohol and drug misuse patients are seen as those inappropriately using A&amp;E.</li> </ul>
	Research manager	<ul style="list-style-type: none"> <li>• Narrowing down systematic review topic.</li> <li>• Weekly teleconferences</li> <li>• Weekly ‘In the news reports’</li> </ul>	
	Trainee	<ul style="list-style-type: none"> <li>• Supervision</li> </ul>	
Feb. 2012	Research and project manager	<ul style="list-style-type: none"> <li>• Weekly teleconferences</li> <li>• Weekly ‘In the news reports’</li> </ul>	

	Surrey consultant	<ul style="list-style-type: none"> <li>• Write up of the report for Surrey, team meetings and discussion of next steps.</li> </ul>	<ul style="list-style-type: none"> <li>• It is good to have the main interviews done and report written. Next steps of the social marketing project need to be taken. I will hopefully be asked to continue to work with them on the project. The next step could be my behaviour change competency.</li> </ul>
	Trainee	<ul style="list-style-type: none"> <li>• University workshops</li> </ul>	<ul style="list-style-type: none"> <li>• x2 – CBT skills for health psychology</li> </ul>
March 2012	Trainee	<ul style="list-style-type: none"> <li>• Systematic review</li> <li>• University workshop – Group supervision</li> </ul>	<ul style="list-style-type: none"> <li>• I have formulated a question for the systematic review and found relevant papers. It will be looking at interventions that target non-adherence to stroke medication.</li> </ul>
	Surrey consultant	<ul style="list-style-type: none"> <li>• Final presentation of findings</li> </ul>	<ul style="list-style-type: none"> <li>• Really positive feedback about how well the project had gone. Agreed I will continue to work on the next stages of the project in a paid manner. I will work as a consultant for Surrey on the social marketing project. This will be used as my behaviour change competency.</li> </ul>
	Research and project manager	<ul style="list-style-type: none"> <li>• Weekly teleconferences</li> <li>• Weekly ‘In the news report</li> </ul>	
April 2012	Trainee	<ul style="list-style-type: none"> <li>• University workshop – Teaching and training</li> <li>• Supervision</li> </ul>	<ul style="list-style-type: none"> <li>• Consultancy signed off</li> </ul>
	Research and project manager	<ul style="list-style-type: none"> <li>• Weekly teleconferences</li> <li>• Weekly ‘In the news reports’</li> <li>• Systematic review</li> </ul>	
May 2012	Trainee	<ul style="list-style-type: none"> <li>• University workshop x2 – Qualitative research methods in health psychology and quantitative research methods</li> <li>• Meeting with Shashi Hirani at City University to discuss working together on a thesis.</li> </ul>	<ul style="list-style-type: none"> <li>• Agreed that I will do my thesis on the Whole Systems Demonstrator Programme. I will be looking carer perspectives of tele-health products.</li> </ul>
	Research and project manager	<ul style="list-style-type: none"> <li>• Weekly teleconferences</li> <li>• Weekly ‘In the news reports’</li> <li>• Systematic review</li> <li>• Sunovian project <ul style="list-style-type: none"> <li>◦ Conducted 12 telephone interviews</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Schizophrenia and mental health is often not paid enough attention to in the NHS. It is important to make sure the right frameworks are in place to support people and avoid ‘stigmatization’.</li> </ul>
June	Trainee	<ul style="list-style-type: none"> <li>• University workshop –</li> </ul>	<ul style="list-style-type: none"> <li>• I am developing a training package for</li> </ul>

2012	Research and project manager	<ul style="list-style-type: none"> <li>• Systematic review</li> <li>• Supervision</li> </ul>	healthcare professionals on patient outcomes. Topics to be included will be patient experience, adherence, patient provider relationship, self-management and help seeking.
July 2012	<p>Trainee</p> <p>Research and project manager</p>	<ul style="list-style-type: none"> <li>• University – annual review</li> <li>• Systematic review</li> <li>• Supervision</li> <li>• Weekly teleconferences</li> <li>• Weekly ‘In the news reports’</li> <li>• Delivery of teaching and training for healthcare professionals at Visions4health</li> <li>• Public speaking training</li> </ul>	<ul style="list-style-type: none"> <li>• Gave my annual presentation which went well.</li> <li>• Delivery of teaching and training went well. I amended it as I went so that it was improved. Feedback was given.</li> <li>• It was good to get training on public speaking. For example, keeps power-point slides very brief and talk around key points to keep people interested otherwise people just read the slide. Try to keep presentations interactive and have breaks.</li> </ul>
August 2012	Research and project manager	<ul style="list-style-type: none"> <li>• Weekly teleconferences</li> <li>• Weekly ‘In the news reports’</li> <li>• Delivery of teaching and training to clients</li> <li>• Literature reviews and attendance at the quality measurement in the NHS workshop for Astellas.</li> <li>• Systematic review</li> <li>• Confirmed that we got the Pfizer project looking into Dupuytren's disease. <ul style="list-style-type: none"> <li>○ 40 telephone interviews to be conducted (20 of them I will do). I will help develop an interview guide, co-write report and present the findings.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Delivery of teaching and training for healthcare professionals went well and they asked a lot of questions.</li> <li>• Systematic review is almost complete.</li> <li>• Dupuytren's contracture is a condition that affects the hands and fingers. It causes one or more fingers to bend into the palm of the hand. It can affect one or both hands and it can sometimes affect the thumb. It is important people get it treated. Men are less likely to seek medical help. This is a condition that affects men more than women.</li> </ul>



	Trainee	<p>telephone (15 - 20 for me)</p> <ul style="list-style-type: none"> <li>• Supervision – new supervisor Dr Vanessa Bogle</li> </ul>	
Dec. 2012	Research and project manager	<ul style="list-style-type: none"> <li>• Weekly teleconferences</li> <li>• Weekly ‘In the news reports’</li> <li>• Sanofi market research project <ul style="list-style-type: none"> <li>○ Conducted all of the telephone interviews, went to meetings, writing report.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Hugely busy doing all the interviews for the Sanofi project. I am finding it interesting although need more time to process the information.</li> </ul>
Jan. 2013	Research and project manager	<ul style="list-style-type: none"> <li>• Weekly teleconferences</li> <li>• Weekly ‘In the news reports’</li> <li>• Consulted to work with the Department of Health on their respiratory programme research</li> <li>• Sanofi market research project <ul style="list-style-type: none"> <li>○ Finalise report</li> <li>○ Final presentation</li> </ul> </li> <li>• Oncology monthly reports commence for GSK.</li> </ul>	<ul style="list-style-type: none"> <li>• Looking at anything relating to oncology that will help to improve patient outcomes. A lot of daily searching of news to see what is happening.</li> </ul>
	Trainee	<ul style="list-style-type: none"> <li>• Supervision</li> </ul>	<ul style="list-style-type: none"> <li>• First teaching and training submitted. Discussion of stress management training in Surrey.</li> </ul>
Feb. 2013	Research and project manager	<ul style="list-style-type: none"> <li>• Weekly teleconferences</li> <li>• Weekly ‘In the news reports’</li> <li>• Department of Health Respiratory Team project</li> <li>• Development of stress management training</li> <li>• Wrote a book review as part of my 10,000 words for publication. Submitted for publication and agreed to be published in May edition of the Health Psychology Update.</li> </ul>	<ul style="list-style-type: none"> <li>• Busy with the DH project and development of stress management training. I have contacted a stress expert and been conducting a lot of background research for the training development.</li> <li>• Good to write a book review as I had never done one. The one I chose was a book by Martin Dempster that has been particularly useful for my Health Psychology Trainee role.</li> </ul>

		<ul style="list-style-type: none"> <li>• Finished ethics for thesis. Waiting on getting it signed off by City so it could be submitted to the NHS.</li> <li>• Oncology monthly reports GSK</li> </ul>	<ul style="list-style-type: none"> <li>• Pleased ethics is finished and am now waiting on sign off before we can submit.</li> </ul>
March 2013	<p>Research and project manager</p> <p>Trainee</p> <p>Surrey County Council</p>	<ul style="list-style-type: none"> <li>• Weekly teleconferences</li> <li>• Weekly 'In the news reports'</li> <li>• Department of Health Respiratory Team Project</li> <li>• Delivery of stress management training and observation.</li> <li>• Oncology monthly report GSK</li> <li>• Supervision</li> <li>• Behaviour change intervention is ongoing</li> </ul>	<ul style="list-style-type: none"> <li>• Delivered the stress management training. I am really proud of the way it went. I enjoyed the topic and had really positive feedback from all the people who attended. People were very open and shared their experiences.</li> <li>• Systematic review signed off. Look to get it published.</li> <li>• Second teaching and training signed off.</li> <li>• Asked Vanessa if I could interview her. Aim would be to get it published and help to show other students the breadth of roles health psychologists can work in, i.e. public health.</li> </ul>
April 2013	<p>Research and project manager</p>	<ul style="list-style-type: none"> <li>• Weekly teleconferences</li> <li>• Weekly 'In the news reports'</li> <li>• Oncology monthly reports GSK</li> <li>• GSK dermatology project <ul style="list-style-type: none"> <li>○ Conduct a literature search around patient's experiences of eczema.</li> </ul> </li> <li>• Department of Health</li> </ul>	<ul style="list-style-type: none"> <li>• Eczema can be painful and embarrassing. The Self-Regulation Model (SRM) that shows how different people respond to illness is very relevant. Illness representations or perceptions are patients own implicit common sense beliefs. Coping is someone's ability to manage symptoms, treatment, lifestyle changes and physical and psychosocial consequences. All these factors need to be considered to understand a patient.</li> <li>• The project found that greater support for implementation of the guidance is</li> </ul>



July 2013	Research and project manager	<ul style="list-style-type: none"> <li>• Weekly teleconferences</li> <li>• Weekly 'In the news reports'</li> <li>• Writing up of NHS project that was my consultancy for publication.</li> <li>• Oncology monthly reports GSK</li> </ul>	
	Trainee	<ul style="list-style-type: none"> <li>• Supervision</li> <li>• Submitted interview publication in The Psychologist.</li> <li>• Ethics granted.</li> <li>• University – annual review</li> </ul>	<ul style="list-style-type: none"> <li>• I have been working on my final publication for my 10,000 words. I am hoping to finish this after maternity leave.</li> <li>• Really pleased that ethics is granted. I will start data collection on my return from MAT leave.</li> <li>• Also very happy to have the publication submitted and hopefully this will actually be published</li> <li>• Annual presentation went well.</li> </ul>
	Surrey County Council	<ul style="list-style-type: none"> <li>• Roll out of the behaviour change intervention/booklet</li> </ul>	<ul style="list-style-type: none"> <li>• The roll out of the intervention took a lot longer than expected. I will now have to analyse it when I come back from maternity leave.</li> </ul>
Aug. 2013- Aug. 2014	MAT LEAVE	<ul style="list-style-type: none"> <li>• Both the interview and systematic review were published whilst on MAT leave.</li> <li>• The systematic review was also presented as part of the European Stroke Conference to hundreds of leaders in the field.</li> </ul>	<ul style="list-style-type: none"> <li>• Feel really proud that the systematic review was published and even more so presented at the European Stroke Conference. All my hard work paid off.</li> </ul>
Sept. 2014	Surrey County Council voluntary consultant	<ul style="list-style-type: none"> <li>• Meeting in Guildford with Surrey County Council regarding the A&amp;E project.</li> <li>• Write up of last paper to be included in 10,000 words. It was on the consultancy competency. Aim to be published in a health psychology or public health journal.</li> </ul>	<ul style="list-style-type: none"> <li>• Feels like the analysis will move forward. Have been promised data and colleague is having a meeting with the CCG so she will raise the topic. <ul style="list-style-type: none"> <li>○ Discussed obtaining statistics from Guildford and Waverly CCG to conduct the follow-up analysis.</li> <li>○ Qualitative analysis will also be conducted.</li> </ul> </li> </ul>
	Trainee		
Oct. 2014	Surrey County	<ul style="list-style-type: none"> <li>• Behaviour change – organisation of the</li> </ul>	<ul style="list-style-type: none"> <li>• Starting to feel very despondent the team are not more engaged.</li> </ul>

	<p>Council consultant</p> <p>Trainee</p> <p>Visions4health consultant</p>	<p>analysis.</p> <ul style="list-style-type: none"> <li>• New supervisor – Dr Triece Turnbull</li> <li>• Thesis has fallen through. I have been thinking about new ideas for the thesis. I have one I will test with Triece my new supervisor in November. It is looking at mastitis in breast-feeding women.</li> <li>• Worked on a proposal, did research and proof reading for a new project <ul style="list-style-type: none"> <li>○ The proposal was for a Shared Decision Making Tool in Haemophilia</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• I will try to conduct qualitative analysis in the meantime with parents who received the booklet.</li> <li>• Feel upset the thesis has been cancelled. I did a lot of work on the ethics and literature searches. I have an idea that I am really passionate about so feel perhaps it wasn't meant to be. <ul style="list-style-type: none"> <li>○ Time was not on our side and all the participants who had been using the tele-health products were no longer using them as funding had been cut.</li> </ul> </li> </ul>
End of Two Years of Training			
Nov. 2014 – July 2015	Trainee	<ul style="list-style-type: none"> <li>• Supervisions.</li> <li>• Behaviour change signed off.</li> <li>• Thesis – agreed. <ul style="list-style-type: none"> <li>○ Interviews conducted and research undertaken.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• After a year and a half of chasing Surrey County Council to work on the analysis, it was suggested I no longer used the analysis for the behaviour change and wrote it up without it. This was disappointing however an internal evaluation was completed and I have learnt a lot from the process.</li> <li>• Really happy with the topic for my thesis. Having had mastitis myself I have empathy whilst conducting the interviews. Women were very open about their experiences.</li> <li>• 16 interviews undertaken and analysed until saturation reached. A lot of rich data collected and analysed using grounded theory.</li> </ul>
July 2015 – Defer course due to second baby being born			
Sept. 2016 – May 2017	Trainee	<ul style="list-style-type: none"> <li>• Professional development</li> </ul>	<ul style="list-style-type: none"> <li>• A&amp;E work was published in the British Journal of Nursing.</li> <li>• Asked to and presented a poster of the publication of A&amp;E article at the BPS in May 2017. Went very well with a lot of interest, especially as A&amp;E rates are so high and psychologists are well placed to conduct research to reduce inappropriate use of services.</li> </ul>

		<ul style="list-style-type: none"> <li>• Thesis write up</li> <li>• Portfolio completed</li> </ul>	<ul style="list-style-type: none"> <li>• Learnt a lot at the conference. Liked the focus on positive psychology and am keen to use this in my career as well as my personal life.</li> <li>• Have been asked to present thesis at DHP conference in September in Cardiff. Feel really happy and proud of my research and need to think about publications and promoting the work in a practical way. i.e. brochure on mastitis for pregnant women, or a leaflet.</li> <li>• Thesis write-up. At times it has been difficult to multi-task but I feel it has come together after a lot of hard work and time.</li> <li>• Triage reviewed thesis 1<sup>st</sup> draft and portfolio. Amendments made.</li> <li>• Triage reviewed thesis 2<sup>nd</sup> draft and full portfolio April 2017. Amendments made and portfolio due to be submitted.</li> </ul>
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## **UNIT 2: CONSULTANCY COMPETENCY**

### **Social Marketing Project:**

### **Inappropriate Use of Accident and Emergency Services in Surrey**

**Setting:** Frimley Park Hospital NHS Foundation Trust Accident & Emergency (A&E) Department

**Client:** NHS Surrey

**Target Group:** Healthcare professionals working in A&E and patients that attend A&E

#### **Objectives of the Consultancy:**

- To gain insight into healthcare professionals perceptions, understanding and behaviours of inappropriate use of the emergency care services in Surrey

#### **Outcomes of the Consultancy:**

- To identify groups of the population (professional and/or public/patient) who inappropriately use Surrey's emergency care services
- To produce a report outlining the findings. This report will inform who will be targeted in a large urgent care social marketing campaign across the whole of Surrey

#### **Introduction**

The consultancy arose in October 2011 out of collaboration between NHS Surrey's public health department and Visions4health. The aim was to conduct a social marketing project to understand inappropriate use of urgent care services in Surrey. Social marketing uses marketing principles and techniques to change behaviour for the sake of improving health (Kotler, Roberto & Lee, 2002). Health psychology theories and skills inform social marketing research in order to understand and change health behaviour. A process is followed in which an issue is identified, researched and understood; interventions/campaigns are implemented and later evaluated to tackle the

issue. It is a growing discipline in the UK and primarily implemented by the NHS and government organisations to influence public behaviour.

The consultancy project lasted six months. Over this period I gained invaluable experience and practical skills whilst fulfilling the criteria required for the doctorate consultancy competency.

## **Background**

NHS urgent and emergency care services provide immediate treatment for serious and life threatening health issues (DH, 2010). Large proportions of people refer themselves or are referred by healthcare professionals to emergency services for conditions/issues which are not either accidents or emergencies (Murphy, 1998). However, some of these people could be better treated elsewhere in the community (Purdy, 2010). For example, NHS Central Lancashire has stated that unnecessary visits to A&E, such as those attending with coughs or colds, cost the region's hospitals £79.25 million a year (NHS Central Lancashire, 2010). The number of people using emergency and urgent care services is increasing resulting in high costs as well as putting pressure on capacity (NHS Central Lancashire, 2010). The reasons people self-refer or are referred to emergency services inappropriately are complicated and involve an interplay of social, individual, psychological, and medical factors (Murphy, 1998). To ensure people are treated in the most appropriate settings and minimise costs, reducing inappropriate emergency attendances is a national priority for the NHS (Purdy, 2010).

