What is the impact of Lyme disease on a patient's quality of life in the Western Isles of Scotland?

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Abstract

Background

Lyme disease is an infectious disease caused by the bacterium *Borrelia,* the bacterium is spread by a tick bite. There is an increasing incidence of Lyme disease being reported worldwide and strong indications are that it is a disease where cases may remain unreported in many countries.

Objectives

This research sought to investigate the physical, mental, social and economic impacts of Lyme disease on the quality of life of people living in the Western Isles of Scotland. It was anticipated that the research would identify strategies used by people to manage any incapacity and the study findings would form recommendations for future research.

Methods

Background information was gathered, and the available literature was reviewed. A qualitative, constructivist approach using focus groups to collect data was applied. Framework Analysis was used to identify relevant themes.

Results

The analysis identified five themes with regard to impacts of Lyme disease. The five themes are cognitive issues, a reduction in the ability to carry out normal tasks, and a reduction in the participation of social activities. In addition to an acknowledgement from the participants that some symptoms may not be due to Lyme disease and lastly the participant's concern around trying to avoid ticks.

Conclusions

Fatigue impacted on the physical, mental, economic and social aspects of nearly all participants irrespective of the stage of diagnosis. However, there was recognition that when Erythema migrans is identified and treated early the participants experience less symptoms and recover well. The results did determine there was a reduction in quality of life in those participants where Lyme disease was diagnosed later, with physical and cognitive impacts reported by participants in all the focus groups.

Chapter 1: Introduction

1.1 Background

Lyme borreliosis also known as Lyme disease is an infectious disease caused by the bacterium *Borrelia (B.),* a bacterium spread by tick bites. It is a complex disease with a variety of clinical presentations dependant on the host immune response to the spirochaetal infection (Steere *et al* 2016) and is further influenced by the individual host genetic response (Strle *et al* 2012). Host responses contribute to the range of clinical presentations: skin manifestations, of which Erythema migrans is the most frequently recognised (Strle and Stanek 2009); neuroborreliosis (Mygland *et al* 2010); carditis (Berglund *et al* 1995) and arthritis (Priem *et al* 2003); these conditions may present as acute or chronic illness (Stanek and Strle 2018). Geebelen *et al* (2017) found that despite the recommended antibiotic treatment a proportion of patients with Lyme disease report continuing non-specific symptoms of such severity that they influence the patient's quality of life.

Lyme disease was first described by Steere *et al* (1977) nonetheless the rash and associated neurologic symptoms were reported previously in Europe (Winterkorn 1990). Seminal studies remain valid and authors such as Steere *et al* (1983); Marques (2008); Aucott *et al* (2013); Halperin, Baker and Wormser (2013); Weitzner *et al* (2015) and Rebman *et al* (2017a) and more recently European studies such as Obel *et al* (2018) and Geebelen *et al* (2017) discuss the symptoms associated with Lyme disease with some studies including analysis of the disease impact.

1.2 Quality of life

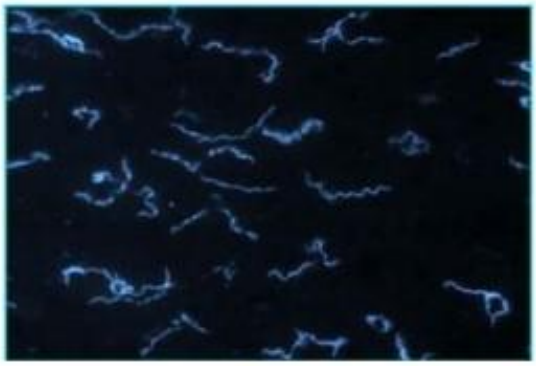
Quality of life is defined as the extent to which an individual makes use of the opportunities that life brings; this includes the dimensions of performance in life roles and general well-being, social functioning and mental/physical health (World Health Organisation (WHO) 2016). The symptoms of chronic illness and the related functional limitations have the potential to adversely impact Health-Related Quality of Life (HRQL) in affected individuals (Bowling 1996; Busija, Tan and Sanders 2017). HRQL is used to assess health in the general population, identify health disparities and unmet health needs and determine the symptom burden (Johnson *et al* 2014; Mielck, Vogelmann and Leidl 2014).

There is an assumption that Lyme disease represents a substantial health and cost burden for the population and health systems (Geebeleen *et al* 2017). North American studies that measure quality of life compare the burden of Lyme disease to other diseases by identifying symptom patterns, functional impairment and clinical severity (Johnson *et al* 2014); or to compare the frequency, severity and impact on life functioning of persons who develop Post Treatment Lyme Disease Syndrome (PTLDS) versus those that do not (Aucott *et al* 2013). Rebman *et al* (2017a) acknowledged that assessing the impact on the quality of life remains unexplored. There is recognition that due to the increasing incidence of Lyme disease it is imperative that a deeper understanding of the impact of the disease is developed to ensure clinicians adopt a holistic approach in the management of patients with Lyme disease.

1.3 Lyme disease

Lyme disease is a tick-borne infectious disease caused by the spirochete bacteria *B. burgdorferi* sensu lato. Picture 1 is of *B. burgdorferi* spirochete.

Picture 1: *Borrelia burgdorferi* spirochete



Picture 1 source: 'CNR *Borrelia*' Centre National de Reference-*Borrelia* (2019)

The bacteria are commonly found in ticks and people develop the disease following a bite from an infected tick (Public Health England (PHE) 2016). Picture 2 is of an *Ixodes ricinus* tick.

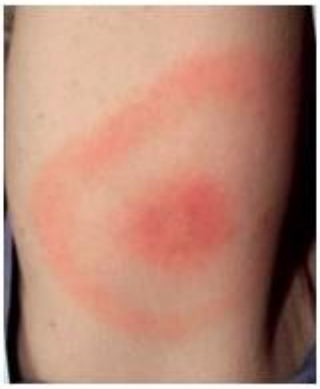
Picture 2: *Ixodes ricinus* tick

Picture 2 source: Lyme Disease Action (2019)

In North America, *B.* burgdorferi is the main causative agent of Lyme disease and the main vectors are *ixodes scapularis* and *ixodes pacificus* ticks (Nadelman and Wormser 1998). The main vector for transmission of *B. Burgdorferi* sensu lato in Europe is the hard-bodied *ixodes ricinus* ticks. Several genospecies of *B. Burgdorferi* sensu lato can cause Lyme disease in Europe *B. afzeilli; B. garini*; *B. Burgdorferi* sensu stricto (Strle, Stanek and Strle 2018). *B. bavariensis; B. spielmanii and B. Burgdorferi* sensu stricto are the principle genospecies in North America (Clark, Leyder & Threlkeld 2014). Although all five genospecies can cause Erythema migrans there are some differences in disease manifestations, i.e. *B. garini* and *B. bavariensis* are associated with neurological manifestations (Stanek and Strle 2003) and *B. afzeilli* is associated with acrondermatitis chronic atrophicans (Wienecke *et al* 1994). In North America *B. Burgdorferi* sensu stricto is closely associated with Lyme arthritis (Stanek and Strle 2003). The different type of genospecies are known to present with different manifestations of disease (Dersch 2018) and this underlines the importance of studies being undertaken on European, UK and Scottish residents as opposed to generalising North American study results. Studies into environmental factors and the epidemiological relevance of ticks and tick-borne infections are becoming common in the UK; however, there is very limited research on Lyme disease from the patient's perspective. Additionally, geographic distribution and incidence of Lyme disease is on the increase worldwide and has become the most common vector-borne illness in Europe (ECDC 2016).

An early sign of *Borrelia* infection and therefore Lyme disease is an Erythema migrans or ‘bulls-eye’ rash (Wormser *et al* 2006). Picture 3 is an Erythema migrans rash.

Picture 3: Erythema migrans rash



Picture 3 source: Health Protection Scotland (2017b)

Late Lyme disease although less common can present sometime after the initial infection. Patients present with symptoms such as fatigue, malaise, headache, myalgia and arthralgia (Stanek and Strle 2018). Subsequently, Lyme disease is confirmed serologically (Dubrey *et al* 2014). It is acknowledged that sero-diagnostics can lack sensitivity to detect disease (Dubrey *et al* 2014). Lyme disease can be ‘microbiologically’ cured in virtually all patients (Wormser *et al* 2003, Mygland *et al* 2010). However, if untreated dissemination of bacteria to other tissues can occur (Obel *et al* 2018, van den Wijngaard *et al* 2017); leading to persistent clinical complications that include skin, neurological, cardiac, musculoskeletal and ocular manifestations (Weitzner *et al* 2015).

The Borrelia spirochetes do not release toxins that damage cells and tissues. However, as the spirochete move away from the site of the tick bite the inflammatory response follows and presents as the Erythema migrans rash. Barbour (2015) suggests that as spirochetes migrate from the site the inner area of the rash becomes paler giving Erythema migrans its distinguished appearance. When a person’s immune system eventually launches a defence against the infection the rash recedes; natural immunity or the prescribed antibiotic treatment will limit the infection to around the site of the tick bite. In some persons when undetected the spirochetes can spread widely from the initial skin entry site to the blood or lymphatic system. Spirochetes can circulate in the blood for a few weeks and cause blood infection symptoms such as fever, headache, muscle aches and tiredness. By the time antibodies attach to the spirochetes in the blood and remove them, the spirochetes may have entered distant organs such as the joints, heart or brain (Sperber and Dattwyler 2018).

1.4 Impact of Lyme disease on quality of life

It is well established that an illness such as cancer has a detrimental impact on the quality of life (Lam and Lauder 2000). However, less is known about the trajectories of illnesses such as Lyme disease. Persistent, post-infection symptoms similar to those described by patients with Lyme disease are also reported following other infectious diseases. Hickie *et al* (2006) described fatigue, musculoskeletal pain, neurological difficulties and mood disturbance in patients with Epstein-Barr virus (glandular fever), *Coxiella burnetii* (Q fever), and Ross River virus (epidemic polyarthritis). There are similar types of symptoms reported by some Lyme disease patients (Aucott *et al* 2013; Rebman *et al* 2017a).