In Surrey each month approximately 45,000 people attend one of the A&E departments within the five acute trusts (Surrey Community Health, 2011). Some of these people, such as those attending for minor illnesses, could have been treated more appropriately elsewhere in the community, such as at their general practice. One of NHS Surrey's priorities during 2011-12 was therefore to reduce inappropriate A&E attendances. Inappropriate was defined as "*inappropriate may be whether the patient can be successfully managed elsewhere, such that these attendances are potentially avoidable*" (Lowry, Kohler & Nicholl, 1994). To tackle the issue in Surrey £100,000 was put aside for a large urgent care social marketing campaign. However, the public health data had not clearly shown who was attending A&E inappropriately. Consequently, the public health team were unclear about the approach to take. Visions4health was consulted to

help identify who was inappropriately using services and how they could approach the campaign.

### **Assessing the Request for Consultancy**

Visions4health was contacted by the Director of Public Health at NHS Surrey and asked to attend the department's team meeting for their urgent care social marketing campaign in August 2011. We were asked to attend on a consultancy basis to help provide a strategic steer for the campaign. I co-facilitated this meeting with the managing director of Visions4health. The client wanted Visions4health to help them clarify what the problem actually was and how they should go about tackling it. We began by having a round table discussion eliciting what they knew already. The group drew '*rich pictures*' in which Surrey's urgent care services were mapped out (see evidence folder). Through this process we defined the aim of the campaign. The group defined it as '*understanding how to change public and professional behaviours to use the urgent care system effectively in Surrey*'. The next step was to agree on an approach to take forward. It has been shown that designing campaigns that are uniquely appealing to a target group, rather than a whole population, improves uptake of the desired behaviour (Kotler, 2002). This is called segmentation. For example, in Tower Hamlets it was found that there was a large young male Bangladeshi community inappropriately using A&E. Specifically targeting young male Bangladeshis rather than implementing a broad brush marketing campaign was successful in reducing inappropriate attendance rates (Levy & Mullett, 2006). It was agreed by the group at hand to take a targeted approach.

NHS Surrey's public health department had already conducted a lot of secondary research but were unable to identify any groups of the population who were inappropriately attending A&E. An issue was raised that a lot of the data from the hospitals was poor and wrongly coded making it unreliable. It was recommended by Visions4health to use one of the five acute trusts in Surrey as a pilot to identify target groups who inappropriately use A&E. High inappropriate attendance was a problem across all of the hospitals in Surrey but Frimley Park Hospital (FPH) NHS Foundation Trust was selected as the client had a good working relationship with them, and they were recognised as having a high standard of data that was coded well. Quantitative and qualitative research was recommended to be undertaken at FPH. Quantitative research of the hospital data would show if certain groups of the population were inappropriately attending. Qualitative research would give a deeper understanding into the issue. For

instance some data was coded as a '*general gastrointestinal*' presentation however, this did show how serious the presentation was, such as a mild stomach ache or a serious issue, and whether the patient could have been better treated elsewhere.

The desired aims of the initial consultancy meeting had been met in that the problem had been identified and an approach decided. I was asked by NHS Surrey to work on the pilot project as a consultant. A contract was drawn up and it was agreed that I would work on the pilot for six months (see evidence folder). I was to work within the public health team and was seconded for one day a week as this was deemed sufficient. At this stage a responsibility project matrix was drawn up by Visions4health. The aim of this was to ascertain who was responsible, accountable, consulted, and informed (RACI).

This ensured everyone was clear on their roles and responsibilities (see evidence folder). The Director of Public Health was ultimately accountable for the overall project as he was responsible for decision making and funding. He was not involved in the day-to-day running of the project; the associate director of public health was responsible for this. The NHS Surrey public health analysts were responsible for secondary data analysis and I was responsible for the primary research. NHS Surrey public health leads were responsible for a telephone audit to see if general practices were appropriately referring patients. Other stakeholders, such as the communication managers were responsible for internal communication of the pilot project. Lastly, the whole team was to be consulted or informed of different elements of the project in order to work collaboratively.

The consultancy project was in line with the Expertise Model and Process Consultation Model of consultancy (Schein, 1997). It fitted both these models as we were contacted as experts to advise on the problem, and then to work in a collaborative relationship with both sides agreeing to provide input throughout the ongoing process. As I was working as part of the team, it was agreed that I would work within the client's confidentiality and ethical guidelines.

### **Planning Consultancy**

Following on from the initial meeting it had been planned that NHS Surrey's public health analysts would conduct secondary data analysis of A&E attendances from FPH to see if there were groups of people who were inappropriately using A&E. It was also planned that the telephone audit of general practice answer machines would begin as

soon as possible by NHS Surrey. I conducted a literature review to help plan the approach I would take to carry out the qualitative research for the pilot. The literature showed that the majority of social marketing A&E campaigns that had been conducted, such as the one in Tower Hamlets focusing on the young male Bangladeshi community, had adopted a qualitative approach in which interviews and focus groups with healthcare professionals were undertaken. These social marketing campaigns were able to identify clear groups of the population who were inappropriately using A&E and adopt interventions that had successful outcomes, such as reduced A&E use. For example, in Tower Hamlets a campaign targeting young Bangladeshi males resulted in fewer A&E attendances and cost savings (Levy & Mullett, 2006). I planned to conduct interviews with healthcare professionals to understand the local Surrey issues.

The Health Belief Model (HBM; Rosenstock, 1974) provided the theoretical framework for the consultancy. The HBM has been successfully applied in research strategies identifying preventative health behaviours and used to understand individuals' core beliefs and perceptions with regard to health action (Connor & Norman, 1995). A thematic approach was adopted. Thematic approaches identify a number of themes which summarise the pertinent issues from the qualitative data (Dempster, McCorry, Brennan, Donnelly, Murray et al 2011).

An implementation plan was drawn up with timelines (see evidence folder). The methodology included eight in-depth one-to-one interviews with a selection of A&E healthcare professionals. The healthcare professionals had to have worked in A&E for a sufficient time period, (e.g. over six months) so that they had a good understanding of the topic. I designed a semi-structured interview schedule for the purpose of the pilot project based on the demographic and psychological aspects of the HBM, for instance perceived barriers (Appendix 1). NHS Surrey was responsible for gaining ethics and approving the questionnaire so that it was in line with their ethical standards. Knowing that A&E departments' busiest time is winter the interview schedule was reasonably short so that it was not too difficult for participants to be included but also ensured that relevant information was captured.

### **Establish, Develop and Maintain Working Relationships with Client**

To maintain a working relationship with the client regular meetings were agreed. When I was in the office at NHS Surrey I would informally catch up with the members of the

team and have project updates. If I did not go in to the office I was in contact via email and telephone. Formal team meetings were organised twice during the project (once at the beginning and once at the end), to discuss the main findings. These were in addition to informal meetings which involved the wider team such as the public health analysts, communications team, associate director and project leads. These meetings were held at prominent milestones throughout the project. For example, they were held to discuss the findings from the secondary data analysis and to explain the methodology for the qualitative research.

NHS Surrey was responsible for forming the relationship with FPH. They already had a good relationship with the medical director of the acute trust and were going to organise for the interviews to take place. Ethical approval had been organised. An issue occurred during the communication phase which influenced the timescales of the project. NHS Surrey had been responsible for organising consent to go to FPH for me to conduct the interviews. It was taking them a very long time to do this because they were very busy. Furthermore, this impacted on the project as I could not begin the interviews within the original timelines. As a result I asked the director of public health to assist. He was not meant to be involved in the day to day running of the project, only to be accountable, however I emailed him to intervene. This resulted in me receiving an email from the medical director of FPH and being able to organise the interviews more quickly. The timescales were readjusted and research commenced.

### **Conduct Consultancy**

NHS Surrey conducted the secondary data analysis focusing on FPH. The data showed that there were high rates of children less than five years of age presenting inappropriately at A&E. No other groups were found to be inappropriately using A&E from the secondary data analysis. The GP telephone audit conducted by NHS Surrey was also undertaken. The results showed that almost all of the answer machines were re-directing people to the right services which ruled out this being a factor influencing inappropriate attendance. The interviews commenced in early January 2012. They took place at the acute trust in a private room and I conducted all of them myself to avoid any interviewer bias. They lasted between 20-30 minutes and were recorded via a Dictaphone. The aim had been to conduct eight interviews. Whilst conducting the interviews there was a recurrent theme that parents of small children were commonly presenting at A&E who could have been more appropriately treated elsewhere in the

community. Therefore, a ninth interview was conducted with a paediatric nurse to confirm the findings.

I transcribed and analysed all of the interviews. The data was consistent and clear themes emerged using thematic analysis and I could see how they related to the HBM. The main themes that emerged were that younger generations (18-30s) were perceived as using A&E more inappropriately out of convenience. They were thought to use it as a *'drop in'* rather than for emergencies. There was a perceived general lack of awareness of alternative services available in Surrey such as general practice out of hours services. Parents with young children were highlighted as being a group that inappropriately used services which was consistent with the secondary data analysis. Alcohol and drug misuse and the Nepalese community were also highlighted as population groups inappropriately attending A&E. Lastly; it was found that improving long-term condition management, such as Chronic Obstructive Pulmonary Disease (COPD), would help to reduce inappropriate attendances as people with these conditions would not have acute episodes leading them to A&E.

An in-depth report was written for NHS Surrey (Appendix 2). This report was structured around the main themes from the data. The report was circulated to the whole team and I presented the findings and recommendations to the client at a wider team meeting. At this meeting the recommendations were discussed in-depth and next steps were decided. The next steps were to use existing services where possible to change behaviours. For example, where there were existing public health work-streams, such as long-term conditions or those working with and alcohol and drug misuse, they could look at service use and see if they could be amended to better suit the needs of the end users. This would mean in a time where there are limited resources they could make changes without having to necessarily spend money. There were not work streams for all of the target groups. Therefore, a further recommendation was to see if the identified target groups and issues, such as younger generations using A&E as a drop in, were common across Surrey. I suggested using a quantitative survey across the other acute trusts. If they were common, I recommended conducting focus groups and interviews to help shape the social marketing campaign or intervention. My consultancy helped to identify target groups that had not been identified before and clarify next steps to take to address trying to reduce inappropriate use of the emergency care system.

## **Monitor the Process of Consultancy**

The process of the consultancy was regularly monitored. For example, timelines were drawn up and communication via email and meetings were frequently circulated and held with those involved. This ensured that the project could be discussed and any problems could be addressed so that the client's expectations were met. As previously mentioned, a problem arose due to the timescales of the project as consent to FPH had not been gained as quickly as we had hoped. The director of public health changed the role requirements and I was put in direct contact with the hospital to arrange the interviews. The timescales were reviewed and adjusted and the new roles and timescales were emailed to all those involved in the project. Throughout the consultancy the process was compared to the project objectives to ensure they were being met. For instance, once the interviews with the healthcare professionals were conducted this was in line with the objective of gaining insight into healthcare professional's perceptions of inappropriately use of A&E. Reviewing the timescales of the project was the main change that was identified, other than this, the project was in line with the plan.

Quality assurance and control mechanisms were implemented throughout the consultancy. Ethical approval was gained via the public health department. All of the interviews were conducted in a private room within the hospital and recorded via a Dictaphone. The interviewer transcribed the interviews and these were anonymous and later kept in a locked computer. The project findings were written up and reported to the stakeholders via a meeting and the final report was circulated to the team via email.

## **Evaluate the Impact of Consultancy**

A meeting was held with the client to review and evaluate the impact of the consultancy. NHS Surrey said they were pleased with the consultancy and that the objectives were met. A formal evaluation was also administered via email (Appendix 3). The outcomes of the pilot project were met. The first being that clear segments of the population had emerged who were perceived as using A&E inappropriately. For example, younger generations, parents with small children, long-term condition management, and the Nepalese community. The second outcome achieved was the report. NHS Surrey looked to implement the recommendations which I had made. For example, one of the themes had been to enhance self-management of long-term

conditions, such as COPD, to prevent hospital admissions. This was looked at within their long-term conditions team.

The project was useful for the social marketing campaign to progress. I was asked to go back and work with the public health team on the next stages of the campaign which was to understand and choose a target group for a community wide intervention aimed at reducing inappropriate admissions.

## **Reflection**

In the past I had gained experience of working in consultancy for the NHS. In 2009 I had been consulted by NHS Berkshire West to work on a community wide social marketing project looking at teenage sexual health as they had higher than the national average teenage pregnancy rates. I was able to draw on this experience and my knowledge and skills of health psychology to enable successful delivery of the consultancy project at hand. I was looking forward to the Surrey consultancy opportunity as I had an interest in the role of Health Psychologists in researching and assessing the effectiveness of healthcare systems and service development.

The HBM is one of the most widely used social cognition models (Rosenstock, 1960). It was applicable to this study as demographic variables such as age, psychological characteristics such as personality, and cues to action all influenced the behaviour taken to seek help. The cues to action could be in the form of a health campaign or lack of one. One of the weaknesses of the HBM is that it does not take into account intentions and self-efficacy which have been shown to be powerful predictors of behaviour (Conner & Norman, 1995). In this project intentions and self-efficacy were not looked at. This project only looked at healthcare professionals' perceptions of inappropriate use of A&E and if further research is commissioned it would be interesting to understand the public's/patients point of view incorporating self-efficacy and intentions.

I found it difficult that the project was held up. It took over a month before any communication was made with the acute trust. In order to move the project forward I emailed the director of public health to see if he could help to move things forward. I was worried about contacting him as I did not want to upset the rest of the team who I had been working with, however I needed the project to progress. He was helpful and from this point I was responsible for communication with the acute trust. I was given access to go into the hospital straight away and a dedicated room to conduct the

interviews. I was also given further contact details to organise the interviews. My working relationship was maintained with the client. NHS Surrey was happy that the communication responsibility had been handed over and that the project was able to move forward. In future projects I have learnt that it is important to understand upfront working relationships and if there will be issues that block the progression of a project. However, I do recognise that sometimes this will be unavoidable.

I enjoyed conducting the interviews. The interviewees were happy to be interviewed as they felt it was an issue that impacted on their roles significantly. I was concerned they could have been too busy and that people might have dropped out yet this was not the case. They were all more than willing to be interviewed and talked openly and honestly. I felt confident conducting the interviews as I have had a lot of experience interviewing in my role at work. Clear and consistent themes emerged straight away. Throughout the process I was aware and reflected on the influence that I had as the interviewer and the impact this had on the interviews and analysis. I read that there are two types of reflexivity, personal and epistemological (Willig, 2001). I applied personal reflexivity as I thought about how my own values, experiences and personal factors influenced the research and also how the research may have changed me. I think I have grown through the process by listening to people's perspectives and realise that my own preconceived notions changed.

I was confident the client was pleased with the project and their expectations were met. The models I applied, collaborative consultation and professional expertise model were appropriate. I learnt that it is important to be clear about the roles and responsibilities and the approach that should be adopted especially with regard to communication. There are bound to be changes in projects and some of these cannot be predicted however I think it is also important to recognise this at the beginning and be flexible and proactive when it occurs.

I was really happy to be contacted regarding further consultancy. It felt it showed they had been pleased with the work, and I was keen to continue working on narrowing down the target group and the execution of the intervention. The next part of the project formed my behaviour change intervention.

## **Conclusion**

Overall this consultancy experience was really positive. I gained invaluable knowledge and practical skills working with the NHS as a health psychology consultant.

Implementing health psychology theory and skills in an NHS setting was useful to explain behaviour and I have learned from the mistakes along the way. This consultancy project gave me the confidence to conduct more consultancies in the future.

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# Appendix 1

## Interview Guide

<b>QUALITATIVE INTERVIEW GUIDE (Health Professionals)</b>
<p><b>Key Information:</b></p> <p><u>Purpose/Objective:</u>            Insights into Surrey’s Health Professionals and Staff.            Insights into attitudes, beliefs, drivers and behaviours of the use of urgent care at Frimley Park Hospital.            How to change public and professional behaviours to use the urgent care system effectively.</p> <p><u>Action To Be Taken as a result of the qualitative interviews :</u></p> <ul style="list-style-type: none"> <li>• Inform segmentation model</li> </ul>
<p><b>Background:</b></p> <p>Approximately 45,000 patients attend one of the A&amp;E departments within the five acute trusts in Surrey each month. Some of them could have been treated more appropriately elsewhere in the community. Identification and reduction of potentially ‘avoidable’ A&amp;E attendances could result in considerable cost savings, as well as ensuring patients are treated in the most appropriate setting. The aim of this social marketing project is therefore to try to understand how to change public and professional behaviours to use the urgent care system effectively.</p> <p>Frimley Park Hospital has been selected to pilot the project. In parallel to analysis of secondary data, qualitative interviews with A&amp;E staff/health professionals will be conducted to gain in-depth insight.</p>
<p><b>Methodology:</b></p> <p>The methodology will include Cognitive Mapping and the Health Belief Model. Cognitive Mapping is a technique which has been developed over a period of time. It is about creating a map of the perceptions of different groups over a certain topic. This method targets structuring messy, complex problem situations, exploring the differing views and perspectives of the group, and facilitating participation and engagement rather than analysing abstract data and models. The Health Belief Model looks at an individual’s core beliefs and perceptions with regard to health action.</p> <p>One to one interviews will be conducted. Interviews are expected to last between 20-30 minutes. A&amp;E staff/Health Professionals who will be interviewed will include:</p> <ul style="list-style-type: none"> <li>- Nurses x 4</li> <li>- Doctors x 4</li> <li>- Reception/Admin x1</li> </ul> <p>The findings of this qualitative research will be transcribed and analysed thematically. The interview guide is an outline of the main topics that we wish to raise. However this is a guideline as the interviews are <u>semi-structured</u> and will depend on the nature of the discussions.</p>
<p><b>Key Dates/Information:</b></p> <ul style="list-style-type: none"> <li>• Final alignment of qualitative questionnaire: 21<sup>th</sup> October 2011.</li> </ul>

- Dates for qualitative interviews: January 2012

### **Interview Questions:**

1. In your view do you think there are people that come to A&E when they could be treated elsewhere more appropriately?
2. Why do you think it happens and what proportion would you say it is?
3. In the last week what cases did you come across that you would consider inappropriate? Could you please give an example?
4. What do you think people's understanding of A&E is?
5. What are the main reasons in your view for people attending A&E when they could be treated more appropriately somewhere else?  
Prompts:
  - Signposting
  - Unaware of other services
  - Demographic reasons
  - Management of symptoms
  - Psychological issues (i.e. anxiety)
  - Social issues
6. Who, if anyone, do you think uses A&E when they could be treated more effectively elsewhere? Are there some people that present more frequently?
7. What impact, if any, do you think the following have on A&E. Think in terms of those who come to A&E who could be treated elsewhere more appropriately (these questions are to be answered on by one):
  - Proximity to hospital?
  - Perception of care being better?
  - Age?
  - Ethnicity?
  - Gender?
  - Referrals?
  - Socio-economic status?
  - Perceived seriousness?
  - Speed of access to other services – such as a GP appointment either in hours or OOH
8. What sort of long term conditions present at A&E/ for what sort of reasons?
9. What, if any, are the issues you have noticed around signposting? I.e. unaware of 'where else to go'?
10. What happens when someone comes to A&E who could be treated more appropriately somewhere else?
  - Does a member of staff discuss other options for treatment?
  - If so, who would have this conversation?
11. What urgent care services are available in Surrey?
12. In your view are professionals, including wider health and social care professionals, aware of the different services available, i.e. walk-in centres, minor injuries units?
  - And aware of where they are and/or what they are most appropriate for?
13. In your view are professionals, including wider health and social care professionals, aware of campaigns such as Choose Well?
14. If people are referred to A&E who could be treated more appropriately elsewhere, is this fed back to those that had referred them?
15. If you had to choose one thing that you think would reduce inappropriate A&E attendance what would that be?

# Appendix 2

## Report



February 2012  
NHS Surrey  
NHS Surrey Social Marketing Scoping Project

**NHS Surrey**  
By Beatrice Chapman  
**Research and Project Manager**  
Visions4health Ltd

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protection reasons**

## Appendix 5

### Evaluation Report: Internal Analysis

#### 1. How would you rate and the methods used?

The planned methods were good. The research at the beginning of the project was very thorough as an in depth amount of research was undertaken to understand the target group's attitudes and behaviours. The online survey and focus groups were very useful and had a very good response rate.

The planning of the implementation of the intervention was good and only hindered by the signing off of the booklet and a lack of engagement by one stakeholder. Once approved and printed it was successfully disseminated.

The analysis was unsuccessful. The proposed method for analysis was not able to be used as the data was not able to be retrieved from the CCG's due to a lack of engagement and perceived need as it had already been deemed as being successful.

#### 2. How would you evaluate the stakeholder engagement?

The original team had been very proactive and engaged. Once the Surrey County Council lead left for maternity, the stakeholder engagement was poor. Role changes in the CCG also meant a lack of engagement from the CCG meaning the evaluation was not possible.

Stakeholder engagement was the issue with the evaluation being unable to be conducted. Keeping to tight deadlines and having contracts in place as vital for future projects.

#### 3. Were the outcomes achieved?

Unknown: The booklet was 'informally successful' so there was a need uncovered by professionals and parents, however it is unknown whether the booklet influenced inappropriate use of A&E.

## UNIT 4: TEACHING AND TRAINING

### Case Study 1:

#### Patient Outcomes Master-Class

##### Introduction

Patient outcomes are becoming increasingly important and high on the UK policy agenda. Patient outcomes incorporate three integral components; ensuring people are given the best care, ensuring better clinical outcomes, and helping people to feel better (Healthcare Quality Improvement Partnership, 2012). Epidemiological changes, such as the rise in long-term conditions and co-morbidities, coupled with the economic downturn have presented a context in which improving patient outcomes are of utmost significance (DH, 2012). Over the last ten years policy has focused on driving patient outcomes via agendas such as self-management, patient experience and quality measurement (King's Fund, 2011). In order to ensure these agendas are appropriately implemented, it is paramount that different healthcare professionals have the knowledge and skills to integrate patient outcomes into their roles at work. A need was identified through my role at Visions4health to train healthcare professionals in the private sector (e.g. pharmacists and doctors working in private consultancy, and health economists in the pharmaceutical industry, on what patient outcomes are, why they are important, and what they entail).

This teaching and training case study describes the '*Patient Outcomes Master-Class*' that I developed and delivered throughout 2012 to healthcare professionals working within or with the pharmaceutical sector. The master-class was set up to be an introduction/overview of patient outcomes that could lead on to further more in-depth training through the delivery of other modules. For example, one of the topics covered within the master-class was patient experience and following delivery there was a request for further training on a '*Patient Experience*' for which a Module was designed and delivered by me. I delivered the '*Patient Outcomes Master-Class*' to several groups and on a one-to-one basis, i.e. to one person at a time, and '*Patient Experience Module*' was delivered to a small group and also on a one-to-one basis. The group training was

delivered face-to-face, and the one-to-one trainings were delivered via distance learning over Skype. For the purpose of this case study the master-class will be discussed predominantly as the modules were designed to complement it.

### **Plan and Design Training Programmes that Enable Audience to Learn about Knowledge, Skills and Practices in Health Psychology**

I was requested by my manager (the managing director at Visions4health) to design and deliver a '*Patient Outcomes Master-Class*' for my team at work and for healthcare professionals working in or with the pharmaceutical sector. The audiences were multi-disciplinary and had expertise in medicine, public health, pharmacy, dietetics, clinical commissioning, health care operations, health outcomes and economics, and social marketing. The managing director had noticed that patient outcomes were being discussed frequently by associates in the NHS and pharmaceutical sector yet there was general confusion around the topic and what it meant for people practically within their roles. The '*Patient Outcomes Master-Class*' training was requested for three reasons. Firstly, to train my colleagues, secondly to '*train the trainer*' so that my colleagues could then deliver the training themselves to clients, and thirdly to train clients working in the NHS or pharmaceutical sector to raise awareness about patient outcomes and give practical advice that people could integrate into their roles.

During the planning stage literature was reviewed and professionals and colleagues were consulted to ensure the training was fit for purpose. The proposed timeframe for the master-class training was 90 minutes to two hours. This was deemed appropriate as it was an introduction to patient outcomes. The overall training objectives were to:

1. Outline what patient outcomes are and why they are important in the current UK healthcare environment;
2. Identify some of the key health psychology factors that influence patient outcomes: help seeking behaviour, the patient provider interaction, self-management, and patient experience and how it can be measured,
3. Equip the audience with patient outcomes knowledge and examples of good practice that could then be integrated into their roles at work.

The plan was to give the audience an overview of patient outcomes using power-point which would include a description of what patient outcomes are, why they are important and the health psychology factors that influence the patient journey. Group exercises

were included to keep the audience engaged. A range of professionals were consulted by telephone discussion and face-to-face meetings including ex-pharmaceutical industry professionals, NHS healthcare professionals and experts in business training to test the concept of the content and training methods. The training plan was finalised (see evidence folder).

The content of the master-class was designed by drawing on my past experiences and knowledge from my academic training and work experience and by conducting extensive secondary research. A range of sources were used to gather information including health psychology text books, the department of health website as well as other relevant websites, lecture hand-outs, and scientific databases. For example, the '*patient provider interaction*' content included a definition of what the '*patient provider interaction*' is, information of what this incorporates in practice (i.e. body language), and examples of empirical research that demonstrate the outcomes of a good patient provider interaction (i.e. improved adherence to a medical regimen). The content was based on psychological theory and was placed within the context of the NHS policy agenda. For example, the topic adherence/non-adherence was included and leading papers were drawn on to form the content such as Horne (2006) who discusses the intentional and unintentional underpinnings of non-adherence. This was put in context to NHS agendas such as reducing medicines wastage and helping people to self-manage (Lorig & Holman, 2003; DH, 2011). The references which informed the content of the master-class are detailed within the '*Patient Outcomes Master-Class*' power-point slide-deck (Appendix 1).

Exercises were designed to test people's knowledge and consolidate learning. Adults have a wealth of experience and building on this promotes learning (Beich, 2005) and teaching strategies maximises learning opportunities for different learning styles, such as the theorist or activist styles (Honey & Mumford, 1982). For example, the theorist learns by thinking about problems and likes lectures and case studies, whereas the activist prefers to learn by new experiences and involvement with others such as discussions and problem solving. The audience were asked to look at case studies and work through them in groups or discuss them. For example, a case study was presented in an area where there were high COPD rates. The task was to discuss what could be done locally by partnering with the NHS to try to improve patient outcomes (i.e. supporting patient's to self-manage better by implementing self-care planning and

increased nurse support). A short video was shown of a woman who delayed seeking medical help when she found a lump and how this had impacted the severity of her cancer and treatment options. This generated plenty of opportunities for discussion and questions for example around what could be done to start to address some of the topics (i.e. promoting early symptom awareness).

Thus the '*Patient Outcomes Master-Class*' was developed and ready for delivery. As aforementioned, if requests for further training were made, other modules were developed in the same format as the master-class for example, research, testing the concept with professionals, planning, and development of the final slide-deck (Appendix 2).

### **Deliver Training Programmes Encompassing Knowledge, Skills and Practices in Health Psychology**

The training was delivered using two methods. It was delivered in a face-to-face group setting using power-point, or via live distance learning via Skype (this allowed screen sharing of the power-point slides). The power-point slides and materials were checked and practiced before the day to make sure they were in order. The venues were also checked beforehand to ensure the necessary resources were available for implementation (i.e. Internet connection). The training was delivered several times to the Visions4health team and clients from the pharmaceutical sector face-to-face. The group sizes varied from three to ten people. One-to-one training was also delivered. The slides were delivered as planned with the objectives being set up front and discussions encouraged. The training sessions generated a lot of discussion. Questions from participants were addressed throughout the training and in some cases further reading was provided at a later date via email. Some of the content of the training was amended according to recommendations or what I learnt through the delivery process. For example, extra exercises were included so that the training was more interactive. During each of the training sessions the allocated time was kept to.

### **Plan and Implement Assessment Procedures for Training Programmes in Health Psychology**

Given the short time frame the most appropriate assessment was to tell the audience at the beginning of the training that they would be asked to consider how they could integrate the patient outcomes agenda into their roles at work. The question was then

posed at the end of the training ‘*what are you going to do differently to integrate patient outcomes into your strategy?*’ This question assessed the audience’s ability to use the information from the training course in real life situations. Assessment was also gaged during the training sessions via the audience participating in group exercises and discussions. This provided a level of assessment of their intent to change behaviour.

### **Evaluate Training Programmes Encompassing Knowledge, Skills and Practices in Health Psychology**

My work place supervisor was present at the ‘*Patient Outcomes Master-Class*’ and ‘*Patient Experience Module*’ group training sessions. She gave me a lot of feedback after each of these. In the first instance she said that there was too much information and that more discussion was needed to keep the audience engaged. The training course was amended to align with these recommendations. Positive feedback was given regarding the delivery of the sessions. However, as I had felt nervous she arranged for me to be trained by a colleague. This included discussion of barriers and how to overcome this and observation of training sessions. I was able to learn from their style of facilitation to improve my skills in this area which was very useful. An evaluation form was designed and sent out to participants (Appendix 3). The form was sent via an email after the training to those who had participated. It provided structured feedback on the training. For example, it included information on how informative the participants felt the training had been; how useful the different components were for their role, how likely they were to use the information, and whether the case studies were useful. There was also a question to ensure there were enough opportunities to ask questions and an open text box for any other comments (see evidence folder).

### **Reflection**

At first I found this competence really challenging. The subject matter, patient outcomes, seemed daunting as it was very broad. At the outset I started to think about the details of patient outcomes and felt bogged down in the complexity. After speaking to professionals I learnt to take a step back and think about the definition of patient outcomes first, and then really think the relevant components for the audience. I was familiar with some of the topics I included which helped form the content and theoretical basis to the training, i.e. adherence. I was less familiar with the other health

psychology topics I included, i.e. help seeking behaviour, so learnt a lot through the process.

I have had experience of delivering training through my role in the past to large and small audiences. In some cases before presenting the master-class I felt nervous as some of the audiences had a high level of expertise. When I delivered the training course to the Visions4health audience I was surprised by the amount of questions and discussion generated. In hindsight the training level may have been too low for this audience yet it was partly designed at this level so that they could train clients themselves (train the trainer). I learnt a lot as a facilitator as it taught me to lead the group and to steer the debate in order to move on with the content. The pharmaceutical client audiences were very interested and the level the training for this audience was set at the right level. I felt confident as they were fully engaged. The one-to-one training via Skype was successful. The participants said that they found it really useful and informative. Delivering over Skype was very time efficient and was also very interactive.

The assessment of the master-class could have been more robust. Although the question at the end of the training gave insight into their intent to change behaviour, the intention-behaviour gap has shown that intentions do not always lead to a change in behaviour (Ajzen, 2011). It would be interesting to follow-up at a later date to see if they actually did change their behaviour. Future training will include a pre and post scale to assess behaviour change and also levels of confidence to use the topics within roles will be assessed pre and post training.

The feedback was invaluable in order for me to further develop in this area. I had found this competence challenging from the start and having come through it with the support of my team and work place supervisor I feel I have learnt a huge amount and have the confidence and ability to develop and deliver training in the future at a much higher standard. In the future I will know how to plan carefully and deliver more confidently than before. I will ensure that careful consideration of evaluation will be in place. I will continue to use a variety of stimulus, i.e. videos and case studies to keep the audience engaged and ensure they have practical skills that they can integrate into their roles. I will continue working on the content of the training at hand is so that it is up to date especially with regard to the changing NHS environment. I will work to develop the in-depth modules so that they can be delivered in the future.

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## **UNIT 4: TEACHING AND TRAINING**

### **Case Study 2:**

#### **Stress Management Group Training Session 27/03/13**

##### **Introduction**

Stress is something that can affect everyone and have a negative impact on people's health and wellbeing (American Psychological Association, 2013). Recent research has found that around 59% of adults feel stressed every day or every few days (Mental Health Foundation, 2013). Learning how to manage stress is very important as it will help people cope better.

Through my role at Visions4health I worked with a medical practice (part of the Guildford and Waverley CCG) on a social marketing behaviour change intervention. This intervention was aimed to reduce inappropriate use of emergency services. A consistent issue arose that people often feel stressed which impacted on them using NHS services more. This was supported by recent data showing that stress can have a negative effect on people's wellbeing resulting in a rise in hospital admissions (NHS Choices, 2012). I therefore decided to design stress management training and offer it to patients as part of an initiative to help reduce stress and subsequently have a positive impact on the NHS. I approached the practice manager and offered the training in January 2013. From there I designed and delivered the '*Stress Management*' training for patients who attended a medical practice in Surrey. The training was designed to help patients identify and understand what stress is, how it impacts on their lives, and effective coping strategies they can adopt. I delivered a one-to-one session and two group sessions and have further group sessions booked in (see evidence folder). This case study will describe my experience of delivering a group stress management training session which took place in March 2013.

##### **Plan and Design Training Programmes That Enable Audience to Learn about Knowledge, Skills and Practices in Health Psychology**

The training was advertised in the local patient newsletter and at the front desk of the practice (Appendix 4). Six people booked for the group session on the 27<sup>th</sup> of March and three attended.

The content was developed by conducting extensive secondary research, using academic resources, psychology textbooks (Bernstein and Nash, 1999) and credible websites. In addition, I consulted with a stress/counselling expert to ensure the training was fit for purpose and to advise on effective coping strategies. Websites were used to gain insight into how cognitive behaviour therapy can be applied to understand and modify stress as this is a proven technique (Royal College of Psychiatrists, 2013).

A plan was drawn up for the training session (see evidence folder). Group exercises and discussions were included throughout the training as this is a successful training method for training adults and keeping the audience interested (Beich, 2011). The proposed timeframe for the training was one hour. This was deemed appropriate as it was enough time to cover the key topics. The overall training objectives were to:

1. Discuss what stress is,
2. Identify how stress can impact on people's lives and wellbeing,
3. Highlight coping skills that can be used to tackle stress.

Once the training slides were finished feedback was gained. The counselling/stress expert provided invaluable feedback. Amended slides were then shown to laypeople to ensure they were comprehensible and interesting. One layperson said there was too much information on the slides so they were made shorter and more concise. The slides were then finalised (Appendix 5).

### **Deliver Training Programmes Encompassing Knowledge, Skills and Practices in Health Psychology**

I arrived early to ensure everything was set up. Power-point slides were used to support the training as the slides provided the backdrop to the information, exercises and discussions. The objectives were stated clearly at the beginning of the training and the knowledge base was taught and exercises and discussions took place. A lot of interesting discussions took place providing a stimulating and safe environment to share experiences. There were very positive group dynamics which I facilitated using reflections to demonstrate I was interested and listening. I offered affirmations when patients shared experiences of strategies they had used. I created a relaxed atmosphere

by using open body language and paid attention to voice tone. The session went over the allocated time frame by 15 minutes. At the end of the session a hand-out was given with the coping strategies so that people could take them home to reflect and/or implement (Appendix 6).