Likewise, a European study by Eikeland *et al* (2011) demonstrated that physical and mental HRQL was reduced in the patients when compared to the control group. In contrast, Wormser *et al* (2015) assessed the long-term HRQL in patients 11-20 years after diagnosis with Lyme disease. This study found the mean summary of scores were similar to those of the general population suggesting that Lyme disease did not have an ongoing impact on the study participant's health at that time.

Notwithstanding; many quantitative studies have looked at the general symptomatology associated with Lyme disease (Steere *et al* 1983; Marques 2008; Aucott *et al* 2013; Ali *et al* 2014; Rebman *et al* 2017a; Keodal and Pfister 2017). The non-specific nature of the symptoms and the many similarities to those found in the chronic disease (Haddad *et al* 2018) and contested illness (Halperin 2014) literature make it confusing and difficult to hypothesize its trajectory. Nevertheless, Ali *et al* (2014) found that symptoms can affect social and physical functioning and studies have not looked at the actual impact of Lyme disease on the lives of patients despite the British Infection Association (2011) in their extensive review of Lyme disease recommending evaluation of the subjective symptoms associated with the disease.

1.5 Summary of the Introduction

There is an increase in the incidence of Lyme disease being reported worldwide and strong indications that it is a disease where cases may remain unreported in many countries. Studies have identified a range of symptoms that can affect patients which highlights that this disease merits further investigation. There are a plethora of studies from North America with limited European studies that present much evidence on symptoms and effects of Lyme disease, nevertheless noting the differences in genospecies and the manifestations underline the fact that studies should be undertaken within Scotland. Therefore, a study that explores the impact of the disease will allow for evaluation of the actual burden on those with Lyme disease within the Western Isles.

Chapter 2: Literature review

2.1 Introduction and approach

The review was undertaken to critically appraise key literature and highlight what is known about the impact of Lyme disease on peoples' quality of life. In qualitative research, the literature review is used to provide evidence for the purpose of the study and to identify the underlying problem that will be addressed by the inquiry (Creswell and Plano-Clark 2017) allowing the researcher to uncover potential research gaps and rule out areas where research exists (Thomas and Hodges 2010).

Literature was identified using 'The Knowledge Network', which allowed the review of multiple databases. Using the advanced search facility and Boolean search terms such as; Lyme disease; Lyme borreliosis; impact of Lyme disease; quality of life; symptoms of Lyme disease, 1197 papers were identified, refining the search criteria with the additional term 'humans' narrowed the selection to 508 papers. The 508 papers retrieved were hand-screened by reading the abstracts to identify those that were relevant. Initially, seventeen articles were deemed relevant, studies that only looked at neuroborreliosis or treatments were subsequently excluded. Selecting articles that looked at the impact of Lyme disease/ Lyme borreliosis reduced the total to seven articles. Six studies were from America, one from Europe and no studies from the United Kingdom (UK) were found. A further search of the UHI library multi-search engine did not elicit any other papers.

2.2 Lyme disease

2.2.1 Epidemiology of Lyme disease

Lyme disease is the most common tick-borne disease in North America and Northern Europe (Stanek and Strle 2018). Etiologic agents, principal vectors and clinical manifestations of disease vary widely from America and Europe (Mead 2018). Although little is known about the actual incidence of Lyme disease in Europe (Rizzoli *et al* 2011; Stanek *et al* 2012; Vandenesch *et al* 2014; Wilking and Stark 2014; Hofhuis *et al* 2015), Lindgren and Jaenson (2006) estimated the annual number of cases in Europe exceeded 85,000 persons furthermore; Sykes and Makiello (2017) estimated the burden is increasing in Western Europe and is now recorded as 56.3 new cases per 100,000 persons each year.

There is acknowledgement the incidence of Lyme disease has increased overall (van den Wijingaard *et al* 2017) with suggestions that the increases reflect a combination of increased disease transmission and improved awareness (Mead 2018).

Health Protection Scotland (HPS) reported 170 cases of Lyme disease in 2016 (HPS 2017a), this number is based on laboratory-confirmed cases of persons who are serologically positive for borrelia. HPS does not hold data for the number of persons who present with Erythema migrans, a clinical sign that is diagnostic of Lyme disease (NICE 2018). In 2018 NHS Western Isles published data that demonstrated a mean incidence across the Western Isles of 30.2 per 100,000 persons. These were patients presenting with symptoms and subsequently identified with positive *Borrelia* serology. This data also showed a mean incidence of 142 per 100,000 persons treated for Erythema migrans (NHS Western Isles 2018).

Lyme disease is not a reportable condition in many countries, and it is recognised the absence of a reporting mechanism leads to an underestimation of the true extent of the disease (British Infection Association 2011, HPS 2017a). Lyme disease does not fulfil the requirements of a notifiable disease in Scotland as set out in the Public Health Act (2016) 'The aim of statutory notification is to give early warning of infectious disease, which may prompt urgent public health investigation and action for example, food poisoning'. Consequently, the absence of a reporting mechanism makes interpretation of the incidence numbers unreliable.

2.2.2 Lyme disease diagnosis

The literature consistently reports a range of designations associated with a Lyme disease diagnosis; Wills *et al* (2016) classified Lyme disease into early localised, early disseminated and late stages. Although asymptomatic infections are frequent (Hofhuis *et al* 2013) Erythema migrans develops in early localised Lyme disease; this is a red rash with central clearing which increases in size (NICE 2018). Early disseminated Lyme disease occurs when the rash is absent or not recognised which delays diagnosis and treatment allowing the bacteria to disseminate hematogenously (Aucott *et al* 2009). In late-stage Lyme disease, the bacteria have the opportunity to disseminate to the skin, nervous system or heart, late untreated disease presents weeks or months after the initial infection and is diagnosed through serological testing (Steere 2001).

A subset of individuals following treatment for Lyme disease in whom symptoms persist for six months or longer are known as having chronic Lyme disease (CLD) (Feder *et al* 2007; Ali *et al* 2014; Patrick *et al* 2015) or Post-Treatment Lyme Disease Syndrome (PTLDS) (Aucott *et al* 2013; Weitzner *et al* 2015; Sharareh *et al* 2017; Koedal and Pfister 2017). The pathophysiology of CLD is unknown (Aucott *et al* 2013), Touradji *et al* (2019) suggest the lack of a consistent definition is a factor, as well as indecision surrounding the wide variation in symptoms (Bakken 2002; Brett *et al* 2014; Henry *et al* 2012; Hill and Holmes 2015; Brunton *et al* 2017). Cameron *et al* (2014) in an uncontrolled case series suggested that CLD is due to persistent infection, yet placebo-controlled trials looking at the efficacy of antibiotic use, found no evidence of persistent infection but they did identify continuing symptoms (Klemper *et al* 2001; Krupp *et al* 2003; Fallon *et al* 2008; Berende *et al* 2016; Di Domenico *et al* 2018). Therefore, physicians remain undecided about the existence of CLD (Johnson and Feder 2010; Halperin, Baker and Wormser 2013; Crowder *et al* 2014; Koedel, Fingerle and Walter-Pfister 2015). PTLDS presents with lingering symptoms after successful treatment of the infection. PTLDS classification relies on well-documented symptom onset following an episode of Lyme disease and adequate treatment with the recommended antibiotics (Rebman *et al* 2017b). Clinicians agree PTLDS exists; however, further research is required to define specific risk factors for PTLDS and the mechanisms of illness in order to guide improvements in diagnostic specificity and treatment options (John Hopkins Medical 2018).

The standard course of Doxycycline or Amoxicillin antibiotics for 21 days (NICE 2018) is curative in the majority of patients with confirmed *B*. *burgdorferi*. Additional antimicrobials are unhelpful but may also cause complications such as septic shock, osteomyelitis, clostridium difficile colitis and paraspinal abscesses (Oksi *et al* 2007; Marzec *et al* 2017; Berende *et al* 2018; Baker 2019). Antibiotic resistance is a growing global threat with an estimated 25,000 deaths in Europe (World Health Organisation 2014), it is extensively described that antibiotic resistance is related to the volumes of antibiotic treatment emphasizing the significance of the preferred shorter-term prescribing of antibiotics in Lyme disease patients (NICE 2018).

It is acknowledged within the literature that there is a Lyme disease 'debate' (Wormser *et al* 2006; Delong *et al* 2012; Cameron *et al* 2014; Haddad *et al* 2018; Vrijmoeth *et al* 2019).The symptomatology and socio-cultural context of Lyme disease overlap considerably with other medically unexplained or contested conditions characterised by diffuse pain and fatigue; such as Fibromyalgia, chronic fatigue syndrome, unspecified chronic neurological disease and unexplained chronic pain (Patrick *et al* 2015; Rebman *et al* 2017b). Physicians have concerns about the underlying cause, severity and prevalence of the disease (Aronowitz 1991; Feder *et al* 2007; Ballantyne 2008; Davies and Nichter 2015). A recent study by Haddad *et al* (2019) has demonstrated that 'a holistic approach in patients with presumed Lyme borreliosis leads to less than 10% of confirmation of disease and more than 80% of antibiotic failures' concluding that the over-diagnosing and over-treating of Lyme disease is increasing. Additionally, Stanek and Strle (2018) warn against labelling patients with symptoms of unknown cause or illness unrelated to borrelia infection as CLD, it has been suggested that this designation should be reserved for patients with objective manifestations of Lyme disease.