### **Plan and Implement Assessment Procedures for Training Programmes in Health Psychology**

A stress knowledge assessment was given to patients' pre and post training (Appendix 7). This assessed whether the patients' knowledge had improved from the training session.

### **Evaluate Training Programmes Encompassing Knowledge, Skills and Practices in Health Psychology**

Patients were asked to fill out an evaluation form (Appendix 8) at the end of the sessions. The evaluation form included six questions and addressed the content of the training and the delivery of the training. Open text box questions were also included so I could gain extra feedback on all aspects of the training (see evidence folder). Comments people found useful included '*hearing others with similar problems,*' '*coping strategies,*' and '*clarifying causes of stress.*' Only one patient fed back about what was least useful and stated '*perhaps needs to be half an hour longer.*' This feedback was an integral part of the teaching and training process in order for it to be improved.

### **Reflection**

I was surprised by the amount of interest in the training from patients. This confirmed there was a need for the training. I had already delivered my teaching and training competence to healthcare professionals so felt confident in developing and delivering this for patients. I have a keen interest in the area of stress which made it interesting. I wanted to develop the training so that it could be informative as well as useful in everyday life, i.e. by giving people different strategies for coping such as exercise, meditation and problem solving.

The training overall was very successful and I was pleased with the participation of the patients. People were willing to share personal experiences and open to learning new coping strategies. I made sure everyone was included and had a chance to share their

experience. The timespan of the training could have been longer. An hour was not quite long enough and I would change this in the future so that it is an hour and a half.

The assessment of the stress management training was assessed positively. Pre and post scales are an effective way to assess behaviour or knowledge change. All scores improved as a result of the training. It would be interesting to do a longer term assessment to see if their knowledge and coping strategies for stress had been put into practice to determine positive behaviour change.

I had very good vocal feedback from the patients at the end of the session. This assured me that the training was well received by the patients. I was glad they felt they took something away and said they would do things differently.

At the end of the group session some of the patients asked about referral services or local services i.e. Pilates groups. As I did not have this information to-hand referred them to the practice and said that I would email this information to them. In the future I will prepare a hand-out listing available local services and contacts, including IAPT services, leisure services, and stop smoking services. The only other amendment I would make would be to make the sessions slightly longer as patients liked to share experiences and this would allow more time to do so.

Overall I was really happy with the way the training went. I believe the patients gained something as did I. I gained skills in managing a group, empathy into people's lives and the different stressors they experience, and confidence from managing and running the session. I already have a list of people for future training and have been offered a room to conduct the training in the future. I will pursue this to develop my career and gain more experience.

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# Appendix 1

## 'Patient Outcomes Master-Class' Training Slides

 <p><b>VISIONS4HEALTH:</b> Patient Outcomes Master-Class</p>	 <p><b>AGENDA</b></p> <ul style="list-style-type: none"><li>• Overview</li><li>• What are Patient Outcomes and Why are they Important?</li><li>• Help Seeking Behaviour</li><li>• Patient Provider Relationship</li><li>• Self Management</li><li>• Measures</li><li>• Summary</li></ul>
 <p><b>OBJECTIVES</b></p> <p>Today's Objectives:</p> <ol style="list-style-type: none"><li>1. Outline what patient outcomes are and why they are important in the current UK healthcare environment</li><li>2. Identify some of the key factors that influence patient outcomes</li><li>3. Equip you with patient outcomes knowledge and examples of good practice that you can integrate into your brand strategy</li></ol>	 <p><b>TODAY'S ASSUMPTIONS</b></p> <ul style="list-style-type: none"><li>• You are a brand manager for a pharmaceutical company responsible for a product that manages a Long Term Condition (LTC)</li><li>• You will be tasked to consider how you could integrate the patient outcomes agenda into the brand strategy</li></ul>
 <p><b>5 GOLDEN RULES</b></p> <ol style="list-style-type: none"><li>1. Be honest and open</li><li>2. To challenge/Question is OK</li><li>3. To be challenged/Question is OK</li><li>4. Respect</li><li>5. Confidentiality</li></ol>	 <p><b>OVERVIEW</b></p> <ul style="list-style-type: none"><li>• Over the next 90 minutes we will look at<ul style="list-style-type: none"><li>○ What patient outcomes are and why they are important</li><li>○ Four key elements that influence patient outcomes<ol style="list-style-type: none"><li>1. Help seeking behaviour</li><li>2. Patient provider interaction</li><li>3. Self management</li><li>4. Measures</li></ol></li><li>○ At the beginning or end of the sections, we will consolidate key learning with exercises or discussions</li></ul></li></ul>

**VISIONS4HEALTH** **AGENDA**

- Overview
- What are Patient Outcomes and Why are they Important?
- Help Seeking Behaviour
- Patient Provider Relationship
- Self Management
- Measures
- Summary

**VISIONS4HEALTH** **WHAT ARE PATIENT OUTCOMES?**

- What are patient outcomes?
- There is no agreed definition, however there are 3 integral components (Healthcare Quality Improvement Partnership, 2012):
  - Giving patients the best care
  - Making sure they are better
  - Making sure they feeling better

**VISIONS4HEALTH** **WHY ARE PATIENT OUCOMES IMPORTANT?**

- Since NHS was established there have been a lot of changes
- Aging population & rise LTCs
- Around 15 million people in England with at least one LTC, that is around one third, and is continuing to rise
  - Over 5m people in the UK have asthma
  - Diabetes affects approximately 2.3 million people
  - An estimated 1.2 million people with heart disease
- Patients with LTCs are the most frequent users of healthcare services
- The number of people with co-morbidities is expected to rise by a third in the next 10 years (DH, 2012)
  - A quarter of patients have comorbidities in primary care, with much higher rates in deprived areas (Pulse, 2012)

**VISIONS4HEALTH** **ECOMONIC BURDEN**

- Current economic climate - £20 billion in **savings** by 2015
- Treatment and care **for LTCs accounts for 70%** of primary and acute budget in England - **Around £77billion** (DH, 2012)
- **Co-morbidities** raise costs even more , e.g. £8 - £13 billion in England each year linked to poor mental health related to LTCs (Kings Fund, 2012)
- **Prescribing costs** are rising - £8.81 billion was spent in primary care last year in England (NELM, 2012)
  - Need to tackle the £300 million lost every year in the NHS because of medicine wastage (DH, 2011)
- **Emergency admissions** have also grown rapidly, rising in England between 2004/5 to 2008/9 by 11.8% (1.35 million extra admissions)
- Reaching & understanding patients more effectively will improve patient outcomes, reduce costs and improve efficiency

**VISIONS4HEALTH** **A CHANGE IN POLICY**

- A move to a **PATIENT CENTRED APPROACH**
  - **Patient outcomes** being the priority
  - **Self care agenda**
  - Focus on **patient empowerment & shared decision making** 'the active patient'
  - Tackling **inequalities**
  - Supporting **LTCs & experience of care**



**VISIONS4HEALTH** **DISCUSSION**

- What are you currently doing in your organisation to address the patient outcomes agenda?

**VISIONS4HEALTH** **ELEMENTS OF PATIENT OUTCOMES**

- We have seen that patients are at the forefront of the NHS and patient outcomes are high on the agenda
- It is also important to identify some of the key factors that influence patient outcomes so this information can be incorporated into your brand strategy



**VISIONS4HEALTH** **AGENDA**

- Overview
- What are Patient Outcomes and Why are they Important?
- Help Seeking Behaviour
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- Summary

**VISIONS4HEALTH** **HELP SEEKING**

**DETECT PROBLEM**

- Seek medical help
- Delay or do not seek help

• [Patient Story Video](http://www.youtube.com/watch?v=GW721EORktA)

**VISIONS4HEALTH** **HELP SEEKING**

- Exercise
- Break into two groups
- List the factors that influence why people seek medical help or not

WHY PEOPLE SEEK HELP	WHY PEOPLE DELAY OR DO NOT SEEK HELP

• 10 Minutes

**VISIONS4HEALTH** **HELP SEEKING**

**PERSONAL, SOCIAL & CULTURAL FACTORS**

PERSISTENCE

AGE KNOWLEDGE SYMPTOM AWARENESS

GENDER FATALISM TIME COST

FEAR SELF MEDICATE SOCIAL NORMS

SOCIAL SUPPORT DENIAL CONVENIENCE EMBARRASSMENT

VISIBILITY CONTROLLABILITY LAY REFERRAL NETWORK

PAST EXPERIENCE PERCEIVED SEVERITY

BELIEFS ETHNICITY

'WAIT & SEE'

**VISIONS4HEALTH** **HELP SEEKING**

- E.g.
- Targeted promotion to encourage bowel cancer screening and identification of cancer
  - Target group: Over 60's
  - Addresses embarrassment
  - Tries to normalise it
  - Makes it assessable and easy

• [http://www.youtube.com/watch?feature=player\\_embedded&v=mVWBb717IQE](http://www.youtube.com/watch?feature=player_embedded&v=mVWBb717IQE)

**VISIONS4HEALTH** **TYPE OF HELP SOUGHT**

- The type of help people seek can impact on patient outcomes, and cost/efficiency of the NHS
  - Average cost per primary care visit of £27.50 (Pulse, 2012)
  - £68 to assess each patient at A&E (Co-Op Pharmacy)
- NHS Central Lancashire found unnecessary visits to A&E locally, i.e. attending with a cold, cost the region's hospitals £79.25 million a year (NHS Central Lancashire, 2010)
- Blanket solutions are ineffective, wasteful of resources and do not tackle health inequalities (Royal Society for Public Health, 2009)
- Need targeted approaches to promote people using the most appropriate services

**VISIONS4HEALTH** **EXERCISE**

- Split into 2 groups
- Aim is to:
  - Improve long term outcomes for patients with COPD locally
  - Improve the quality and effectiveness of COPD care delivered in primary care
  - Reduce avoidable admissions to hospital for COPD
- Nottinghamshire CCG has asked you to partner with them to try to reduce COPD admissions locally. What are some ideas on how you could approach this?

• 10 Minutes

**VISIONS4HEALTH** **CASE STUDY**

- Newark and Sherwood in Nottinghamshire
- Strong coal mining roots
- Prevalence of COPD is higher than national average
- Prevalence is 1.72%, according to the QOF, compared with the UK average of 1.57%
- A further 1,000 people living in the area have undiagnosed COPD
- Between April 2010 and March 2011, 227 patients were admitted to hospital suffering from an exacerbation of their COPD
- Cost of these admissions is estimated at £645,000

**VISIONS4HEALTH** **CASE STUDY RESULTS**

- Pharma supported:
  - Practices undertake systematic Gold Standard **treatment reviews** in line with NICE Guidelines for all COPD patients on COPD registers
  - Developed **integrated care pathways** so care was provided closer to home
  - Provided structured education and support for patients to empower and encourage **self management and shared decision making**
  - Providing **training and education for healthcare professionals** & support for improved utilisation and ensuring clarity around the role and purpose of community specialist nursing teams
- COPD admissions have already **decreased by 18%, in the 6 months** the project has been live which has been remarkable given that this was over the winter period

**VISIONS4HEALTH** **KEY CONSIDERATIONS**

- **KEY CONSIDERATIONS IN YOUR ROLE**
  - Inform patient campaigns promoting **appropriate diagnosis**
  - **Profile patients** for your products
  - Conduct **market research to segment** patients beyond the obvious
  - **Joint working opportunities** for the NHS and pharma. to promote positive help seeking

**VISIONS4HEALTH** **AGENDA**

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**VISIONS4HEALTH** **ELEMENTS OF PATIENT OUTCOMES**

**VISIONS4HEALTH** **PATIENT-PROVIDER INTERACTION**

- The process in which health care professionals and patients **work together** to select tests, treatments, management or support packages, based on clinical evidence and patients' informed preferences (The Health Foundation, 2012)
- Effective interactions can result in improved use of time, increase patient experience, improved adherence, and better patient outcomes
- How much is this happening in your own experience?

**VISIONS4HEALTH** **DISCUSSION**

- Think about your role at work over the last 6 months, what have you done to help providers communicate and interact with patients?

**VISIONS4HEALTH** **BEST PRACTICE INTERACTION**

- Commenting**
  - Establish supportive environment and rapport
  - Develop awareness of patient's emotional state
  - Id all of the patient's issues
  - Establish a mutually agreed plan for the consultation
- Gathering Information**
  - Explore issue to gather information you require, the patient's perception and background
  - Ensure information is accurate, complete and understood
  - Ensure they feel listened to
  - Continue a supportive and collaborative relationship
  - Structure the consultation so the patient's expectations are met
- Examination & Planning**
  - Amount and type of information
  - Provide explanations that the patient can remember and understand
  - Provide explanations that relate to the patient's perspective
  - Interactive approach and shared understanding of the problem
  - Involve them in the planning to improve commitment, self management and adherence
- Closing the Session**
  - Confirm the established plan of care
  - Clarify next steps
  - Establish contingency plans
  - Maximise adherence and outcomes
  - Encourage patient to feel part of a collaborative process, this will help build on the relationship for the future

**VISIONS4HEALTH** **PATIENT-PROVIDER INTERACTION OUTCOMES**

- Positive patient-provider interaction has shown to have an influence on:
  - Reduced anxiety levels
  - Increase patient satisfaction
  - Increase adherence to medication
  - Increased recovery
  - A reduction in repeat consultations and costs

(Kidd, 2008)

**VISIONS4HEALTH** **KEY CONSIDERATIONS**

- **KEY CONSIDERATIONS IN YOUR ROLE**
  - Support **training** i.e. new and existing GP training
  - Use as **best practice**
  - Use within **joint working** projects (within personalised care planning, communication, to support positive experience and outcomes for patients)
  - Support brief **interventions** to use in the provider consultation

**VISIONS4HEALTH** **AGENDA**

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**VISIONS4HEALTH** **ELEMENTS OF PATIENT OUTCOMES**

**VISIONS4HEALTH** **SELF MANAGEMENT**

- Self management/self care is a treatment approach in which patients assume responsibility for their behaviour (Lorig, 2003)
- This is a key component of the governments strategy as it directly impacts patient outcomes and reliance on the NHS
  - Management of LTCs
- There are a lot of interventions trying to promote self management (educational, care planning, tele-health)
- One of the biggest factors influencing self management is **adherence**

**VISIONS4HEALTH** **ADHERENCE**

- Adherence is "the extent to which a person's behaviour - taking medication, executing lifestyle changes - corresponds with agreed recommendations from a health care provider" (Horne, 2006)
- Both the efficacy of a medication and patient adherence will influence the effectiveness of a treatment



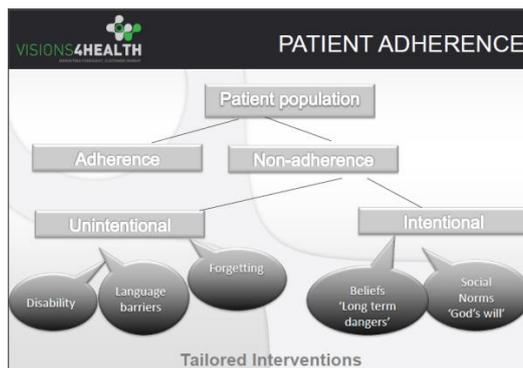
**VISIONS4HEALTH** **PATIENT NON-ADHERENCE**

- Most people with LTCs need to take regular medication
- Yet, WHO (2012) has found that **around 50% of patients** from developed countries with chronic long term health problems do not use medications as prescribed
- Issue across all conditions:
  - Asthma non-adherence rates are often around 30-70% (Bender and Bender, 2005)
  - 20-30% of patients with HIV or AIDS don't adhere (Chesney, 2000)
  - 1/3 of patients with diabetes admit to regularly missing/not taking insulin treatment 3 days a month (McConaghie, 2011)

**VISIONS4HEALTH** **ECONOMIC BURDEN OF NON-ADHERENCE**

- Economic burden is huge!
- £300 million lost every year in the NHS because of medicine wastage (DH, 2011)
- Approx. £230 million of medicines are returned to pharmacies in the UK per year
- + a great deal more disposed of by patients themselves

*34% of non-adhered hospital admissions are medicine related and 30% of these are due to non-adherence to medicines for chronic conditions (School of Pharmacy, 2011)*



**VISIONS4HEALTH** **NON-ADHERENCE**

- Need to understand both the intentional and unintentional factors
- Actual severity of an illness is not related to adherence, but patient perception of severity is
- If medication is prescribed over a long period of time, it is more likely to be discontinued early (Haynes 1976)
- Patients often develop their own incorrect theories about their illnesses
- What can be done to tackle non-adherence?

**VISIONS4HEALTH** **EXERCISE**

1. You are managing a product for stroke. What are some of the reasons for non-adherence?
  - 3<sup>rd</sup> most common cause of mortality and one of the main causes of adult physical disability in England
  - Medical treatment is imperative for the management of stroke and the risk reduction of recurrent stroke
  - The risk of recurrent stroke is reduced by up to 38% when antiplatelet agents are adhered to (Fan, Mysak, Jeerakathil et al, 2010)
2. What could be done to address non-adherence in stroke patients

- **Take a 10 minutes to discuss**

**VISIONS4HEALTH** **TACKLING NON-ADHERENCE**

- **Evidence based research and systematic reviews**
  - Need to really understand patients beliefs, behaviours, knowledge
  - Condition specific (i.e. diabetes, epilepsy, asthma), age, ethnicity
- **Design and tailor interventions**
  - Reminder packaging, carers and social support...; intentional need to understand and focus on beliefs
  - Education/leaflets, tele-health, support groups,
  - Utilise appointments/interactions such as pharmacists, nurses, GPs, by training healthcare professionals to provide brief adherence interventions, or self care planning, tackling beliefs
- **Stroke – (RCT) self-management** that included education and counselling led by Stroke Nurse Specialists. Individual advice on lifestyle and medication adherence, goal setting, self care plans. Improved adherence at 5mths by lowering BP (Ellis et al, 2005)

**VISIONS4HEALTH** **KEY CONSIDERATIONS**

- **KEY CONSIDERATIONS IN YOUR ROLE**
  - Conduct research to inform your brand strategy
  - Design **patient adherence interventions**
  - Develop **patient resources** that will improve patient outcomes i.e. using technology and self management planning

**VISIONS4HEALTH** **AGENDA**

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**VISIONS4HEALTH** **ELEMENTS OF PATIENT OUTCOMES**

**VISIONS4HEALTH** **MEASURING PATIENT EXPERIENCE**

- The NHS **needs to become better** at measuring **patient experience** to improve outcomes
- Gathering information on patient experience will inform why someone may choose one service over another (help seeking) or patient provider interaction
- Designing and measuring **patient experience** needs to be carefully planned and implemented

**VISIONS4HEALTH** **PATIENT EXPERIENCE**

- Patient experience and satisfaction are often used interchangeably but are different
- How are patient satisfaction and patient experience different?
- **Patient experience** is understanding what is important to patients and what actually happened, not how satisfied they were
- **Patient satisfaction** is important as it measures the process of care/ organisation, i.e. timing, food

**VISIONS4HEALTH** **PATIENT EXPERIENCE**

- Use evidence based frameworks to measure patient experience
- Several organisations have developed frameworks to define what makes up good patient experience
  - The Picker Institute
  - NHS Patient Experience Framework
  - PROMs
- Patient experience is made up of lots of factors and can be difficult to define and measure as it is very subjective
- Experience based co-design methodology (Kings Fund, 2012)

**VISIONS4HEALTH** **MEASURING INTERVENTIONS**

- A lot of interventions are not designed or measured properly
  - New companies using technology to measure behaviour change
  - Biased
  - Robust research to support long term changes
- NHS needs support in benchmarking and auditing patient outcomes

**VISIONS4HEALTH** **KEY CONSIDERATIONS**

- **KEY CONSIDERATIONS IN YOUR ROLE**
  - **Audits**
  - Designing measurement **frameworks**
  - Sharing **best practice**
  - **Risk sharing schemes**

**VISIONS4HEALTH** **AGENDA**

- Overview
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**VISIONS4HEALTH** **SUMMARY**

- Patients are at the forefront of the NHS
- Patient outcomes are high on the agenda in the current UK environment
- Help seeking, the patient provider relationship, self management and measures are all factors that influence patient outcomes
- There are opportunities to support the NHS in joint working, training, promoting help seeking, benchmarking and measuring to improve patient outcomes
- Integrating the patient outcomes agenda into your product strategy will enhance long term behaviour change and positive patient outcomes

**VISIONS4HEALTH** **KEY LEARNINGS**

- What are you going to do differently to integrate patient outcomes into your brand strategy?

**VISIONS4HEALTH**

**THANK YOU**

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# Appendix 2

## 'Patient Experience Module' Training Slides

 <p>VISIONS4HEALTH: Patient Experience Module</p>	 <p>Overview</p> <ul style="list-style-type: none"><li>• Overview</li><li>• Defining Patient Experience &amp; Why is it is Important</li><li>• Measuring Patient Experience</li><li>• Case studies</li><li>• Opportunities</li><li>• Summary</li></ul>
 <p>OBJECTIVES</p> <p>Today's Objectives:</p> <ol style="list-style-type: none"><li>1. Outline what patient experience is and why it is important in the current UK healthcare environment</li><li>2. Identify some of the ways that patient experience can be measured</li><li>3. Equip you with patient experience knowledge and examples of good practice that you can integrate into your role</li></ol>	 <p>5 GOLDEN RULES</p> <ol style="list-style-type: none"><li>1. Be honest and open</li><li>2. To challenge/Question is OK</li><li>3. To be challenged/Question is OK</li><li>4. Respect</li><li>5. Confidentiality</li></ol>
 <p>OVERVIEW</p> <ul style="list-style-type: none"><li>• Over the next 45 minutes we will look at<ul style="list-style-type: none"><li>o What patient experience is and why it is important</li><li>o How patient experience is being measured</li><li>o Examples of best practice</li><li>o At the beginning or end of the sections, we will consolidate key learning with exercises or discussions</li></ul></li></ul>	 <p>OVERVIEW</p> <ul style="list-style-type: none"><li>• Overview</li><li>• Defining Patient Experience &amp; Why is it is Important</li><li>• Measuring Patient Experience</li><li>• Case studies</li><li>• Opportunities</li><li>• Summary</li></ul>
 <p>EXERCISE/ DISCUSSION</p> <ul style="list-style-type: none"><li>• How would you define or explain patient experience?</li><li>• Take a few mins to write this down for your self</li></ul>	 <p>BACKGROUND TO PATIENT EXPERIENCE</p> <ul style="list-style-type: none"><li>• Things have changed a lot since the NHS was established</li><li>• Aging population</li><li>• Rise in long term conditions and co-morbidities</li><li>• Increasing use of the healthcare system and reliance will continue to grow</li><li>• There has been a change in policy aimed at delivering better experience for patients to try to improve care, health, and efficiency</li></ul> <p>(DH, 2012)</p>

## VISIONS4HEALTH BACKGROUND TO PATIENT EXPERIENCE

## VISIONS4HEALTH BACKGROUND TO PATIENT EXPERIENCE

- Thus, there has been a drive towards delivering patient centred care especially in the current economic climate and with increasing demands on the NHS
- Understanding patient experience will influence:
  - The quality of care delivered
  - (Re)designing or refining service delivery as appropriate
  - Patient outcomes

## VISIONS4HEALTH DEFINING PATIENT EXPERIENCE

- Patient experience is very subjective and can therefore be difficult to define
- Patient experience is understanding what is important to patients and what actually happened, not how satisfied they were (Chandola, 2008)

## VISIONS4HEALTH PATIENT EXPERIENCE OR PATIENT SATISFACTION

- Patient experience and satisfaction are often used interchangeably but are different
- Patient satisfaction is also important as it measures the process of care/ organisation/ professional performance by looking at outcome measures and the patient's point of view (Bate & Robert, 2006).
- Can you give an example of patient experience and patient satisfaction that demonstrates how they differ?

## VISIONS4HEALTH PATIENT EXPERIENCE OR PATIENT SATISFACTION

- The important difference is that someone can have the perfect process (fast, efficient, no bottlenecks) or pathway, but an incredibly poor experience, or even a poor quality process and pathway, and a reasonable or good experience
- **Patient experience** - when someone was in the hospital for a knee operation what happened during the discharge process and how did they perceive this experience
- **Patient Satisfaction** - when someone was in the hospital how satisfied were they on a scale of 1-10 with the nursing, and food

## VISIONS4HEALTH PATIENT EXPERIENCE

Example:

- Research shows that waiting times, in which patient expectations are managed, are not predictive of negative patient experiences. People are prepared to wait longer if their expectations are set and their consultation is then fulfilling (Thompson et al. 1996).

## VISIONS4HEALTH WHY IS PATIENT EXPERIENCE IMPORTANT?

*No industry has survived without input from end users!!  
(DiGioia, 2011)*

## VISIONS4HEALTH OVERVIEW

- Overview
- Defining Patient Experience & Why it is Important
- **Measuring Patient Experience**
- Case studies
- Opportunities
- Summary

**VISIONS4HEALTH** **EXERCISE/ DISCUSSION**

- Think about a recent healthcare experience you had/or were part of, and what was good or bad
- Take a few mins to discuss

**VISIONS4HEALTH** **WHY IS PATIENT EXPERIENCE IMPORTANT?**

- The NHS **needs to become better** at measuring **patient experience** to improve outcomes
- Gathering information on **patient experience** will inform why someone may choose one service over another, what happened during the process of care
- Designing and measuring **patient experience** needs to be carefully planned and implemented

**VISIONS4HEALTH** **HOW DO YOU DEFINE AND MEASURE IT?**

- Designing, or redesigning, healthcare processes from the patient's perspective has been a key concept in existing improvement efforts in the NHS (Bate & Roberts, 2006)
- Gathering information about patient satisfaction is usually done through:
  - Audits
  - Complaints
  - Surveys
- These methods can be unsophisticated tools for discovering what really matters to patients

**VISIONS4HEALTH** **HOW DO YOU DEFINE AND MEASURE IT?**

- Patient experience is made up of lots of factors and can be difficult to measure as it is very subjective
- Several organisations have developed frameworks of what makes up good patient experience

**VISIONS4HEALTH** **HOW DO YOU DEFINE AND MEASURE IT?**

- The Institute of Medicine (2001), described 6 'core domains':
  1. Compassion, empathy and responsiveness to needs, values and expressed preferences
  2. Co-ordination and integration
  3. Information, communication and education
  4. Physical comfort
  5. Emotional support, and relieving fear and anxiety
  6. Involvement of family and friends
  - Note: they say due to the complex nature of patient experience there is no way all aspects can be measured

**VISIONS4HEALTH** **HOW DO YOU DEFINE AND MEASURE IT?**

- The Picker Institute in 2009 identified 8 core domains:
  1. Respect for patients' values, preferences and expressed needs;
  2. Coordination and integration of care;
  3. Information, communication and education;
  4. Physical comfort;
  5. Emotional support and alleviation of fear and anxiety;
  6. Involvement of family and friends;
  7. Transition and continuity;
  8. Access to care
- They recommend the NHS encourages staff to use these core domains as their main measures of patient experience of inpatient care, to help build up comparable datasets that can be shared between acute trusts
- They recognise there are many aspects of care that affect a patient, it proposes findings should be used as a guide for the development of quality markers in England

**VISIONS4HEALTH** **HOW DO YOU DEFINE AND MEASURE IT?**

- Patient Reported Outcome Measures (PROMs) are another way of measuring patient experience (The Health and Social Care Information Centre, 2011)
  - Tend to look at the way patients perceive their health and the impact the intervention has had on their Quality of Life (QoL)
  - PROMs are often questionnaires designed by academic institutions that take years to develop and have DoH backing
  - They are self reported and filled out pre and post intervention.
  - Usually administered in acute settings
  - They are broad as well as specific, i.e. Specific to epilepsy
  - They often aren't implemented properly and so don't measure what is important to the patient
  - They are not consistently rolled out across the country and therefore it is hard to benchmark

**VISIONS4HEALTH** **HOW DO YOU DEFINE AND MEASURE IT?**

Primary care

- QOF: one of the QOF domains is patient experience (DoH, 2009). It has 3 indicators:
  1. Information for patients
  2. Medicines management
  3. Length of consultations and access to GP
- DES: GP practices have recently been advised that until 31/03/13, additional payments will be available under a new 'Patient Participation Directed Enhanced Services (DES)' (British Medical Association, 2011)
  - Practices undertaking actions to actively engage with representative cross-sections of their populations to get feedback

**VISIONS4HEALTH** HOW DO YOU DEFINE AND MEASURE IT?

The Kings Fund – Experienced Based Co-Design (The King's Fund, 2011)

- A methodology used to capture the experiences of patients, carers and staff through discussion, observation and filmed interviews. It then brings staff and patients together to explore the findings and to work in small groups to identify and tackle areas for service improvement.
- It was designed for and within the NHS to develop simple solutions that offer patients a better experience of treatment and care.

Experience Based Design

- Shadowing: walk the walk of patients – observations > empathy > insights > Implementation.
- Focus groups and interviews.
- Staff experiences. If patients want dignity and respect then this needs to be reciprocated to staff.
- Map patient experience & map staff experience.

**VISIONS4HEALTH** HOW DO YOU DEFINE AND MEASURE IT?

- Other methods:
  - Self report questionnaires
  - Technology
    - Online Systems and surveys
    - Kiosk & Handheld Devices
    - Text Messaging
    - Integrated Patient Experience Feedback Systems

**VISIONS4HEALTH** OVERVIEW

- Overview
- Defining Patient Experience & Why is it is Important
- Measuring Patient Experience
- Case studies
- Opportunities
- Summary

**VISIONS4HEALTH** CASE STUDY

- Video - [Best Practice - Patient Experience Videos](#)
- Demonstrates the benefit of gaining patient experience feedback
- Shows how trusts can share these experiences to improve services
- Can you see this being applied to other services, i.e. primary care?

**VISIONS4HEALTH** CASE STUDIES

Case study - Musgrove Park NHS

- DGH – 700 beds, 4000 staff
- Developed 'simple acts in change'
- 12 clinical teams looked at re-designing pathways to improve them with patient perspective
- Mapped from point of admission to discharge in the stroke pathway
- Got baseline measures and follow-up
- Then with data they refined the pathway using the insights
- Found that people wanted a document when they arrived on what to expect, improved signposting and support—they produced a leaflet
- Results: 15% decrease in mortality and improved outcomes (Price & Whiting, 2011)



**VISIONS4HEALTH** OVERVIEW

- Overview
- Defining Patient Experience & Why is it is Important
- Measuring Patient Experience
- Case studies
- Opportunities
- Summary

**VISIONS4HEALTH** KEY CONSIDERATIONS

- KEY CONSIDERATIONS IN YOUR ROLE
  - Audits
  - Designing measurement frameworks
  - Sharing best practice

**VISIONS4HEALTH** OVERVIEW

- Overview
- Defining Patient Experience & Why is it is Important
- Measuring Patient Experience
- Case studies
- Opportunities
- Summary

- Patient experience is becoming increasingly important in the healthcare system
- It is high on the national policy agenda
  - Health and Social Care Bill: Improve outcomes by taking into account and showing "the quality of the experience undergone by patients."
  - Outcomes Framework Domain 4 - Ensuring that people have a positive experience of care.
  - QIPP: gather baseline patient experience data over a period of time (in advance of making any changes) and use this to identify possible areas for improvement.
  - DES
- There are lots of opportunities to start to think differently and innovatively about patient experience
- Understanding and measuring patient experience more will improve patient outcomes, costs and efficiency

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# Appendix 3

## Evaluation - Template

**1. The Patient Outcomes Training was informative (with 1 being do not agree and 5 being highly agree)**

1 2 3 4 5

Other (please specify)

**2. The components of the training were useful for my role (with 1 being do not agree and 5 being highly agree)**

1 2 3 4 5

Other (please specify)

**\*3. The most useful components of the training were (please rank from highest to lowest with 1 being low)**

Help seeking

Patient provider interaction

Self management/adherence

Measures/patient experience

**4. The training was delivered to a good standard (with 1 being do not agree and 5 being highly agree)**

1 2 3 4 5

Other (please specify)

**5. There were plenty of opportunities to ask questions (with 1 being do not agree and 5 being highly agree)**

1 2 3 4 5

Other (please specify)

**6. I found the case studies relevant and interesting (with 1 being do not agree and 5 being highly agree)**

1 2 3 4 5

**7. I am likely to use the information in my role (with 1 being do not agree and 5 being highly agree)**

1 2 3 4 5

**8. Any other comments/feedback**

# Appendix 4

## Stress Management Advertisement



### Practice Newsletter – February 2013

#### Latest news from the Team

As you may already know, Dr Norris has reduced his working hours at the Practice. We are very pleased to announce that Dr Kerry Angiolini has joined the Partnership and 50% of Dr Norris' previously registered patients have been re-allocated to Dr Angiolini by the Primary Care Support Service.

#### Flu season has ended

We have had a record year for the uptake of flu vaccinations. We managed to vaccinate 81% of our eligible patients between September and the end of January and have already placed our order for next season!

#### Save the date...

Don't forget to mark a reminder in your diary or calendar at the end of August for all those who are eligible to contact the surgery & book a 'flu vaccine. Please remember that a diagnosis of asthma does not automatically entitle you to receive a vaccination as a personal medical history and current repeat medication are reviewed in line with national eligibility criteria. To check your status, please contact an asthma nurse at the Practice and we would be happy to clarify your situation.

#### Appointment system

Subject to daily availability, we would like to remind you that we have

- 2 week book ahead appointments
- 48 hour book ahead appointments
- Same day appointments
- Internet appointments (beginning & end of day at BOTH SITES)

These appointments are at 10 minute intervals. Please try to bring only ONE problem per appointment.

The 5 minute lunchtime slots are intended for those patients with acute (i.e. not longstanding) medical problems who need to be seen that day. Patients with longstanding problems are requested to make a routine booked appointment with the doctor of their choice, as these consultations will often take longer than the allocated 5 minutes and a delay often frustrates those who are waiting to be seen.

#### A new computer system for appointments and medical records

In mid-February a new system for appointments, prescriptions and medical records is being installed at both sites. Please bear with us whilst we all navigate our way around the system as it may take a little longer until we become familiar with it.

#### Stress management

Stress is something that everyone experiences. It can be mild or more severe depending on life circumstances. It might be something you feel every so often or something that affects you on a day to day basis. You might find it useful to understand what triggers stress in your life and some of the coping strategies that can be put in place to combat it. We have a Health Psychologist trainee running a **one off free hour long stress management course**. During the hour you will discuss what stress is, how it can impact our lives and bodies, and some good strategies that can be used to start to tackle it. The aim is for everyone to take away something useful. People do not have to share personal experiences if they do not want to. Please contact reception if you are interested in taking up this offer.