2.2.3 Lyme disease- symptoms reported

Generally studies utilise general health surveys to gather data; the survey is a self-administered instrument to list their state of functionality including physical and mental health (Wormser *et al* 2006; Cerar *et al* 2010; Eikland 2011; Johnson *et al* 2014; Dersch *et al* 2015; Wills *et al* 2016;Eliasson *et al* 2017; Geebelen *et al* 2017). Some studies include clinical assessments along with the surveys adding integrity to the study findings (Aucott *et al* 2013; Bechtold *et al* 2017; Rebman *et al* 2017a).

The diagnosis of confirmed early Lyme disease is based on the identification of the hallmark Erythema migrans rash, which may occur in isolation or in conjunction with viral-like symptoms (Wormser *et al* 2006). Arthralgia, fatigue and memory problems were identified in a person within three months of the tick bite (Aucott, Seifter and Rebman 2012) and Aucott *et al* (2009) reported persistent malaise in a person ten days following the detection of Erythema migrans. While Cerar *et al* (2010) compared healthy controls to persons with Erythema migrans, those with Erythema migrans were treated with appropriate antibiotics and both groups were observed for twelve months. There was no statistical difference in the symptom frequency; with the study finding fatigue increasingly reported in the control group. Similarly, Wormser *et al* (2015) and Eliassen *et al* (2017) found symptom load in persons treated for Erythema migrans was comparative to the general population. Moreover, Wormser *et al* (2015) followed the patients for 11-20 years.

The recommended regimens of Doxycycline or Amoxicillin antibiotics for 21 days (NICE 2018) are uniformly successful in resolving Erythema migrans (Kowalski *et al* 2010; Geebeleen *et al* 2017; Bechtold *et al* 2017). Therefore; the observations from the studies looking at early Lyme disease support the opinion that Erythema migrans when treated according to guidelines has a good prognosis, and the symptoms reported can be observed in the general population with similar frequency.

It must not be overlooked that approximately 10-20% of persons experience a constellation of prolonged symptoms following standard antibiotic treatment for early or late LD (Marques 2008; Rebman *et al* 2017a). The literature presents a consistent repetition of the symptoms reported when the diagnosis was delayed. Some of the commonly reported prolonged symptoms are fatigue (Chandra, Keilp and Fallon 2013; Weitzner *et al* 2015; Wills *et al* 2016, Wormser *et al* 2016; Weinstein *et al* 2018); musco-skeletal pain (Rebman *et al* 2017a, Bechtold *et al* 2017); cognitive symptoms (Steere 2001;Eikeland *et al* 2011; Touradji *et al* 2019); sleep difficulty (Johnson *et al* 2014; Rebman *et al* 2017a; Bechtold *et al* 2017); facial palsy (Kalish *et al* 2001) and somatic depressive symptoms i.e. sleep disturbance, changes in appetite and energy levels (Rebman *et al* 2017a, Bechtold *et al* 2017; Touradji *et al* 2019). Nowaskowski *et al* (2003) found 10% of patients experienced persistent symptoms for more than one year after treatment and persons with PTLDS or CLD report significantly more physical and mental health symptoms (Chandra, Keilp and Fallon 2013; Wormser *et al* 2015; Wills *et al* 2016; Rebman *et al* 2017a; Touradji *et al* 2019).

There is a plethora of evidence from Aucott *et al* (2009); Aucott, Seifter and Rebman (2012); Chandra, Keilp and Fallon (2013); Weitzner *et al* (2015); Wills *et al* (2016); Wormser *et al* (2016); Rebman *et al* (2017a) and Weinstein *et al* (2018) where persons are reporting life-altering symptoms within a short time frame from detecting Erythema migrans and receiving treatment, indicating that symptoms are not exclusively resolved in all cases. Most of the disease burden appears to be with PTLDS, whether Lyme disease is the cause of these persistent but non-specific problems is uncertain given that the pathophysiology of chronic problems like fatigue, pain and diminished mental acuity are poorly understood. The studies also identify similarities between the symptom load of Lyme disease and other conditions seen in the general population.

It has been suggested that media reports on the dangerous consequences of Lyme disease can form expectations of poor health and therefore influence the answers given on questionnaires (Eikland *et al* 2011). Therefore, a qualitative study with face to face discussion will document the persons' experience and add credibility to the fact that Lyme disease can impact on a person's quality of life.

2.3 Impact on quality of life of persons with Lyme disease

Studies by Johnson *et al* (2014); Dersch *et al* (2015); Rebman *et al* (2017a); Geebelen *et al* (2017); Bechtold *et al* (2017) use quality of life indicators to compare patients with Lyme disease to healthy controls or people with other long-term conditions and build knowledge on the impact of disease. WHO (2016) encourages the use of quality of life indicators to offer a complete assessment covering different aspects of a person's functioning providing meaningful assessments that clinicians can more astutely identify the appropriateness of treatment (Sosnowski *et al* 2017).

Predominantly quantitative studies utilise large samples, with data collected via questionnaires with results reported statistically to demonstrate the validity, reliability and generalisability of the results. A European study by Eliassen *et al* (2017) used a randomised controlled trial comparing three antibiotic regimens for treatment of Erythema migrans; the study identified symptom load and general function of the participants. Samples of 188 participants were recruited, and all were clinically diagnosed. Baseline questionnaires were completed on the day of diagnosis and followed up one year later, 85.1% participants completed both questionnaires. 70.5% patients reported their general function 'as usual' at the baseline visit and 68.3% at the follow up visit. Symptoms reported in the study are similar to previous findings in general population studies, fatigue, sleep problems, joint problems and dizziness. A major strength of a prospective cohort study is the accuracy of data collection with regard to exposures, confounders, and endpoints, but this is realised at the cost of an inevitable loss of efficiency, for this design is both expensive and time-consuming because of a usually long follow-up period (Creswell 2014). Eliassen *et al* (2017) utilised a small sample size. However, the high completion rate reduces the bias caused when large numbers of participants are lost to follow up adding credibility to the findings. However, the absence of a comparison group omits the reflection of the prevalence of these symptoms in the general population.

Wormser *et al* (2015) used a 36-item short form questionnaire to study the long-term assessment of HRQL in patients after diagnosis with Lyme disease. The study found the mean summary of scores were similar to those of the general population suggesting that Lyme disease did not have an ongoing impact on the study samples health at that time. From an initial cohort of 283 adults, 100 subjects were followed for 11-20 years, all subjects attended with Erythema migrans and were treated with the appropriate antibiotics. Although the study gathered valuable information on the physical, mental, social and role functioning, the responses lack the depth of explanation for the impact of symptoms that would be obtained through qualitative research.

Wills *et al* (2016) also used a self-administered questionnaire and scale measurement. Over 100 persons with Lyme disease were followed for an average of three years, the subjects had physical and mental health impacts with a subsequent reduction in quality of life considered being at or just above the national average. The participants were all diagnosed with Lyme disease and 58% were untreated at study enrolment. 57% of participants had a pre-existing co-morbidity and these participants were noted as having a lower quality of life scores at the baseline visit acknowledging the significance of the impact of co-morbidities when assessing Lyme disease. Only 47% patients continued for longer than two years of follow up. Reduced attendance is a limitation of this study design. Study findings should be based on complete follow up information, which in reality is not practical, as long as studies declare follow up readers can judge the validity of the results (von Allmen 2015).

Aucott *et al* (2013) identified that fatigue was the most important contributor to perceived impairments in overall mental functioning and subsequently reported cognitive deficits which affected memory, verbal fluency and psychomotor speed and lead to a functional decline in daily activities. This prospective cohort study was a subset of a larger study, the 63 participants were untreated and had early Lyme disease. The study findings were strengthened with physical examinations and clinical assessments along with the completion of the short-form questionnaire which was followed up in five visits over six months. These additional physical examinations add rigor to the study results. The questionnaires were completed through a structured interview, in a consistent fashion and there was no probing for specific symptoms. Fatigue was identified as the most important symptom and defined by self-report of new or worsened fatigue since diagnosis. Prior to the diagnosis the cohort was very active and healthy.

The study focused on the easily diagnosed manifestation of Lyme disease, however, the follow up did identify that 35% of the sample met the definition of PTLDS and the method of six-monthly follow up which helped to track symptom development could be significant for future prediction of patients who may go onto develop PTLDS. The small sample size and single context design limit generalisability of the results (Flick 2014) but the results offer evidence for the merits of further studies into the trajectory of PTLDS.

Johnson *et al* (2014) undertook an employment survey with over 3000 CLD participants with persistent symptoms lasting more than six months. The study sample came from individuals who visited a Lyme disease patient-centred online forum and were asked to complete an online survey. The results identified a heavy burden of illness with reports of impairment inability to work as 42% had to stop work and 25% reduced their work hours or changed the nature of their work. Those who continued to work reported missing 15 days of work in the preceding year with an inability to concentrate or fatigue being the main contributing factors. This diminished work performance exacts a toll on the worker, the worker's family and the employer (Johnson *et al* 2014). There has been an increase in usage and acceptance of online health forums and the increase is associated with self-diagnosis and non-adherence to treatment. Anker, Reinhart and Feeley (2011) found patients want a second opinion inferring they are not content with the assessment and treatment they are receiving and continuing to exhibit symptoms.

In Johnsons *et als* (2014) study all participants had a confirmed diagnosis of Erythema migrans or positive serology. In total 5,357 subjects responded and people were excluded as they did not have a clinically confirmed diagnosis. The final sample size was 3,090 indicating 43% of respondents were excluded as they did not fulfil the diagnostic criteria listed, postulating that many people consider they have Lyme disease without objective clinical signs. However, the researchers made no effort to confirm the diagnosis so ultimately participant's diagnosis was self-reported. Another limitation is the strong selection bias offered as participants were self-selected from those seeking online support and by design may be considered more symptomatic therefore not a random sample. This correlates with the study findings of the high number of activity limited days reported by respondents indicating the sample is drawn from people who are sicker and consequently the findings may not be fully representative of those with Lyme disease.

Internet surveys can be delivered widely within a population; however, a factor that can impact on the generalisability of internet surveys is the pre-disposition to selection bias (Liu *et al* 2010). The study tried to mediate this by using weighting adjustments to compensate for response variation. However, the authors noted the lack of definition of CLD and the suspected under-reporting of Lyme disease as factors that make generalising the results to the clinical population problematic.

A quantitative study by Weitzner *et al* (2015) followed patients with PTLDS for >10 years following diagnosis and treatment for Lyme disease found that 48% of participants reported fatigue that was not associated with functional impairment. The study does provide evidence of continuing symptoms that resolve as the study time period lengthens with only 4.7% of the subjects tabling residual symptoms within their last assessment. The reduced number of participants being followed up is a limiting factor of the study raising the possibility of selection bias as 128 of the initial 283 were considered at the last assessment. Another limitation is that over time other factors may be causing the symptoms of fatigue, memory or concentration difficulties and joint pains, however, by virtue of being in the study the participants attribute all to the prior episode of Lyme disease (Dersch *et al* 2015; Weitzner *et al* 2015).

Berende *et al* (2016) who undertook clinical trials looking at the re-treatment with antibiotics of individuals with Lyme disease and found the quality of life much lower than those in the general population with associated evidence of higher healthcare consumption and productivity losses. This view was supported by Fallon *et al* (2012) and Klemper *et al* (2013) who reviewed previous clinical trials. However, these studies concluded that re-treatment with antibiotics did not improve the symptoms which could suggest that the continuing symptoms were not related to Lyme disease. It was overlooked within these studies that impaired function due to requiring re-treatment was an entry criterion therefore it would be erroneous to conclude that all Lyme disease patients are at high risk of having residual impairment; this should only be a consideration for those persons reporting continuing symptoms.

Rebman *et al* (2017a) compared patients with PTLDS against a sample of healthy controls. The study used standardised symptom questionnaires and identified that Lyme disease patients had clinically significant symptoms and poor HRQL reported. However, these findings were not supported by the physical examination and clinical tests undertaken within the study. To capitalise on a representative post-treatment sample, Rebman *et al* (2017a) recruited the study sample retrospectively from patients referred to an academic research centre/clinic for patients with post-treatment symptoms. This selection was hypothesized as a contributing factor in the discrepant findings in symptom severity; as the referral to the clinic is likely to have been executed due to the higher symptom burden in the patients. The 61 participants were selected by having confirmed, or probable Lyme disease and the healthy controls were recruited from the same geographic location, ensuring an accurate representation of the population (Bowling 2014). The study did elicit information on the presence or absence of symptoms associated with Lyme disease; however, the retrospective nature of the study could be postulated as a factor in recall bias and therefore affects the accuracy of the recall of the extent and severity of symptoms.

2.4 Strategies used to cope

Studies from Weitzner *et al* (2015) and Dersch *et al* (2015) acknowledged a limitation of longitudinal studies is that irrespective of what other illnesses develop over time, participants will consider all symptoms related to the Lyme disease diagnosis. This is further complicated by the medical viewpoint where a diagnosis focuses on clinical and laboratory evidence. In contrast, lay perspectives of illness are affected by issues of treatment and the susceptibility or severity of their complaints (Zavestoski *et al* 2004). Illness is recognised as a confounding factor in the general capacity for the effective performance of valued tasks (Parsons 1951). This concept by Parsons includes patients being exempted from particular duties over a period of time and not accountable for their sickness. However, a person is responsible for cooperating with medical help and desiring to recover (Vahdat *et al* 2014). Access to the sick role can only be achieved if a diagnosis is given and so becomes legitimised. A Lyme disease diagnosis is unique as it can be both an uncontested and contested illness. Aside from the fact that symptom complexes identical to that of PTLDS occur frequently in the general population (Weitzner *et al* 2015; Wills *et al* 2016; Wormser *et al* 2016; Rebman *et al* 2017a; Weinstein *et al* 2018); the association with Lyme disease could be by chance and therefore be an example of anchoring bias within the studies. This evidence indicates that for many the symptoms of Lyme disease are real and therefore deserving of further investigation.

There is very little high-quality evidence in the research of the strategies used by persons to cope with the impact of Lyme disease. There are no recommendations within any of the guidance documents. Two different strategies were found in Lyme disease literature. D' Adamo *et al* (2015) undertook a feasibility study of a four-week programme of resistance exercises and found an improvement in vitality and quality of life scores. The study only had eight participants and further larger controlled studies should be selected to confirm the improvements found. Also, the researchers used a novel exercise exertion scale, where participants chose the level of exertion, they felt they had achieved, this scale was an unvalidated test and would require testing to ensure the results obtained are sensitive and reliable.

The second strategy used was complementary therapies such as acupuncture and reiki. The participants utilised by Ali *et al* (2014) consisted of those who self-identified as having CLD irrespective of whether they had objective evidence of Lyme disease. The authors commented that it was the first study to report frequent use of complementary medicine. Nevertheless, given that the study included 12 participants would suggest that any such affirmation is not truly representative; along with the lack of objective signs of disease and self-diagnosis of the participants.

In the absence of any particular strategies to help with the cognitive impacts of Lyme disease an article that looked at the reversal of cognitive impairment in Alzheimer's research was identified. The study demonstrated that 51% of the participants demonstrated reversal from mild cognitive to normal cognitive function. The reversal was significantly associated with lifestyle activities such as driving a car, reading books or newspapers, participating in hobbies or sports activities, and gardening (Shimada *et al* 2019). The study identified the importance of maintaining these lifestyle activities, this guidance could be generalisable across other conditions where cognitive function is impaired.

2.5 Current gaps in our knowledge

The literature acknowledges the differences in the clinical presentations noted between Europe and North America (Stanek *et al* 2012), these differences are thought to be due to the different pathogenic species on the two sides of the Atlantic. Erythema migrans presentations in America have greater severity of constitutional symptoms and there are even greater distinctions observed with the later manifestations of disease (Strle, Stanek and Strle 2018). These acknowledged differences make it difficult to generalise the results from American studies to the European populations therefore it is imperative further studies are undertaken within Europe and the UK.

2.6 Summary of the Literature Review

The literature review has identified that there are uncertainties around a diagnosis of Lyme disease and the contention around treatments which can leave patients feeling vulnerable and unsupported. Equally, regardless of the contention around symptoms there is evidence of the impact and chronicity of the disease that influences peoples' daily living and the impact is evident across all designations of Lyme disease. There are no UK studies that scrutinise the impact of Lyme disease. Therefore, with the increasing levels of disease it is imperative that recognition is given to the impact the disease can have on the functioning of those who suffer. The literature review identified many studies that discuss Lyme disease; the quantitative nature of the studies offer dialogue on the wide range of problems associated with Lyme disease yet lack detailed analysis of the actual impact.

2.7 Aim of study

The increasing incidence documented in the Western Isles stimulated the researcher to undertake a study and this research while considering the quality of life will explore the physical, mental, social and economic impacts of Lyme disease on the lives of patients living in the Western Isles (WI) of Scotland. Also whilst developing an understanding of how Lyme disease impacts on an individual's ability to function it is hoped to identify what if any strategies, they use to manage any incapacity. The study findings will then form recommendations for future research and treatment interventions if applicable.

Chapter 3: Methodology

3.1 Introduction

This section will explain the chosen research methodology and discuss why a qualitative approach was used in the study. The researcher will discuss how the interview guide was developed as well as the merits of the data collection method and the data analysis framework used within the research. Ethical issues will be considered in detail. A clear research design involves the connection of philosophy, strategies of inquiry and specific methods (Creswell 2014) and is the framework that acts as a firm foundation for the entire research.

3.2 Research question

Creswell (2014) suggests establishing the direction of the study, narrowing the focus to a specific question. This study sets out to answer the following question:
What is the impact of Lyme disease on a patient's quality of life in the Western Isles of Scotland?

3.3 Research Aims and Objectives

The study aim was to investigate the impact on the quality of life since the diagnosis of Lyme disease from the participant's point of view

The study objectives were:

- To explore participant's experiences of living with Lyme disease.
- Identify the physical, mental, social and economic impacts on participants in the study.
- To analyse the data collated to form conclusions relating to the quality of life of participants in the Western Isles and develop hypotheses for further research.
- To make recommendations to NHS Western Isles and other health boards about treatment.

3.4 Research paradigms and methodology

3.4.1 Research paradigms

Research approaches differ in their inherent philosophies and each has specific strengths and limitations, and academics identify that research approaches should fit the research aim (Bowling 2014). A paradigm leads researchers to ask certain questions and use appropriate approaches to systematic inquiry (Patton 2002). For example, paradigms in research, postpositivist epistemology is scientifically concerned with cause and effect and testing theories by manipulating variables (Creswell 2014); where deductive reasoning commences with generalisations and seeks to see if these apply to specific instances (Guba and Lincoln 1994). This approach lends itself to quantitative research. The advocacy/participatory paradigm is concerned with society or issues of social justice (Creswell 2014). Issues of empowerment, inequality and oppression are usually the focal point of research based on this paradigm with the aim of creating political debate or discussion. However, these paradigms would not be a compatible fit for the aim of this study. They would not gather the rich data thus an understanding of subjective experience would have been unobtainable.

A constructivist or interpretative paradigm is a companionable fit for qualitative research. The concept addresses understanding the world as others experience it (Creswell 2014), gaining from the exploration and understanding of the phenomenon to understand what it means to people (Holloway and Wheeler 2010; Denzin and Lincoln 2011). Underpinning this research with a social constructivist theory should fulfil the research aim of this study.