# Appendix 5

## Stress Management Training Slides

VISIONS4HEALTH

# STRESS MANAGEMENT

Beatrice Chapman  
(Trainee Health Psychologist)

VISIONS4HEALTH

## AGENDA

- Introduction
- What is stress?
- How can stress impact people's lives?
- Coping strategies
- Summary

VISIONS4HEALTH

## OBJECTIVES

Today's Objectives:

1. To discuss what stress is
2. To identify how stress can impact on our lives and wellbeing
3. To highlight coping skills that can be used to tackle stress

VISIONS4HEALTH

## AGENDA

- Introduction
- What is stress?
- How can stress impact people's lives?
- Coping strategies
- Summary

VISIONS4HEALTH

## WHAT IS STRESS?

- Stress means lots of things to different people

How would you define or explain stress? Take a few mins to discuss

- People often think of stress as pressure, tension, and emotional responses

VISIONS4HEALTH

## WHAT IS STRESS

- There is a difference between stress that is beneficial and stress that is harmful<sup>2</sup>
- Eustress
  - Getting into college
  - Skiing down a slope
  - Going on a roller-coaster
- Distress
  - Difficult work environment
  - Overwhelming sights and sounds
  - Threat of personal injury




VISIONS4HEALTH

## WHAT IS STRESS

Why do you think eustress is important?

- Everyone needs a bit of stress in life in order to be motivated, challenged and productive



- It is when stress is negative and overwhelming that it can harmfully influence our lives and health

VISIONS4HEALTH

## WHAT IS STRESS?

- The negative **emotional & physiological** process that occurs as individuals try to adjust or deal with circumstances which disrupt, or threaten to disrupt, a person's **daily functioning**<sup>1</sup>
- **Stressors/triggers:** Events of situations to which people must adjust. I.e. exams, work, accidents...
- **Stress reactions:** Physical, psychological, and behavioural responses to stressors, i.e. increased heart rate
- People cope differently to different levels of stress<sup>3</sup>

3 different types of stress....

**VISIONS4HEALTH** **3 TYPES OF STRESS**

**1. Acute Stress<sup>4</sup>**

- The most **common** form of stress
- It comes from **demands and pressures**
- It can be the **difference between expectation and event<sup>6</sup>**
- **Too much is exhausting**. A fast run down a challenging ski slope, is exhilarating early in the day. That same ski run late in the day is taxing
- Overdoing on short-term stress can lead to **psychological distress, tension headaches, upset stomach, and other symptoms**
- As it is short term, it doesn't have enough time to do the extensive damage. It can crop up in anyone's life, and it is **highly treatable and manageable**

American Psychological Association, 2013

**VISIONS4HEALTH** **3 TYPES OF STRESS**

**2. Episodic Acute Stress<sup>4</sup>**

- Some people suffer **acute stress frequently**
- **Persistent** worries
- The symptoms are the symptoms of extended over arousal: **persistent tension headaches, migraines, hypertension, chest pain, and heart disease**
- Lifestyle and personality can contribute and sometimes stress becomes **ingrained and a habit**
- People may have **'displaced emotion'** whereby they put one's anger or frustration onto other people who they often feel safe with

American Psychological Association, 2013

**VISIONS4HEALTH** **3 TYPES OF STRESS**

**3. Chronic Stress<sup>4</sup>**

- This is **grinding stress** that wears people away day after day, year after year. I.e. stress from poverty, being trapped in an unhappy marriage or in a despised job or career, living in a warzone
- It comes when a person **never sees a way out** of a miserable situation
  - Can stem from traumatic events
- People can get used to it. They forget it's there
- May need specialist support

American Psychological Association, 2013

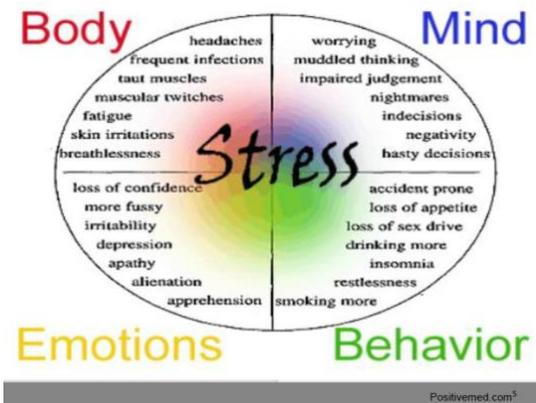
**VISIONS4HEALTH** **AGENDA**

- Introduction
- What is stress?
- **How can stress impact people's lives?**
- Coping strategies
- Summary

**VISIONS4HEALTH**

Start to think about stressors in your life, what causes them, how they make you feel, and some of the negative and positive coping strategies you use

- Discuss the triggers in your life
- What are some of the **symptoms** of stress? i.e. tension. Take a few minutes to discuss



**VISIONS4HEALTH** **LONG TERM IMPACT OF STRESS**

- **Over time** the more stressors there are and the **longer they last the more the body will try to resist them**. This can use a lot of your body's energy and you may become **exhausted or burnt out**
  - It will result in wear and tear
- Your body may go into 'flight or fight' mode and after time can result in **long term damage** to your health
  - When people are stressed adrenaline is released which is responsible for physical symptoms such as tension, headaches....
- Stress has been linked to high blood pressure, viral infections or diminished immunity, heart disease...<sup>1</sup>

**VISIONS4HEALTH** **LONG TERM IMPACT OF STRESS**

- People cope differently. There are negative and positive coping strategies

Can you list a few?

- I.e. smoking, drinking, overeating, denial .....

What do you use

**VISIONS4HEALTH** **EXAMPLE**

- This women has a highly stressed job
- She works in excess of 50 hours a week
- The company have been making people redundant
- She is socialising less and spending less time with her family
- Her family rely on her income



**VISIONS4HEALTH** **EXAMPLE**

What do you think she could do to address her stress?

Body

- Headaches
- Tiredness

Mind

- Worry
- Negativity

Emotions

- Irritable
- Vulnerable

Behaviour

- Restless
- Increased smoking



**VISIONS4HEALTH** **AGENDA**

- Introduction
- What is stress?
- How can stress impact people's lives?
- Coping strategies
- Summary

**VISIONS4HEALTH** **COPING STRATEGIES**

- It is useful for everyone to learn to **manage stress**
- There are **many ways** to manage stress
- Which methods you choose **depends on which suits you best**, as well as the severity of the stress which you are experiencing
- Whatever you choose, it is worth making a commitment to yourself to do it regularly for a period and then reassess

**VISIONS4HEALTH** **9 TOP TIPS**

1. Be **flexible**. Know what you can change and can't, be open to changes
2. **Relax and laugh**. Watch a funny film, read a good book
3. **Breathe** slowly, deeply, and well. Relaxation begins with slow, deep breathing from your diaphragm
4. Learn to say "**no**". It's hard to sometimes, but you can't do everything
5. Go ahead and **make mistakes**. No one's perfect. The only way we really learn is from our mistakes. Accept them as the natural process of growing in wisdom
6. Take up a **hobby**. **Do something different**

**VISIONS4HEALTH** **9 TOP TIPS**

7. **Eat well and avoid stimulants**. A healthy diet makes the body strong and increases a sense of well-being. Caffeine and nicotine put stress on our bodies
8. **Face your difficulties**. Problems have a tendency to mount quickly, until there can seem so many as to be overwhelming. Tackle them **one at a time**. Set achievable goals. Your day will seem appreciably lighter after even one dreaded task is tackled
9. Be good to yourself and try to challenge your stress. **Re-think stress**

**VISIONS4HEALTH** **PROBLEM SOLVING**

- If you find that you are repetitively thinking about a number of problems, often without making much progress, then it is worth setting aside some time to look at the issues
- The table below is a useful format for problem solving
- It will be necessary to update and amend the table on a regular basis as situations and decisions change

List problems in order of priority	Brainstorm all the options for each problem	List the advantages	List the disadvantages	Decisions about future actions	Time planning	Review date
2 Big Projects to complete by end of the week	Prioritise one first Get help from a colleague Do overtime	This one will be done well It will ease the workload I will get both done	I might run out of time to do the 2nd one They might not do it to my standard I am already tired	I will ask colleague to help and if they can I will work on the main project	Finish by Thursday and then spend Friday checking other project	Thursday

**VISIONS4HEALTH** **EXERCISE**

- **Get active!**
- Exercise brings out the body's **endorphins**, natural pain-killers and pleasure-producing substances
- Try several different ways to exercise and see which is best for you at that time

**VISIONS4HEALTH** **MEDITATION**

- **Meditation**
  - The principle of being fully involved in what is actually happening in that moment
  - Results in calming the mind and body, rather than constantly thinking through other things in your head
- Most are learned in a class with a leader but can be practiced at home
  - **Yoga** - slowly into a series of stretched positions which increase flexibility, improved circulation, concentration and mental calming
  - **Sitting meditation** - empty the mind of the busy chatter

**VISIONS4HEALTH** **STRUCTURING YOUR DAY**

- If your day is not already structured with work, family commitments or other things it is worth **making a routine for yourself**
  - Time to get up, times to eat, shop, cook, see other people and a time for some other activities
- It is better to be in charge of a routine for yourself rather than be free-floating through the day

**VISIONS4HEALTH** **SOCIAL SUPPORT**

- **Talk to others**
  - Sharing difficulties and problems allows one talk through and feel better
  - "A problem shared is a problem halved"
- **Find a good listener**
  - Frequently 'good advice' from a friend is anything but that, and what one really needs is someone who is good at being there for you in an open, non judgemental way, empathic, supportive and responsive, but not directive.
- If you choose someone and it does not seem to be working well for you, then don't give up on it altogether, but know that this is common and it is good to move on to try someone else

**VISIONS4HEALTH** **AGENDA**

- Introduction
- What is stress?
- How can stress impact people's lives?
- Coping strategies
- **Summary**

**VISIONS4HEALTH** **SUMMARY**

- Today we talked about **what stress actually is**
  - Discussed stressors, events or situations that we have to adjust to and deal with
- Stress can have a **positive influence** on us by increasing motivation and drive but continuous or **negative stress can be harmful**
- Negative stress can impact on our mind, body, behaviour and emotions and **tackling it is key**
- There are lots of **great coping strategies** and finding the one that best suit you will help you to feel less stressed and happier!

**VISIONS4HEALTH** **REFERENCES**

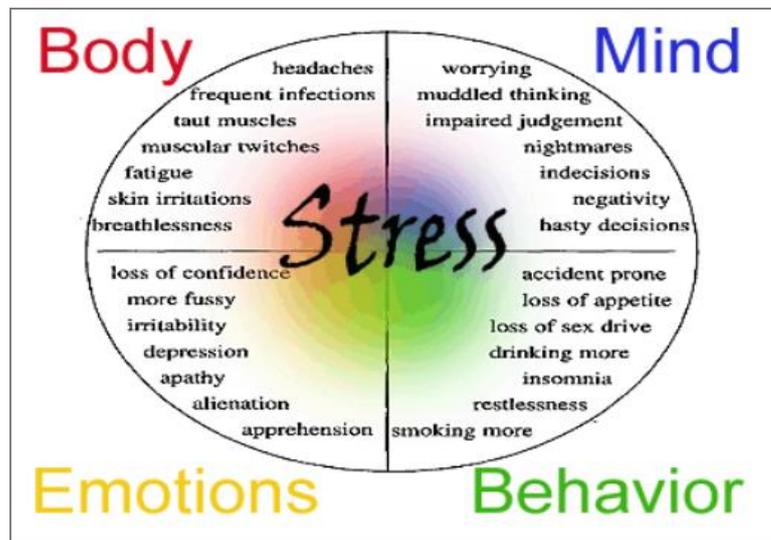
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## Appendix 6

### Stress Management Coping Strategies Handout

Step 1: Identify the stress in your life. What is causing you to feel stressed?

Step 2: How is it impacting on you and your life? And what are the consequences of this in the short term and longer term?



Step 3: What can you do to tackle stressors? Choose the most appropriate method for you for that particular stressor

#### **9 Top Tips**

1. Be flexible. Know what you can change and can't, be open to changes
2. Relax and laugh. Watch a funny film, read a good book
3. Breathe slowly, deeply, and well. Relaxation begins with slow, deep breathing from your diaphragm
4. Learn to say "no". It's hard to sometimes, but you can't do everything
5. Take up a hobby. Do something different
6. Go ahead and make mistakes. No one's perfect. The only way we really learn is from our mistakes. Accept them as the natural process of growing in wisdom
7. Eat well and avoid stimulants. A healthy diet makes the body strong and increases a sense of well-being. Caffeine and nicotine put stress on our bodies
8. Face your difficulties. Problems have a tendency to mount quickly, until there can seem so many as to be overwhelming. Tackle them one at a time. Set achievable goals. Your day will seem appreciably lighter after even one dreaded task is tackled
9. Be good to yourself and try to challenge your stress. Re-think stress

#### **Problem Solving**

- If you find that you are repetitively thinking about a number of problems, often without making much progress, then it is worth setting aside some time to look at the issues
- The table below is a useful format for problem solving

- It will be necessary to update and amend the table on a regular basis as situations and decisions change

Table: *Problem Solving*

<b>List problems in order of priority</b>	<b>Brainstorm all the options for each problem</b>	<b>List the advantages</b>	<b>List the disadvantages</b>	<b>Decisions about future actions</b>	<b>Time planning</b>	<b>Review date</b>
<i>2 Big Projects to complete by end of the week</i>	<i>Prioritise one first Get help from a colleague Do overtime</i>	<i>This one will be done well It will ease the workload I will get both done</i>	<i>I might run out of time to do the 2<sup>nd</sup> one They might not do it to my standard I am already tired</i>	<i>I will ask colleague to help and if they can I will work on the main project</i>	<i>Finish by Thursday and the spend Friday checking other project</i>	<i>Thursday</i>

### **Exercise**

- Get active!
- Exercise brings out the body's endorphins, natural pain-killers and pleasure-producing substances produced inside every one of us
- You could try several different ways to exercise, seeing which is best for you at that time
  - Walking is often the simplest as we do it every day and can be incorporated into daily living, perhaps walking instead of bus or car. Running and swimming are also good
  - Sports, especially team sports are good, being both a physical activity as well as interacting with others

### **Meditation**

- There are several activities based around meditation
- All include the principle of being fully involved in what is actually happening in that moment, which results in calming the mind and body, rather than constantly thinking through other things in your head
- Most are learned in a class with a leader but can be practiced at home
  - Yoga involves moving slowly into a series of stretched positions which both increase strength, flexibility, improved circulation, concentration and mental calming
  - Sitting meditation involves emptying the mind of the busy chatter which can be so pre-occupying and staying in the immediate present, which leads to an expansive calmness and clarity

### **Structure your day**

- If your day is not already structured with work, family commitments or other things it is worth making a routine for yourself, time to get up, times to eat, shop, cook, see other people and a time for some other activities

- It is better to be in charge of a routine for yourself rather than be free-floating through the day

### **Social Support**

- Talk to others. Sharing difficulties and problems with another person allows one talk through and feel better “A problem shared is a problem halved”
- Find a good listener. Frequently ‘good advice’ from a friend is anything but that, and what you really need is someone who is good at being there for you in an open, non-judgemental way, empathic, supportive and responsive, but not directive
- If you choose someone and it does not seem to be working well for you, then don’t give up on it altogether, but know that this is common and it is good to move on to try someone else till you find the person who is right for you

## Appendix 7

### Stress Knowledge Pre and Post Training Session Fairland's Medical Centre

4. I have a good knowledge of what stress is (please tick which one applies to you)

*Very High*      1      2      3      4      5      *Very Low*

5. I understand what causes stress in people (please tick how much you agree with this statement)

*Agree*              1      2      3      4      5      *Disagree*

6. I feel I know what triggers stress in my life (please tick how much you agree with this statement)

*Agree*              1      2      3      4      5      *Disagree*

7. I am aware of coping strategies for stress (please tick how much you agree with this statement)

*Agree*              1      2      3      4      5      *Disagree*

# Appendix 8

## Evaluation Report: Stress-Management Training Fairland's Medical Centre

### Patient Feedback

1. What did you think of the training session overall?

*Very Good*      1      2      3      4      5      *Very Bad*

2. What did you think of the content of the training?

*Very Good*      1      2      3      4      5      *Very Bad*

3. How do you rate the delivery of the training?

*Very Good*      1      2      3      4      5      *Very Bad*

4. What did you find most useful about today's session?

5. What did you find least useful about today's session?

6. Any other comments

---

## **SECTION D: SYSTEMATIC REVIEW**

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# **The Effectiveness of Self-Management Interventions to Improve Adherence to Medication in Stroke Patients: A Systematic Review**

## **Abstract**

*Background:* Stroke is the third most common cause of mortality and one of the leading causes of adult physical disability in England (Public Health England, 2012). Medical treatment is imperative for the management of stroke and the risk reduction of recurrent stroke and the success of a medical treatment is determined largely by adherence. However, research has shown that adherence to medication in patients who have had a stroke is often sub-optimal. Self-management interventions have been shown to improve adherence in long-term conditions. The impact of self-management interventions specifically on the outcome medication adherence in stroke is unknown.

*Objective:* To systematically review the impact that self-management interventions have on the outcome adherence to stroke medication.