3.4.2 Research approach

Quantitative research deals with relationships and quantities to understand the factors and variables that influence an outcome (Bowling 2014). Data collection involves the analysis of structured information in the positivist paradigm. The literature review identifies many quantitative articles that have produced evidence of the symptoms presented by those with Lyme disease (Aucott *et al* 2013; Johnson *et al* 2014; Weitzner *et al* 2015; Wormser *et al* 2015; Wills *et al* 2016; Eliassen *et al* 2017). These studies utilised theories or hypotheses to deduct their findings into an explanation for answers to their questions. With the studies concluding through completed questionnaires the array of symptoms associated with Lyme disease whereby participants acknowledged statistically that the measures impacted on quality of life (Wormser *et al* 2006; Cerar *et al* 2010; Eikland 2011; Johnson *et al* 2014;

Dersch *et al* 2015; Wills *et al* 2016; Eliassen *et al* 2017; Geebelen *et al* 2017). These study results lacked exploration of the phenomenon with regard to how the symptoms impacted on a person's quality of life.

This study aims to understand individual's meanings of their personal experience of the impact of Lyme disease and given there is minimal research on the subject it is important to elicit specific information which may be relatable to another's experience. This strategy relies on the researcher to have an interpretative perspective, and as suggested by Denzin and Lincoln (2011) this is best undertaken during naturalistic or qualitative research. A view supported by Flyvbjerg (2011) who thought it more important to clarify the consequences of a problem than to describe the frequency of symptoms. There is no current theory, therefore it can only be understood through social constructions and interactions with patients, making qualitative study an appropriate approach to gain information on the impact of Lyme disease on participants' quality of life.

The inductive nature of qualitative research tasks the researcher with building up information and forming general themes enabling the generation of meaning from study data (Bowling 2009). Although, this inductive nature has been recognised as a limiting factor by Denzin and Lincoln (2011), who suggested that researchers cannot accept their personal biases and the absence of variables can limit the approach, thus findings of studies will not be generalisable. Yet generalisability is not the aim of qualitative research but the fit (Denzin and Lincoln 2013). Also, Flick (2009) suggests these limitations are in direct association to the small sample size utilised in this study. There are no pre-determined categories or directions with the researcher as an "instrument" (Patton 2002). Indeed, McNamara (1999) and Silverman (2010) recognised this as a strength allowing the researcher to understand the participant's experiences reflexively. The in-depth discussion elicits the participant's construction of reality, not the researcher's assumptions, with the conversation provoking the release of specific information (Jayasekara 2012).

3.5 Research Method

Quantitative methods of research generally include surveys to measure attitudes, knowledge and behaviour; it is concerned with generating facts through testing theories and ultimately support or reject the theory (Creswell 2014). Studies by Wormser *et al* (2006); Wills *et al* (2016) and Eliassen *et al* (2017) were designed using a 36-item short form General Health Survey with an analytical format where the studies were longitudinal aiming to analyse cause and effect relationships (Bowling 2014). Larger numbers of participants complete questionnaires with a major advantage being the questionnaires are completed in natural settings and random sampling is possible. However; the structured and closed questions used in questionnaires would generate a limited set of responses and lack the depth required in qualitative research (Fontana and Frey 2008). Another method used in quantitative research is the experimental strategy where the exposure, intervention and the experiment are carefully manipulated by the researcher (Bowling 2014). This would not be suitable for this study as the experimental strategy would separate the phenomenon from the context due to the unknowns that accompany the illness trajectory associated with Lyme disease (Creswell and Creswell 2018).

Qualitative research collects data on the knowledge, attitudes, and experiences of participants (Dilaria *et al* 1994). Yin (2003) identifies case study as useful for an interpretative/constructivist view of the world, which uses exploration of the phenomenon to understand what it means to people. Also interviewing by means of a face-to-face interview would gather similar in-depth information (Bowling 2014). However, to interview a representative cohort would be very time consuming and difficult to collect or analyse, also Bowling (2014) suggests this presents greater opportunity for researcher bias. This study will use focus groups to collect data. Increasingly in health care, focus groups are used (Gill *et al* 2008), this method facilitates a narrative of shared experiences, fosters group comfort and cohesion (Traynor 2015). As the data is being retrieved through social research there are many unknown factors (Pole and Lampard 2002). Berg and Lune (2012) highlight that focus groups could give insight and data into a situation, but sensitive matters could arise, and confidentiality has to be protected. The active participation in qualitative studies, as opposed to participant completed questionnaires, would allow for probing and clarification of the meanings gained from participants (Holloway 2005; Gerrish and Lacey 2010) ensuring the researcher understands the participants' perspective.

Qualitative research offers the potential for interviewer bias and to mitigate this the researcher has to identify his/her own views, biases, values and background to minimise any influence on the emerging themes or theories (Creswell 2014; Guest, McQueen and Namey 2012). This precaution this is in order to make an objective analysis of the information participants bring to the investigation (Padilla-Diaz 2015). Thereby it is essential for the researcher to suspend his/her preconceptions and focus on grasping the experiential world of the participant. The focus groups have to be large enough groups to facilitate discussion without inhibiting balanced participation (Jayesakara 2012) and to further enhance the findings four sessions were arranged in locations across the Western Isles. The geography of the Western Isles is dispersed across ten islands and 185 miles in length, holding a group on the Islands participants lived on ensured equity of access.

This study was designed for a small number of participants and therefore it was essential that the questions would capture implicitly the spontaneous yet complex information without limiting the field of inquiry (Silverman 2010). An interview guide with semi-structured; open questions that were built upon from the literature review was developed (Kitzinger 1995; Maxwell 2005). This semi-structured format supports the narrative developed by the participant (Flick 2014) and ensures they had the opportunity to be understood and the concepts to be portrayed were clear (Ritchie *et al* 2014).

The question guide was based on emotional, physical, social, general health and the impact on the participant's role (Appendix 1). The literature review allowed the researcher to synthesise the themes and the context they may come in (Flick 2009). Maxwell (2005) suggested having themes to prevent drift from the main subject matter. The themes identified are

- What are the physical impacts
- What are the mental impacts
- What are the cognitive impacts
- What are the limitations on usual role activities
- Is there any change in ability to undertake social activities

Incorporating these themes into the question guide helped align discussions to the relevant subject matter. In addition, identification of the impact assists in identifying appropriate interventions to manage the symptoms and improve life functioning.

The group sessions were recorded to ensure an accurate record of each participant's perspective the data was transcribed verbatim to accurately record the conversations.

3.6 Participants and recruitment

3.6.1 Inclusion and Exclusions

For this study purposive sampling was used to recruit participants; this was characterised by the incorporation of specific criteria that participants met at the moment of selection (Padilla-Diaz 2015). Participants were asked to contact if they had an initial Lyme episode marked by either (a) the presence of an Erythema migrans rash or (b) a positive blood serology. To add integrity to the study findings the ethical review committee insisted that a respondent's diagnosis was confirmed by a general practitioner therefore, respondents were excluded if a diagnosis could not be confirmed.

3.6.2 Recruitment

Posters were sent to General Practitioners (GP) and local newspapers and web-based news services. On responding the researcher discussed the content of the participant information sheet (Appendix 2) and the consent requirements (Appendix 3). This telephone meeting facilitated informed consent and answered questions to allay any fears the participant may have. Following receipt of GP confirmation of the Lyme disease diagnosis the participant was invited onto the study and provided with information of the focus groups. The participants were given the opportunity to choose the most convenient group for them. Following the recruitment of participants, three venues were confirmed and meeting rooms were booked in Kildonan Museum on South Uist, Hebridean Housing Partnership office on Benbecula and The Bridge Centre in Stornoway, Lewis. The researcher deliberately sought venues out-with the NHS to highlight that the research is independent and not linked to health services.

Prior to commencing the focus group, the researcher allocated half an hour to speak individually with all the participants. This was to review the completed documents and confirm that they were content to proceed with the focus group. Tea and coffee were offered to waiting participants with a view to relaxing the participants and to allow some social engagement to occur in advance of the group.

3.7 Data analysis

It is important to develop and apply an analytical framework that matches the aim and objectives of the study (Creswell 2014). The framework method offered the opportunity to compare the data by themes and across different participant perspectives (Spencer *et al* 2014; Gale *et al* 2013). This would assist in this study as the data will come from four different focus groups. Ritchie and Spencer (1994) identified this method would aid a novice researcher to make sense of data and structuring the information gathered to ensure comparable conclusions were possible (Pope, Zeibland and Mayes 2000).

The data analysis needs to establish clear links between the research objectives and the emergent themes, and the links need to be transparent and defensible (Thomas 2006). Padilla-Diaz (2015) suggests that the textual analysis refers to the description of what is expressed by the participants consequently, the researcher has to find the meaning in what they were told. Quantitative research uses grounded theory and inductive analysis to identify core meanings and condenses data through open coding and axial coding to emergent themes only and discourse analysis which describes multiple meanings (Thomas 2006). However qualitative research involves the rigorous attempt to produce findings or results by describing, explaining or interpretation of patterns in terms of words (Chenail 2011). Gerrish and Lacey (2010) advise logically organising the data accordingly, thematic analysis using immersion; coding; development of categories and developing themes will be utilised (Creswell 2014).

Stage one is immersion where the transcripts are typed verbatim by the researcher this being critical ensuring the narratives are correct. Watson *et al* (2008) suggest this familiarisation gives a deeper understanding of the data for the analysis process and allows for identification of emergent themes and truly understanding the lived experience of participants. The transcripts were sent to participants to check for error.

The second stage involves the coding of the transcripts. This was carried out inductively and classified the data into meaningful and relevant categories (Bowling 2014). It will be a flexible approach identifying words, statements, phrases, causality and relationships (Guest, McQueen and Namey 2012), offering the opportunity to develop new categories that may not have been previously considered.

Stage three linked the emerging codes and arranges the data into subsets to define the categories and themes (Creswell 2014). This process helped with the theoretical developments and provided structure for the analysis.