*Method:* The online databases that were systematically searched included PsychINFO, MEDLINE, EMBASE, Scopus, Cochrane Database of Systematic Reviews, CINAHL, and Web of Science. Only RCTs and quasi-experimental design studies were included. The search terms included: (stroke OR 'cerebrovascular accident' OR 'cerebrovascular disease' OR 'transient ischaemic attack' OR 'TIA') AND (adherence OR 'non-adherence' OR compliance OR 'non-compliance' OR concordance) AND (intervention\* OR trial OR programme OR program). This was limited to humans and adults ( $\geq 18$  years), and journal articles published in the preceding 10 years. Reference lists of retrieved studies were hand searched.

*Results:* Six studies met the criteria for inclusion for the systematic review. The quality of the studies overall were good, although there were some methodological issues. Self-management interventions for stroke patients were effective in improving adherence to stroke medication in the short-term. However, in the longer term these benefits were not maintained.

*Conclusions:* Applying self-management interventions to improve medication adherence in stroke patients across integrated clinical settings show promise. However,

further development of such interventions and research is recommended, using more stringent methodologies and with longer follow-up periods.

## **Introduction**

### **Stroke**

Stroke is one of the leading causes of mortality and disability in the UK and can have a long lasting and profound impact on a person's life (Public Health England, 2012). A stroke occurs when there is a blood clot or bleed in the brain. In England there are approximately 110,000 people who have a stroke each year. The effects can vary widely and can result in damage to physical, cognitive and emotional functioning (Department of Health, 2007). Some people may only be mildly affected whereas others are severely affected (Brain Foundation, 2012). This will depend on the type of the stroke and the area of the brain that is damaged (National Stroke Association [NSA], 2012). There are three main types of stroke, ischaemic, haemorrhagic and Transient Ischaemic Attack (TIA). Ischaemic strokes occur when arteries carrying blood to part of the brain are blocked. A haemorrhagic stroke occurs when a blood vessel ruptures. A TIA is a mini stroke and similar to an ischaemic stroke but symptoms usually pass within 24 hours. Those affected are at very high risk of a recurrent stroke which may result in more severe outcomes. The overall possibility of a recurrent stroke for all types of stroke is high, with 30-43% of people likely to have one within five years (O'Carroll, Whittaker, Hamilton, Johnson, Sudlow, et al., 2011).

Stroke has been highlighted as a major challenge for the National Health Service (NHS) and emphasised recently by national guidance such as the National Stroke Strategy, as an area requiring improvement (DH, 2012). It has been estimated that approximately 5% of the total NHS costs are spent on treatment for stroke, amounting to approximately £9 billion a year (Saka, McGuire & Wolfe, 2008). Age is a major risk factor for stroke, and with an aging population epidemic the number of people at risk of stroke will continue to grow (Di Carlo, 2009). Therefore designing and evaluating interventions for the primary and secondary prevention of stroke that can be implemented easily into clinical practice is key to reduce costs and prevent the occurrence and manage the condition better.

Over the past few decades medical and technological advances have transformed our understanding and the treatment of stroke, which has led to opportunities to save lives

and reduce disability. After a stroke has occurred there are medical treatment options available that restore blood flow and enhance brain function when parts of the brain have been damaged (DH, 2007). These include anticoagulation and antiplatelet treatments (Alberts, 2011). Cholesterol and blood pressure medicines are also available. The Royal College of Physicians (2012) recommend that the management of patients after a stroke or TIA should be the same. Research and clinical guidance therefore support the use of medicine for the treatment of all types of stroke and to reduce the risk of recurrent stroke (DH, 2007). They should be initiated as early as possible to reduce further damage and improve patient outcomes (Menard, Smith and Taormina, 2011).

### **Adherence**

Adherence to a medical regimen and is defined as “*the extent to which a person’s behaviour corresponds with agreed recommendations from a health care professional*” (Lehane & McCarthy, 2009). Medicine is the most frequent type of intervention used by patients with health problems and long term conditions and is relied heavily on to improve health and manage illness (Picton & Wright, 2012). The success of a medical treatment is determined largely by adherence; however non-adherence to prescribed medication is widespread and perceived to be a significant problem (Chambers, O’Carroll, Hamilton, Whittaker, Johnston et al., 2011; Horne, 2007). The negative consequences of non-adherence to medication are considerable and can include poor health outcomes, increased morbidity and substantial costs to the NHS (Horne, 2006). Around 50% of patients from developed countries who have one or more chronic conditions do not adhere to their medication as recommended. In the UK it has been estimated that £230 million worth of medicines are returned to pharmacies. This cost does not take into account the waste by patients themselves (Horne, 2006). The cost of wastage coupled with loss of therapeutic benefit is of a huge concern (DiMatteo, Giordani, Lepper & Croghan 2002).

Despite the evidence that stroke medication is imperative for the management and prevention of recurrent stroke, adherence is frequently sub-optimal (O’Carroll et al., 2011). It has been reported that adherence to stroke medication may be less than 50% (Ireland, MacKenzie, Gould, Dassinger, Koper, et al., 2010). Furthermore, half of patients starting antihypertensive medication following stroke stop taking it within one year (Adie & James, 2010). Randomised Controlled Trials (RCTs) have shown that the

risk of recurrent stroke is reduced by up to 38% when antiplatelet agents are adhered to (Fan, Mysak, Jeerakathil et al, 2010).

### **Self-Management Interventions**

The National Stroke Strategy (DH, 2007) has emphasised that money should be invested into helping people who have survived stroke to live independently through the provision of support in the community and in helping them manage their condition. Reviews have found that self-management interventions are effective in improving outcomes in people with long-term conditions (Barlow, Wright, and Sheasby, Turner & Hainsworth, 2002). Self-management interventions aim to support people to manage their condition better. Generally they are comprised of several components including provision of information, medication, problem solving and support (Newman, Steed & Mulligan, 2004).

In stroke it has been found that patients perceive the educational information they receive as inadequate (Rodgers, Bond, & Curless, 2001). Inadequate education can adversely impact on adherence to preventative strategies and psychosocial outcomes (O'Mahoney, Rodgers, Thomson, Dobson, & James, 1997). Integrating advice/information and counselling into interventions targeting adherence to stroke medication has shown to be been advantageous. In accordance with this, studies have shown that combined education and counselling interventions can improve adherence to medication; and interventions that include motivational interviewing, goal setting, and emotional support delivered face-to-face or over the phone have been influential in helping people adhere to their medication (McManus, Craig, McAlpine, & Langhorne, 2008; Ireland et al., 2010; Adie et al., 2010). The impact of self-management interventions specifically on the outcome adherence to medication in stroke is unknown.

An important issue for self-management interventions is ensuring duration of effects are sustained. Maintaining long-term benefits following an intervention is essential to change behaviour. It has been found that several factors influence long-term maintenance of behaviour change. These include the use of problem solving and coping skills (Newman, Steed and Mulligan, 2009). Booster sessions of an intervention have also been shown to be effective in maintaining long term change (Newman, Steed & Mulligan, 2009). In line with this a systematic review found that interventions that were deemed as being more complex in that they included a combination of information,

support, reminders and self-monitoring were more effective in sustaining medication adherence than more basic interventions such as information giving alone (Haynes, McKibbon and Kanani, 1996).

With the knowledge that there is a pressing need to improve stroke care due to an ageing population epidemic, coupled with the evidence that adherence to stroke medication is sub-optimal, the aim of this systematic review is to assess the effectiveness of self-management interventions aimed at improving adherence to medication in stroke patients. The outcome adherence to medication was specifically focused on as it is one of the major factors influencing mortality, morbidity and is a major predictor of recurrent stroke (DH, 2007). The objectives of this systematic review were to:

- assess the effectiveness of self-management interventions on adherence to stroke medication,
- assess the short ( $\leq 6$  months) and long term ( $\geq 6$  months) impact of self-management interventions on adherence to stroke medication.

## **Method**

### **Inclusion Criteria**

Studies that were eligible were those that:

- (1) were published in the English language,
- (2) were quantitative studies,
- (3) were published in peer reviewed journals,
- (4) investigated an adult population ( $\geq 18$  years of age),
- (5) investigated a population who had had a stroke but were not severely cognitively impaired, i.e. were able to remain independent,
- (6) applied pre-post and controlled trial design, with follow-up being at least three months post intervention,
- (7) included RCT or quasi-experimental design studies
- (8) included a self-management intervention,

(9) included interventions that measured medical adherence as an outcome in context to stroke.

### **Exclusion Criteria**

Studies were excluded that:

(11) contained duplicate data,

(12) included patients who had been severely cognitively impaired as a result of stroke,

(13) did not include a measure of medical adherence,

(14) that did not include a control group or pre-test measures.

### **Types of Studies**

This review included only RCTs or quasi-experimental trials. Initially only RCTs were going to be included but due to the limited number of studies this was extended to include quasi-experimental research design trials. The review included published studies covering a 10 year period from 2002 to 2012.

### **Participants**

The review included studies where the participants were diagnosed to have had a stroke or TIA. Studies were excluded if they included participants who were at risk of having a stroke but who had not actually had one. Of those that were included, the participants could not have been severely cognitively impaired as a result of stroke or TIA. Patients with severe cognitive impairment may not have been well enough to be included in the study and may have experienced speech difficulties which could have influenced their ability to give informed consent. This review only included participants who were adults. An adult was defined as 18 years of age or above. The causes, treatment and management of stroke in children and adolescents are different to that of adults (American Stroke Association, 2012). Interventions for children are tailored according to their requirements and would be likely to include the role of a care giver. Hence, adults were only included in this review. Participants were recruited through health or social care settings. It has been determined that health care settings such as a hospital offer unique opportunities to recruit and conduct interventions for stroke patients (Ovbiagele, Saver, Fredieu, Suzuki, Selco, et al., 2004).

## **Self-Management Intervention Components**

Only self-management intervention studies were included. Self-management interventions have been described as including three components: information/education, problem solving/goal setting, and support (Lorig and Holman, 2003). The studies did not always explicitly state that interventions were self-management interventions. However, if the intervention included all three components in some form they were included, for example, a nurse led intervention that included information on stroke medication, support and strategies to cope with side-effects. The studies included interventions that were delivered in person or over the telephone on a one-to-one basis or in a group. Follow-up had to be measured at least 3 months post baseline to ensure an adequate length of time for behaviour change. The interventions included were to be conducted by health care or social care professionals or a researcher.

## **Outcome Measures**

The studies were included if the intervention measured adherence to stroke medication. Most of the studies measured other outcomes as well as medical adherence. As long as medication adherence was one of the outcomes the studies were included. This systematic review only focused on medication adherence as an outcome as it has been shown to be one of the biggest predictors of morbidity, mortality and recurrent stroke (DH, 2007). The measures could be self-report, medical markers, and recording incidences of non-adherence. For example, the medication compliance scale (Morisky, Ang, Krousel-Wood, & Ward, 2008), blood pressure ([BP] Ellis et al., 2005), and self-report measures (i.e. number of incidences in which a patient did not take their stroke medication).

## **Search Strategy to Identify Studies**

A systematic review of the literature was conducted on multiple online databases, namely PsychINFO, MEDLINE, EMBASE, Scopus, CINAHL, and Web of Science February 2012 and July 2012. The search terms used were (stroke OR “cerebrovascular accident” OR “cerebrovascular disease” OR “transient ischaemic attack” OR “TIA”) AND (adherence OR “non-adherence” OR compliance OR “non-compliance” OR concordance) AND (intervention\* OR trial OR programme OR program). This was limited to humans and adults (>18 years), and journal articles published in the preceding

ten years. Figure 1 shows the results of the database search. In addition reference lists of retrieved studies were hand searched, the Cochrane Database of Systematic Reviews and Database of Abstracts of Reviews of Effectiveness (DARE) were hand searched.

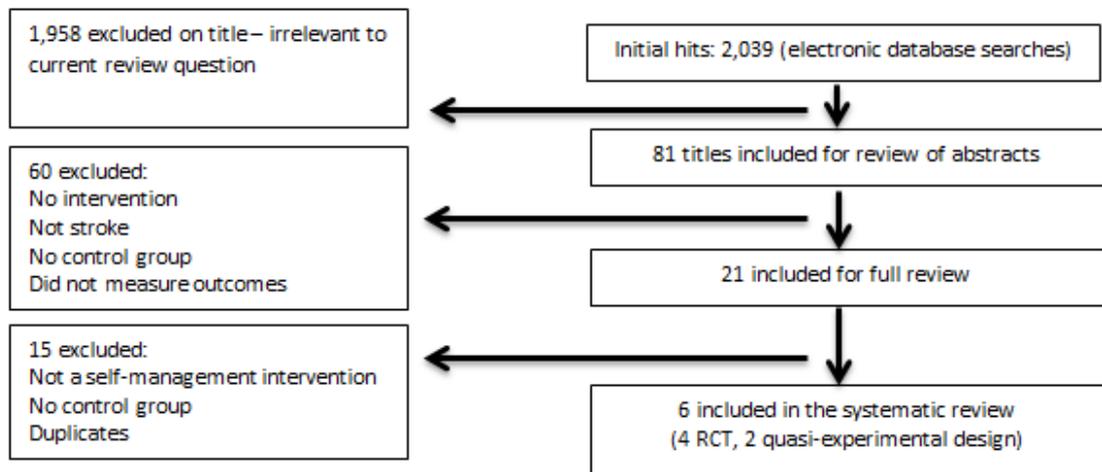


Figure 1: Overview of Search Process and Identification of Studies

The search began by looking for self-management intervention studies that incorporated stroke medication adherence as an outcome measure. Eligible studies were obtained by reading abstracts. In circumstances whereby the search only generated a small number of studies, human and age limitations were not required. However, if the search generated a large number of studies (e.g. EMBASE), these limitations were added. It was apparent from many of the abstracts that studies were evaluating the clinical efficacy of a drug rather than a behaviour change intervention. These studies did not fit the inclusion criteria and were therefore excluded.

The studies that were deemed appropriate were then screened for type of intervention. Initially only RCTs were going to be included, however only four studies were generated. The study type was expanded to include quasi-experimental trials and two more studies were identified. Hence, pre and post measures were a requirement as was a control group. This ruled out further studies. Studies were excluded if they did not include a measure of medication adherence. Some of the studies only included measures for lifestyle adherence (i.e. adherence to an exercise or diet regimen). As this systematic review was concerned with assessing the effectiveness of self-management interventions on adherence to stroke medication, these eight studies were excluded. The

studies were then screened to ensure they included self-management interventions. None of these studies were excluded.

The studies were then screened for participant type (i.e. adults who were not cognitively impaired). All studies described the type of stroke the participant had had and limitations were in place so that only participants who were independent or had not been severely cognitively impaired were included. No studies were excluded.

From this process five studies were identified. One of these studies was a long-term follow-up RCT of a study that was already included. It was decided to include this study as it was important to evaluate the long-term impact of the intervention and had been published as a separate paper. A hand search of abstracts was also conducted to detect any more relevant papers. From this process two further studies were found. One of these was missing the results and the author was contacted. However, they had not been published yet (Cheng, Cunningham, Towfighi, Towfighi, Sanossian, et al., 2011). The other study was included (Adie & James, 2010). Therefore in total six papers were included in the systematic review (see reference list of studies included in this review).

#### *Quality Assessment*

Quality assessment was conducted to highlight any biases that may have occurred. A quality assessment tool was designed for this systematic review and based on some of the criteria of the Quality Assessment Tool for Quantitative Studies (Jackson and Water, 2005). The designed quality assessment tool used seven criteria. These included:

1. Sample size
2. Appropriateness of the population and description of stroke
3. Drop-out rate
4. Follow-up length
5. Length of intervention
6. Appropriate person delivering intervention
7. Appropriateness of adherence to stroke medication outcome measured

Criteria were ranked from 1 – 5 for quality with 1 being low and 5 being high. The studies were assessed by two reviewers. The studies were independently reviewed using the tool discussed. The total score was the average score of the two reviewers.

Discrepancies over the scores were resolved via meeting if more than a two point difference was found.

## **Results**

Six studies met the inclusion criteria for this systematic review. Four of these were RCT studies and two were quasi-experimental design studies. The quality rating of the studies was ranked between one and five and all of the studies included in the systematic review were ranked above three. A meta-analysis was not conducted as the studies used different measures of medication adherence. A synthesis of similarities across the studies was examined as well as the heterogeneity across findings, which is presented in narrative form. Most of the studies analysed the data using t-tests or ANOVA/ANCOVA, and chi-squared tests and stated the version of SPSS that had been used. There was adequate information to report effect sizes in the majority of the studies.

### **Overview of interventions**

Adie and James's (2010) intervention was delivered over the telephone by a researcher. It included brief motivational interviewing, counselling, goal setting and educational material that was tailored to the patients' needs. Claiborne's (2006) intervention was delivered face-to-face by a social worker initially and subsequently via telephone. Problem solving, medication issues, education and enhancement of self-care and counselling was included. Ellis et al., (2005) and McManus et al., (2009) was nurse-led and included face-to-face visits. The patients received individual advice and counselling around medication adherence, all verbal information was backed up with written educational information. Extra time was available for question and answer problem solving. Hohmann, Klotz, Radziwill, Jacobs and Kissel (2009) was a pharmacist-led intervention delivered face-to-face. It included medication review, a counselling interview focusing on specific actions to be taken, side effects, and detecting and solving stroke drug-related problems. Lastly, Sit, Yip, Ko, Gun and Lee (2005) was led by nurses and delivered face-to-face. The sessions included teaching, experience sharing, individual goal setting and action planning, games and reflection. Table one provides a summary of the six studies included in the systematic review.