The final stage of the analysis was the development of themes, Bruce (2007) points out that themes may not emerge automatically, therefore, to aid the process Srivastava and Hopwood (2009) suggested using three questions

- What do I want to know?
- What is the data telling me?
- What do the answers to these questions imply?

These questions helped the researcher to remain focused on the research question. The data was collated ensuring it was repeatable and reflective (Creswell 2014). It was then analysed alongside the literature review (Maxwell 2005) to ensure validity is adhered to throughout (Miller and Creswell 2000). This appears the most effective method as each area being researched could be reviewed individually and merged with similar themes then related to the theory gathered through the literature review. Extracting the themes, commonalities and differences helped identify the relevant topics expressed by the participants and group the topics into units of meaning, thus postulate further areas of research or recommendations (Flick 2014).

3.8 Ethical approval and consent

To carry out this study the researcher considered the mitigation of the ethical principles which form the founding philosophy for decision making in research (Gelling 1999). Each principle will now be considered within the context of the proposed research.

Beneficence

This is the requirement to benefit the patient (Gelling 2015.) The research has the potential to demonstrate to participants strategies used by others to help them cope. By using focus groups, the researcher hoped the participants received a sense of validation when they hear others speak of their experiences. This research may also benefit the wider community as it aims to improve the understanding of the impact of Lyme disease and raise the profile of how patients are affected.

Non-maleficence

The Nursing and Midwifery Council (NMC) code of conduct states, ‘a nurse must be aware of, and reduce as far as possible, any potential for harm’ (NMC 2018). Flick (2006) identified that research into how people are living and coping with illness could produce an internal crisis for the participants. This was mitigated by ensuring the participant was clear on the purpose of the study and what they were expected to contribute. The researcher’s role was to collect data not to work with participants on their situation (Flick 2014) nonetheless, throughout the process the researcher was alert to the participant’s wellbeing. The Royal College of Nursing (RCN) research guidelines (RCN 2004) identifies that it is not always possible to predict problems in advance especially in qualitative research. As such, the researcher provided the Participant Information Sheet (Appendix 2) which included information on support organisations.

Fidelity

The development of a trusting relationship between the researcher and participant was important to ensure all participants could discuss their experience. Therefore, for the credibility of the study and to minimise alternative explanations the researcher had to ensure all participants’ symptoms were related to Lyme disease (Thomas and Hodge 2010). The researcher had to explain to each potential participant that GP confirmation of the diagnosis of Lyme disease was required; GP’s were asked to complete page three of the consent form (Appendix 3).

Justice

By asking the participants to volunteer for the study the researcher respected the participant’s right to participate. When a participant made contact an initial discussion took place to clarify the study expectations. This would be exercised by keeping participants fully informed, seeking their consent throughout the process and reminding them that they can withdraw at any time without fear of reprisal (Creswell 2014).

Veracity

Any changes to activities throughout the research process would not occur without the participant's consent. A copy of the final dissertation will be available for the participants to read if they request it.

Confidentiality

Participant anonymity would be protected by removing identifying details (Creswell 2014). As this is qualitative research, thick descriptions and quotes will be utilised to aid the credibility of findings; participants were made aware of this and as Thomas and Hodges (2010) suggested participants are shown all quotes about themselves thus ensuring no information is revealed inadvertently in the dissertation.

Respect for Autonomy

This concept covers participants' understanding of what they have committed to and remaining free from influences by others. To minimise these risk participants were given an information sheet and allowed to volunteer to participate by responding to the adverts as opposed to being referred by their GP.

NMC code of conduct and Professional accountability

As a Registered Nurse, the researcher must uphold the standards, values, and principles included within 'The Code' (NMC 2018). The code is used to advise Nurses on their professional accountability in terms of standards of practice and care and concerning this study participant's welfare was considered throughout the process.

Data Protection and General Data Protection Regulation (GDPR)

Digital recordings were kept on a secure computer. All computerised data was encrypted, and password-protected, no personal information of participants was stored on the computer and storage of data was in line with the Data Protection Act 2018 (Health Research Authority 2018). Transcribed data was stored within a locked filing cabinet; with all digital recordings being erased after the dissertation has been completed. In compliance with the GDPR, the personal data collected was only used for this study.

Following the discussion of the research proposal (Appendix 4) with the local NHS research and development officer, the researcher was advised the study required submission onto the Integrated Research Application System (IRAS). The forms were completed and submitted online on 4th December 2018; project ID number 254643. The researcher attended a Skype interview on 8th January 2019 with the REC. The first response from the Research Ethics Committee (REC) asked for clarification on some points and recommended that patients were recruited to the study by referral from General Practitioners (GP's). When planning the study, the researcher had sent the research proposal to the chair of the GP committee on 15th November 2018, for discussion with Western Isles GP's.

A follow-up discussion with the chairperson informed that due to work pressures GP referral to the study was not possible. It was agreed that GP's would complete a tick box sheet to confirm a Lyme disease diagnosis.

The researcher responded to REC giving an affirmation that GP's would confirm a diagnosis of Lyme disease. A second letter was received from REC re-iterating the request of GP referral; the researcher re-contacted the GP committee chairperson on the 5th February 2019 who reiterated that GPs would not refer but they would confirm the Lyme disease diagnosis. At this point, the study proposal and associated papers were also sent to the Medical Director, Director of Public Health and the GP cluster lead for the Western Isles. No concerns were raised by any of the recipients of the documents. The researcher contacted the REC chairperson directly and explained the outcome of the GP committee decision.

The researcher was asked to inform the REC of the GP sub decision in writing. A favourable outcome letter was received from REC on 19th March 2019 (Appendix 5). Following this, the study gained permission from the NHS Western Isles board research and development officer (Appendix 6) and acknowledgement from the University of the Highlands and Islands Ethics committee (Appendix 7).

Chapter 4: Data Analysis

4.1 Introduction

This chapter will present the findings which explore the participants' experience of living with Lyme disease. The results include demographic background data which is summarised into charts/figures and an interpretation of data highlighting the main study findings. Extracts from transcripts will be provided enable the reader to understand the researcher's findings.

The thematic analysis required familiarisation, and this involved typing the recordings verbatim and then re-reading the transcripts highlighting relevant points. The transcripts were anonymised. Development of the themes through classifying the data into meaningful and relevant categories was achieved by identifying words, statements, phrases; there was further analysis undertaken to identify causality and relationships. The final step was to arrange the data in defined themes and sub-themes to interpret meanings from the data. The focus group transcriptions were independently coded by the researcher. A copy of the transcript of one of the focus groups is included in appendix eight.

The study was designed to explore the experiences of living with Lyme disease. The overarching themes that emerged from the data were:

- Cognitive impacts
- Impact on ability to carry out usual tasks
- Impact on ability to participate in social activities
- Acknowledgement that symptoms may not be due to Lyme disease
- Impact of trying to avoid tick bites

4.2 Response rate

In total 22 people responded to the adverts looking for participants. Two were excluded; one because although originally from the Western Isles she resided in the central belt of Scotland and had received her tick bite causing Erythema migrans on the east coast of Scotland. The second exclusion was because there was no GP confirmation of the diagnosis; the respondent was utterly convinced her symptoms were attributed to Lyme disease as her symptoms were similar to what she read in the media. A final 20 respondents had a

discussion with the researcher and were sent the consent and participant information sheets. During this initial discussion three participants expressed concern about being in a large group as they had problems with the recall of information. Prior to the focus groups taking place two participants withdrew for personal reasons one due to a bereavement and one due to work commitments.

4.3 Participant characteristics

Eighteen participants attended four focus groups; two groups were held on Benbecula with six and four participants each. There was one group held on South Uist with five participants and one group on Lewis with three participants. No-one from Barra or Harris volunteered for the study. All participants were asked to complete a participant data form. Two-thirds of the participants were female, and the ages ranged from 41-77 years old. Figure one shows the ratio of males to females that attended the focus groups. Figure two shows the age range of participants.

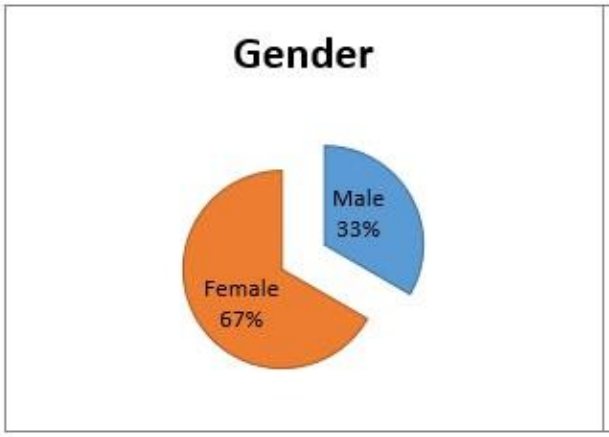


Figure 1: Ratio of participants gender

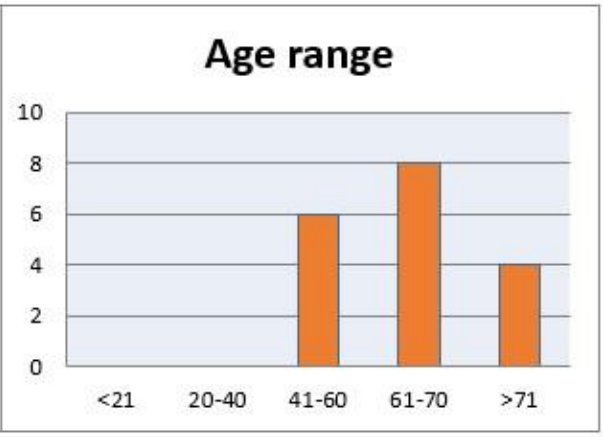


Figure 2: Age range of participants

The geographic split of participants was 15 from Uist and three from Lewis. 89% of participants had lived on the Western Isles for more than ten years. Figure three shows how long participants had been living within the Western Isles.

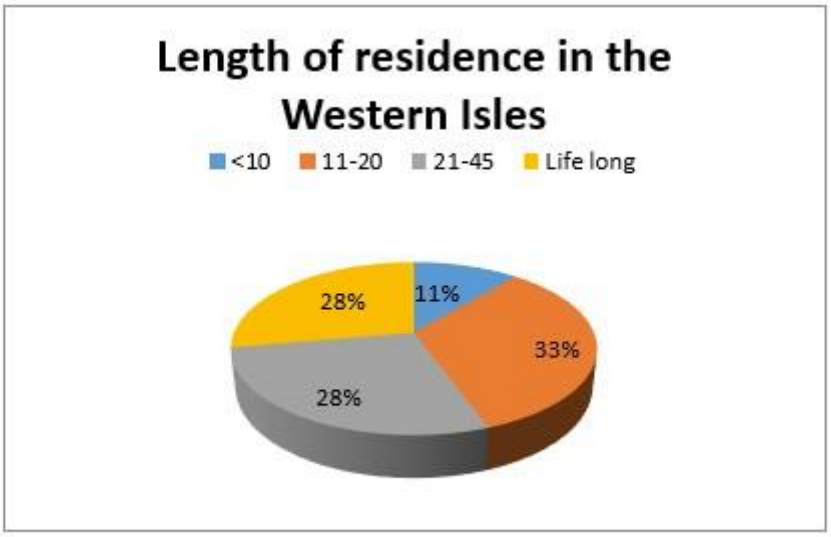


Figure 3: Length of residence of participants in the Western Isles

4.4 Lyme disease diagnosis

All participants in the study had GP confirmation of the diagnosis. Four participants had Erythema migrans on more than one occasion. Totals of 19 Erythema migrans and ten positive serology results were recorded among the 18 participants. Three participants Erythema migrans diagnosed and due to continuing symptoms had serological blood tests taken also. Figure four shows the method of diagnosis of all the participants.

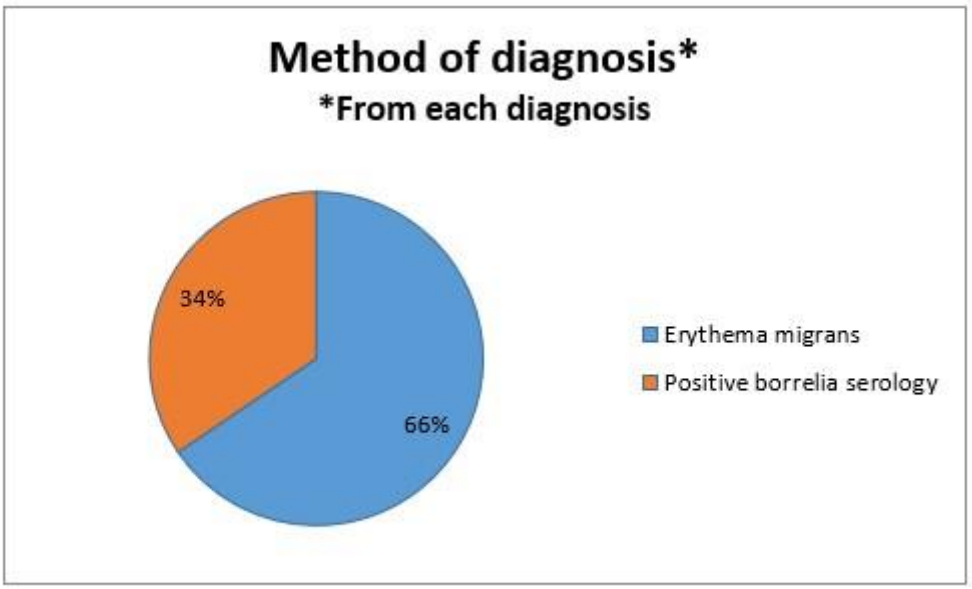


Figure 4: Method of diagnosis for all participants

The time since diagnosis was also recorded. 84% of the cases had been diagnosed in the last ten years. Figure five shows how many years since each participant was diagnosed.

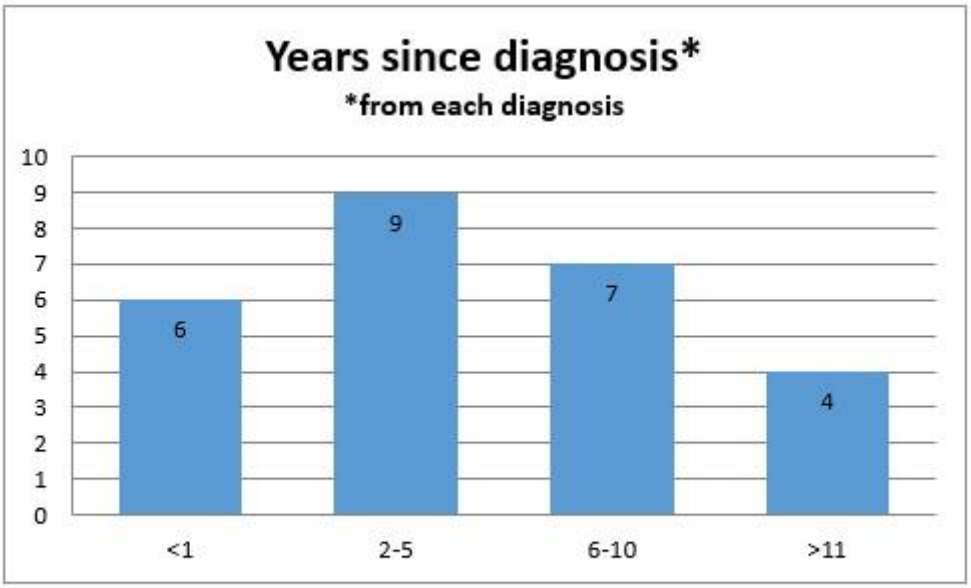


Figure 5: Years since diagnosis for all participants

4.5 Treatment for Lyme disease

All participants received treatment for Lyme disease. Five participants required to have retreatment due to continuing symptoms. Figure six shows where known, which antibiotic was received and the percentage of participants who required retreatment for the same episode of Lyme disease.

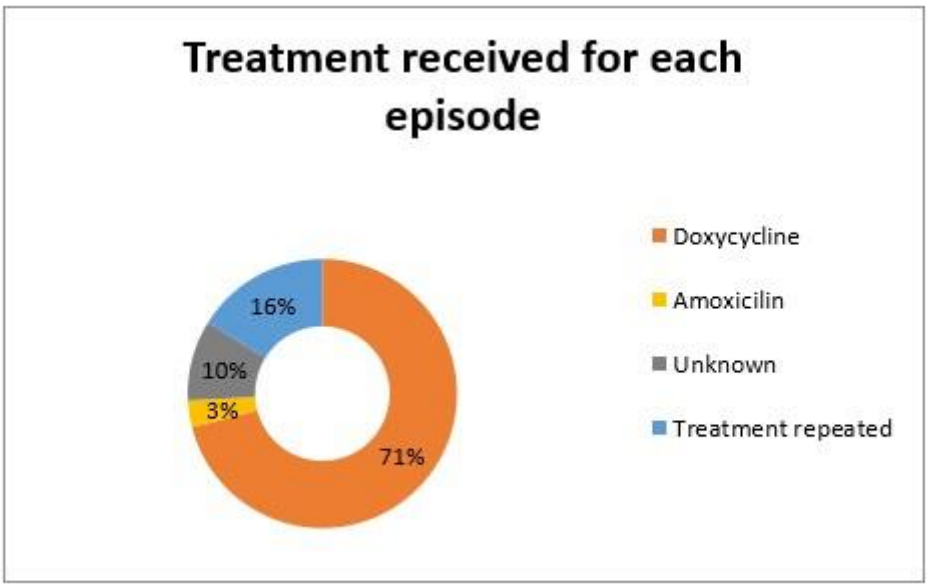


Figure 6: Treatment received for each episode of Lyme disease

5. Themes

The focus groups revealed a high level of thematic consistency where the identified themes were discussed within all group discussions. Table 1 shows the themes and sub-themes developed from the focus group data.

Table 1: Themes and sub-themes from focus group data:

Themes	Sub-themes	Participant examples
Mental/cognitive/social	Wording finding	Cannot remember words Cannot finish sentences Causes avoidance of contact with others
Mental/cognitive	Memory problems	Cannot remember how to do things Cannot remember people/places/names Lack of concentration/loses track of conversation/tasks
	Low mood/depression	Tears pouring down your face Feeling flattened
Physical/economic	Unable to carry out tasks	Couldn't work- absent Reduced work hours Needed people to help
Physical	Limited mobility and movement	Pain Problems with legs Reduced ability to perform tasks
Physical/social/economic	Feeling of extreme tiredness	Take more rests/Exhaustion Unable to do physical and social activities Unable to complete chores Unable to undertake work activates
Physical/social/mental	Impact on ability to participate in social activities	Others do not understand Physically cannot do things they used to. Don't enjoy drinking Memory problems stop participating in social encounters
Symptoms may not be Lyme disease	Other causes of symptoms	Ageing menopause
	No symptoms following antibiotic treatment	No symptoms following rash Good health
Impact of trying to avoid tick bites	Don't want to have another episode of Lyme disease	Don't want contact with ticks Increasing precautions Fear of going outside
Actions that helped	Complementary	Herbal Turmeric aromatherapy
	Exercises	Yoga Stretches Swimming Mental exercises
	Treatments	Antibiotics
		Private treatment
		Sauna

Many participants spontaneously expressed that their cognitive function was altered when compared to pre-illness, this manifested in the focus group discussions in two distinct themes, word-finding and memory problems.