Table 1: Characteristics of the Included Studies

Study Id. Author(s)	Design	Participants	Intervention	Medical Adherence Outcome	Findings	Quality score
Adie & James (2010)  Study conducted in the UK	RCT: Participants were randomly allocated to intervention or control using block randomisation at the end of their first stroke visit. Sample size: N=56 I=29 C=27  Did not discuss dropout but follow-up data shows no dropouts	Age: Mean age 72.5 years, range 54-90 years. Gender: 54% were female Health and medications: 57% had minor stroke, 43% had had a TIA. Participants were taking a median of 2 stroke medication a day.  Participants had had a minor stroke and were living at home, no dementia or significant disability	Telephone intervention that targeted patient's goals, discussed medicine, educational material was given and it was tailored to individual patient needs for support.  Usual care group had GP appointments. Intervention had 20 minute telephone support at 7-10 days, then at 1 month, 2 months and 4 months (therefore 4 calls)  Intervention was delivered by a researcher  Initiated within 1 month of stroke or TIA and follow-up was at 6 months.	Medical marker: BP  Differences in medication taking – implies self-reported  Effect size: 0.93	Intervention did not improve BP control over 6 month follow up in primary care after stroke/TIA. There was an increase in medication knowledge.	3.8
Claiborne (2006)  Study conducted in the United States	RCT: Participants were randomised to intervention or control  Sample size:	Age: mean age of the intervention group was 70, and of the control group was 65. Gender: chi-	Managed across health services and led by social workers with the aim of integrating the	Self-report: Number of incidences in which a patient did not follow their medication	There was significant improvement for the intervention group. The study showed an	3.07

	<p>N = 28 I – 16 C – 12</p> <p>Dropout rate was poor: (n=5)</p>	<p>square analysis showed there were significantly more women in the intervention group (7 men, 9 women) than in the control (10 men, 2 women). Ethnicity: in both groups the sample was predominantly white. Socioeconomic data: Most of the participants were married and had private healthcare (US study). Household income approximated \$36,000.</p> <p>Participants were not severely cognitively damaged</p>	<p>intervention into coordinated care. Intervention involved additional social care as well as usual treatment which were medication and medical appointments. Additional social care included problem solving, education, holistic care, practical solutions for addressing barriers to treatment</p> <p>Involved weekly telephone interventions for up to one hour for 3 months. Initiated within 2 weeks of discharge and follow-up was at 3 months.</p>	<p>regimen Effect size: -0.61</p>	<p>effect of medication adherence</p>	
<p>Ellis et al., (2005)</p> <p>Study conducted in the UK</p>	<p>RCT: Participants were randomly allocated to intervention or control via a computer generated random sequence</p> <p>Sample size:</p>	<p>Age: average age of intervention group was 64.3; average age of control group was 65.8 years.</p> <p>Gender: 54% of the intervention was male, and 50% of the control group</p>	<p>Involved individual advice on lifestyle and medication compliance. All information was discussed and then written for patients and targets were</p>	<p>Medical markers: BP</p>	<p>The intervention was effective in lowering systolic BP</p>	4.07

	<p>N = 192 I – 94 C – 98</p> <p>Fair dropout rate: (n=4)</p>	<p>were male.</p> <p>Condition: diagnosis of TIA or stroke.</p> <p>Socioeconomic: 76% smoked. No other factors stated.</p> <p>Participants were excluded if cognitively impaired according to Abbreviated Mental Test score &lt;5</p>	<p>decided (self-care planning). It also included education and counselling</p> <p>It was delivered through Stroke Nurse Specialists (SNS)</p> <p>The control group had care as usual, generic advice in outpatient clinic only and GP appointments</p> <p>If a risk factor was found i.e. non-adherence then they were recommended to contact GP for 30min appointment (GPs were aware of study)</p> <p>Initiated at discharge and Involved monthly reviews by a SNS for 3 months/once a month in hospital</p> <p>Baseline pre study (week 1) and follow-up was at 5 months</p>			
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<p>McManus et al., (2009)</p> <p>Study conducted in the UK</p>	<p>RCT: This was the same intervention as Ellis et al (2005) however it was a long term follow-up study and separately published paper</p> <p>Sample size: N = 102 I – 49 C – 52</p> <p>Fairly high dropout: n=103</p>	<p>Age: average age of intervention group was 64.3; average age of control group was 65.8 years.</p> <p>Gender: 54% of the intervention was male, and 50% of the control group were male.</p> <p>Condition: diagnosis of TIA or stroke.</p> <p>Socioeconomic: 76% smoked. No other factors stated.</p> <p>Participants were excluded if cognitively impaired according to Abbreviated Mental Test score &lt;5</p> <p>Description good of initial study but follow-up descriptives less clear: Patients were recruited via letter initially and then via telephone to arrange an appointment</p> <p>Excluded patients who were now in nursing homes</p>	<p>As above</p> <p>Baseline pre study (week 1) and follow-up was 3.6 years</p>	<p>Mixed: Checked medication for out of date tablets</p> <p>Patients asked if they considered themselves to be taking medication regularly. Inconsistent medicine checked</p> <p>Effect size: 0.19</p>	<p>The intervention did not have any long term benefit of medication adherence</p>	<p>3.56</p>
<p>Hohmann et al., (2009)</p>	<p>Quasi experimental design: Patients were</p>	<p>Age: Average age of intervention participants</p>	<p>Led by community based pharmacies.</p>	<p>Medical markers: Hypertension (prescribed</p>	<p>Findings show that although pharmacists</p>	<p>4.12</p>

<p>Study conducted in Germany</p>	<p>either assigned to intervention or control. Assigned to intervention or control based on type of local pharmacy to which patient belonged</p> <p>Sample size: N = 255 I – 90 C – 165</p> <p>Fair dropout rate: (n=25)</p>	<p>68.2 and control group 68.1 years.</p> <p>Gender: 35% of the intervention group were female, and 58% of the control group were female.</p> <p>Medication: twice daily administration of stroke medication.</p> <p>Patients were only included if not severely cognitively impaired (based on the Barthel index over 30 points at time of discharge, clear level of condition and sample)</p>	<p>Intervention involved counselling/ discussion of side effects and medication and goal setting with a local pharmacist in the community. Participants had one hospital session with a clinical pharmacist and then further sessions within the community with a pharmacist.</p> <p>Patients were assigned to intervention at least one session every 3 months. The length of the intervention is not stated, The control had standard care – no individualised support/does not describe at length but stated standard advice from pharmacist given but no counselling</p> <p>Baseline measured at the stroke unit at week</p>	<p>in accordance with the DGN and DSG)</p> <p>Effect size: 0.54</p>	<p>may have a positive impact on quality of life and satisfaction, no impact on stroke medication adherence was noted.</p>	
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			1, and then follow-up was at 12 months.			
Sit et al., (2005)  Study conducted in Hong Kong	Quasi experimental design: Participants were assigned to intervention group or control  Sample size: N = 147 I – 77 C – 70  Dropout was high: (n=44)	Age: average age of intervention participants was 62.8, and control group was 64.02 years.  Gender: 55% of the intervention group were male, and 50% of the control were male.  Socioeconomic variables: the majority of participants were married (70.9%), the majority had a high educational level with most achieving at least secondary school level education, most were retired and lived with family.  Level of stroke was minor and participants were medically stable, cognitively intact and independent in activities of daily living.	Conducted in the community and led by nurses. It included individual goal setting and action plans, problem sharing and discussion of experiences in a group setting. This was incorporated into written action plans which were reviewed in sessions. Each group had 10-12 participants.  Included x8 weekly 2 hr sessions with a focus on goal setting and action plans or control (only medicine)  Baseline was measured at week 1 with follow-up at 3 months	Mixed: BP  Medication compliance scale (Morisky et al, 1986).  Effect size: 0.23	Found a three month effect of stroke medication adherence in participants who undertook the nurse led intervention.	4.15

\* N= total number of participants, I= intervention group, C= control group; quality assessment was rated on a scale of 1-5 (1=low and 5=high)

## **Intervention Findings**

Of the six studies, three had an effect of the intervention on adherence to stroke medication. Claiborne (2006) reported that there was an effect of medication adherence from their social worker-led intervention,  $p < 0.05$ . Hohmann et al., (2009) stated that there was no impact of the pharmacy led intervention on medication adherence. A  $p$  value was not reported. Ellis et al., (2005) reported that the stroke nurse specialist intervention was effective in lowering BP and reported significance at five months,  $p < 0.05$ . (CI-13.1 to -2.6). Sit et al (2007) also conducted a nurse-led intervention and reported significance of medication compliance at  $p < 0.001$ . No statistical significance was found by McManus et al., (2009) who conducted a long-term follow-up stroke nurse specialist intervention,  $p > 0.05$ . Lastly, Adie and James (2010) reported no significant effect of the telephone intervention on medication adherence at  $p > 0.05$ . However, they did report an increase in medication knowledge.

## **Sample**

### *Participants*

The majority of the studies described the sample in detail. This included descriptive variables such as age, gender, ethnicity, and socio-economic variables. There was a total of 789 participants in the included studies with an average age of 67 years: 57% male and 43% female (determined from the available data). Sit et al., (2005) had a sample that had a high level of education therefore generalisability may be limited. All of the studies described the type and severity of stroke. Although different measures were used to assess severity of stroke damage, it was clear across the studies that participants were only included if they were not severely cognitively damaged. For example, “*patients with impairment (defined as an Abbreviated Mental Test (AMT) score < 5 on screening) were excluded from involvement*” (Ellis et al., 2005). The studies also described when the participants had experienced the stroke. For example, patients who had had a stroke within the preceding three months. All of the interventions were initiated soon after the stroke had occurred which was positive as guidance suggests intervening as soon as possible (Menard, Smith & Taormina, 2011).

### *Sample Size*

The sample sizes across the studies differed largely. Some studies such as Claiborne (2006) had a very small sample size of 28 participants, whereas other studies had much

larger sample sizes, such as Hohmann et al., (2009) with 255 participants. Withdrawals and drop-outs in most of the studies were also discussed in detail. Dropout rates were overall fairly mixed in relation to sample sizes. They ranged from no drop outs (Claiborne, 2006; Adie & James, 2010) to 23% of drop outs (Sit et al., 2005). This was a limitation of some of the studies. The longer term studies (> 6 months) had higher rates of dropout and larger sample sizes. Given the nature of stroke, during the long term follow-up period some participant's conditions had deteriorated and some participants had died.

## **Design**

### ***Method of Randomisation***

Method of randomisation was clearly stated. All of the studies that were RCTs, four out of the six, stated how they had been randomised and in the main this was computerised. In accordance with the inclusion criteria for this review, the remaining studies had quasi experimental design and included pre and post measures and a control and intervention group. These two studies assigned participants to a control group in the form of 'standard care' or to an intervention group, which was clearly explained.

### ***Intervention Design***

The designs of the self-management interventions were of good quality. The main components of the interventions were consistent. For example, they all included advice about stroke, self-care planning, goal setting, personalised feedback, education, and support. In the interventions participants could discuss medication issues they were having and then put strategies in place to overcome these. Although the components were described, they were not described in detail.

All but one of the interventions included face-to-face visits. The remaining intervention was delivered over the telephone (Adie & James, 2010). This study did not have an effect on medication adherence. One study (Claiborne, 2006) began with a face-to-face visit and then subsequent sessions were delivered over the telephone. This did have an effect on medication adherence. Including at least one initial face to face visit may be beneficial, however further research is needed.

There was disparity in the frequency of the interventions. One was conducted monthly via face-to-face interaction or via telephone (Ellis et al., 2005; McManus et al., 2009).

Another (Adie and James, 2010) was sporadic whereby there was an initial phone conversation followed by one at 1 month, 2 months and then at 4 months. Others were weekly (Claiborne, 2006; Sit et al., 2005). Some were less frequent such as every three months (Hohmann et al., 2009). The two that were the most frequent, weekly, had a significant effect on medication adherence (Claiborne, 2006; Sit et al., 2005). These same studies also involved more time input as the sessions were two hours or one hour whereas some of the studies that had poorer outcomes had involved 20 minute sessions (Adie & James, 2010). The third study that had a significant finding was conducted once a month, however the intervention lasted for 5 months. Therefore, although it was less frequent it was longer in duration which may have been advantageous. Overall those that were less frequent were less effective.

The timespan in which baseline to follow-up was measured differed. Some interventions measured follow-up at three months post intervention (Claiborne, 2006, Sit et al., 2005). One measured follow-up at five months (Ellis et al., 2005). The remaining studies measured longer term follow-up, i.e. post 6 months (McManus et al., Hohmann et al., 2009; Adie & James, 2010). The studies that measured follow-up in the shorter term, (i.e. three to five months) had better outcomes compared to those that measured follow-up in the longer term, indicating the effects were lost over time.

### **Medical Adherence Outcome**

The studies measurement of medication adherence differed. Some used biological markers such as blood pressure, whereas others used self-report measures such as the Medical Compliance Questionnaire (Morisky et al., 2008) which is a widely used scale that identifies if people do not take their medication. Others measured the number of incidences people did not take their medication (Claiborne, 2006). There are limitations with all of the different measures that were implemented. For example, self-report measures may be unreliable due to patient recall and bias, and using BP as a measure of adherence may be influenced by confounding factors such as the effects of weight loss or physical activity. As stated earlier, as different measures were used, a meta-analysis was not possible.

## **Discussion**

This systematic review assessed the effectiveness of self-management interventions on the outcome medication adherence in stroke patients, and the short and long-term

impact on stroke medication adherence. Overall half of the findings support self-management strategies becoming an integral part of stroke management, however half do not and therefore firm conclusions cannot be made. The studies in this review that had significant findings had regular and frequent sessions. This is one of the main findings from this review and is in line with literature that has found that increased exposure to an intervention is associated with improvements and increased likelihood of positive effects (Rubak, Sandbaek, Lauritzen, & Christensen, 2005). Future self-management interventions for stroke that target medication adherence are strongly recommended to be initiated soon after the stroke and delivered frequently (i.e. weekly or monthly).

The impact that self-management interventions had on the outcome medication adherence in stroke patients was mixed with half having an effect. All of the studies included in this review incorporated education, problem solving, counselling and medication advice. Previous literature has found that a combination of lifestyle changes and medicines management is successful in improving patient outcomes (Powers, Danus, Grubber, Olsen, Oddone, et al., 2011). The evidence from this review cannot draw a firm conclusion, however all of the studies that were effective included all of these components plus had frequent and regular sessions. Therefore, self-management interventions incorporating a combination of these components as well as being delivered frequently show promise.

A further objective of this systematic review was to ascertain the impact of the interventions on short and long-term medication adherence in stroke. Overall the interventions were effective in improving adherence in the short term. However, in the long-term this was not upheld. This may have been due to the frequency of the interventions. For example, one study was effective in the short-term, however three years later the positive outcomes were not sustained. Implementing booster sessions may overcome this, although this is unknown. This would be in line with Newman et al., (2009) who state that self-management interventions with booster sessions are more effective in the long term than those that do not have any. Further research to examine whether this would be effective is recommended.

This systematic review found that from the descriptions given the studies at hand did not appear to be explicitly grounded in theory. According to Horne (2007) there is a lack of interventions that have been developed using theoretical models. Many are

developed using ad hoc approaches making them insufficiently comprehensive. For example, there is evidence that interventions targeting intentional and unintentional factors of adherence (intentionally choosing not to take medication, and passively inconsistent medication-taking behaviour such as forgetting) are more affective (Horne, 2007). Although most of the studies incorporated strategies aimed at intentional and unintentional determinants of adherence, this was more as part of the design rather than being clearly defined. More use of and clearer definition of the theoretical models is recommended.

It is important to highlight some limitations of this systematic review. The studies in this review were conducted across different countries including the UK, Germany, America and Hong Kong. The generalisability of the findings therefore may be limited. Some of the studies included in this review did not have sufficient sample sizes and dropout rates in some circumstances were high. Future studies with adequate sample sizes are highly recommended. This systematic review only examined the outcome medication adherence. The justification for this is that medication adherence is one of the biggest influencers of recurrent stroke and poor medical outcomes and with the aging population endemic this will continue to grow (Fan et al., 2010). In addition, interventions enhancing medication adherence have been highlighted as a priority for people with long term conditions and stroke guidance is in accordance with this (Haynes, Ackloo, Sahota, McDonald, & Yao, 2008; O'Carroll et al., 2011). As the interventions main outcome was not always adherence this may have impacted on the findings.

A further limitation was that the studies used different measures of medication adherence. According to Fairman and Motheral (2000) although there are a variety of methods that can be used to measure medication adherence, there is no gold standard approach. In all of the literature searched, studies and systematic reviews measured adherence to medication differently.

## **Practice Implications**

Previous literature has found that there is a lack of evidence based interventions for prevention and management of stroke (Wei, Wang, Huang, et al., 2010; Cheng et al., 2011). There is no doubt that further research is needed. Many of the negative health and social effects of stroke are preventable and treatable and can be greatly reduced

with appropriate medical treatment and interventions that are integrated into clinical practice (Saka et al., 2008). It was interesting to see the range of health and social care settings that self-management interventions incorporating medication adherence can be successfully applied. It is important for future interventions to be integrated into existing primary and secondary clinical practice, to be grounded in theory, include several components of self-management, and delivered regularly and frequently. For long term benefits to be upheld investigating the impact of booster sessions is recommended. With an aging population the time is apt to start to address this in order to improve health outcomes and reduce healthcare costs.

### **Reflection**

I was surprised how much I enjoyed conducting the systematic review. It was a methodical process and required meticulous concentration however, I chose a topic that was of interest to me and I therefore enjoyed reading the studies. I was able to do it at work and I was very pleased that it was published, and even more so when it was presented as part of the booklet at the European Stroke Conference in 2014.

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