5.1 Cognitive symptoms

5.1.1 Word-finding

Participants in two focus groups spoke about difficulties with word finding. There was an inability to think of the right words, which was worse in social situations.

'If I can't remember the word in my mind for dustbin or something, I would be rabbiting on you know the thing you put your rubbish in' (Focus Group 1 Participant 1(FG1P1)).

'You're not finishing your sentence- I can't remember the finish' (FG1P3).

'You would say a sentence and the words would come out wrong and you haven't realised' (FG4P18).

*'I have word finding difficulty- worse when I'm tired' (*FG1P1).

5.1.2 Memory problems

In all focus groups participants spoke about the impact of memory problems.

*'I can't remember things, I go to the wrong cupboard, I know it's the wrong cupboard, but I still go to it. You stand and you think what I was going to do' (*FG1P5).

'*I lose my train of thought as well and when I was in an interview for a teaching job and they ask you questions but within that question there could maybe 4 aspects that you, well I couldn't remember. I could only focus on the first one and didn't have a clue about the rest*'. (FG3P14).

'I couldn't be left alone- I would put two eggs on to boil and walk off my mind was all over the place' (FG4P18).

'I've lost some little bits of elements of time and it's not a question of forgetting' (FG2P10).

There was also evidence of the combined impact of word-finding and memory loss.

'My memory is terrible and my ability to articulate like I lose words' (FG3P14).

'*The sort of memory loss I have, a word I know or something like a word I've used loads of times before can't remember it and when you do remember it the word somehow seems strange'*(FG3P12).

5.2 Impact on ability to carry out usual tasks

In this study most participants volunteered how their physical health limits activities such as household chores, gardening, grocery shopping, crofting activities and sometimes requiring asking for help from others or pushing themselves to complete activities.

'*I've had to make adjustments or find someone to work with me' (FG1P6).*

'Getting to the shop, getting five things and being totally drained' (FG1P1).

'I've had to get a cleaner' (FG1P5).

'*I can't walk. I can't stand for long out in the garden'* (FG3P15).

The physical impact of carrying out activities was not only discussed in terms of chores and reduction in daily activity but also the impact of fatigue on their will and desire to perform these tasks.

'*I had times of extreme tiredness, just needing to go and lie down and go to sleep'* (FG3P11).

'*I was 22 hours a day in bed; I could only get up for 1 hour in the morning'* (FG1P1).

'I wasn't feeling like I could do the housework, I'm having to go to bed in the afternoon I'm so tired' (FG1P5).

A reduction in mobility and movement was also a factor in the reduced performance of activities although only directly reported in three focus groups.

'I felt as if I had dead weights in my legs, I was dragging them along' (FG1P4).

'I have to physically think about right I have to get up' (FG2P8).

'I went to put my feet down and my legs gave way, so I had to pull myself back up to the bed and then go through to the toilet on my knees' (FG4P16).

'*I don't view it as a health problem. It's a pain problem and stiffness. It impacts on my mobility'* (FG1P6).

'*I didn't take any time off work at all, but it was difficult working really hard. I'd go home at lunchtime and if I got to sit down at lunchtime it was a nightmare getting up to go out to do the afternoon calls'* (FG3P12).

The impact of fatigue resonated within all the groups and within the responses. Most participants were over retirement age however, participants relayed changes in the ability to carry out their usual work activities, which in turn can impact on the economy of the participants.

*'I can't go rushing off up a hill to get the cows, I sometime have to wait for the cow to come to me' (*FG1P6).

'*At the weekends the fatigue is worse, and I force myself to go down the croft knowing that I'm going to have to sit down because my heart palpitations will start, and I won't be able to breathe' (*FG4P16).

'*When I was weaving, I would have to have a sleep in the afternoon, even after I'd been treated'* (FG4P18).

'*I work for myself, so I would have to work around these things' (*FG3P11).

'*I had to go part-time at work in early 60's due to fatigue. It was either just go and do my work and be absolutely exhausted on the settee or go part-time and have some quality of life''* (FG4P18).

'I had to cancel flights to a meeting in Glasgow I couldn't make it I had to stay in bed it drained me of strength' (FG2P10).

5.3 Impact on ability to participate in social activities

When asked about social impacts, participants felt that it was difficult for family to understand that they could not take part like they used to.

'*Your kids don't want you to be ill. Difficult for them to understand why you can't do the things you always did, like swimming, going up and down the street in the city'* (FG1P5).

'They think you are a malingerer- well not with everyone, I stopped discussing it (Lyme disease) my symptoms you can't' (FG4P18).

Several participants spoke about being less active socially, not participating in events that include physical activities.

'I cannot dance, I used to dance all the time, I've now got no strength to lift my body of the floor. I've lost my spring' (FG1P5).

'I can't skip, and I used to do about a hundred skips, and I can't I can't' (FG1P3).

'*Before Lyme I was really active, kayaking, sea kayaking, hill climbing, dancing, I was very active but it all completely stopped'* (FG1P1).

'*I had no energy for hill walking, I was managing to work but I didn't do anything else really'* (FG3P12).

'*I go hillwalking but sometimes I hit a wall and have to stop'* (FG4P18).

Two participants spoke about the change it has made to their alcohol intake.
'I do take an odd pint now but for years I didn't take any, so I had to give up my pub life '(FG4P18).
'I have a sore head almost before I'm finished the glass; I can't take alcohol' (FG3P13).

One participant spoke about the negative impact of the development of food allergies and intolerances has had:
'*I've had a lot of backlash so it's easier and safer just to eat at home than it is going out and because I don't; well apart from breathing you can tell there's issues there I don't look ill, I get comments oh you look fine'* (FG4P16).

When talking about word finding and memory problems participants identified how this impacted on social encounters.
'When you meet someone new, I then have the embarrassment factor and it makes things worse' (FG1P1).
'*I couldn't remember people I had known for all my life'* (FG4P18).

5.4 Acknowledgement that symptoms may not be due to Lyme disease

Throughout the focus groups participants considered that other factors could be causing the symptoms and were hesitant about assigning all their problems to Lyme disease.
'*Thought memory problems were down to age'* (FG1P3, 4, 6).
'*Apart from getting mild arthritis in my hands, which you would probably get at 67 and getting forgetful another thing you can blame on getting old I haven't really had any symptoms'* (FG3P13).
'*I do have difficulty, a general slackening off in ability but I felt it was part of the menopause'* (FG1P2).
'*I just thought it was old age'* (FG4P17).

There were six participants who articulated that following completion of the course of antibiotics they had no symptoms that they were attributing to Lyme disease.

'General health is pretty good, but I have joint pain which comes in cycles and I just assumed, honestly, that it was to do with my hormones' (FG1P2).

'*I haven't been ill with it. For me it was a nuisance but not really a problem or a disabling condition'* (FG2P7).

'*Apart from that the rash I didn't get any more after that'* (FG2P9).

'*I wouldn't like to blame the Lyme disease for all the things'* (FG3P11).

'*I haven't really had any symptoms'* (FG3P13).

I've been lucky, very lucky I went to my doctor, I got very weak. I didn't get full-blown flu, but I had flu-like symptoms for a while I took the antibiotic and I got away with it' (FG4P17).

5.5 Impacts of trying to avoid tick bites

A concerning theme that had not been anticipated and was repeated through the groups was the impact the 'fear' of contracting Lyme disease was having on participants.

'*I've been pretty paranoid about them to be honest since that happened'* (FG1P2).

'*All the precautions that I'm taking the other day there do a tick check woke up in the morning and there was this huge tick'* (FG2P8).

'*It's actually the ticks themselves and you go out there and it's such a nuisance. It puts you off going for a walk'* (FG3P11).

'*I was worried yesterday the school were taking a day trip up a hill*' (FG3P14).

5.6 Actions taken that helped

Participants were asked to discuss anything that had relieved their symptoms in any way. Some participants appear to be drawn to specialisations in complementary therapy (herbal remedies). The use of turmeric was mentioned at two focus groups, as participants stated it had anti-inflammatory actions. Many respondents reported symptomatic relief while consuming antibiotics, yet all mentioned that the antibiotic doxycycline had some difficult to tolerate side effects, severe heartburn and extreme sun sensitivity.

'I've gone herbal and turmeric works for me' (FG1P6).

'I've used aromatherapy and it helped me' (FG1P1).

Things that help physical health impacts include:
'*I do yoga as well twice a week that's my two-I also take an immune booster'* (FG3P13).
'A little non-impact exercises every day, I exercise even though I've had problems, up and down with toes' (FG1P5).
'*I go swimming and stretching'* (FG1P6).
'*Sauna, it used to be once a week but now sometimes its twice a week'* (FG4P18).

Things that help with the mental health impacts:
'*I mentally watch TV quiz programmes'* (FG1P5)
'*I started to go to knit and natter and library on a Friday afternoon to be able to get myself to follow through with things, to actually do projects with a start and a finish and sort of manage to get to the end of things'* (FG3P11).
'Managing the pain by distraction' (FG4P16).

One of the participants mentioned how getting a diagnosis of Lyme disease was an action that helped:
'It's worth mentioning that actually getting a diagnosis of Lyme disease is in some ways a positive thing, it's a good thing because I certainly felt I had these lymph nodes; I was losing weight; I was exhausted, and I thought I had a malignancy. So, to get a diagnosis of Lyme disease which yes ok it causes us all problems but it's not half as bad' (FG3P12).

Chapter 5: Discussion

5.1 Introduction

This study was designed to explore the impact of Lyme disease on participants' quality of life. The literature review identified that mental, physical, social and economic impacts were common in Lyme disease. By analysing the focus group transcripts five themes emerged from the data. These were as follows:

- Cognitive impacts
- Impact on ability to carry out usual tasks
- Impact on ability to participate in social activities
- Acknowledgement that symptoms may not be due to Lyme disease
- Impact of trying to avoid tick bites

The findings relating to each theme will be discussed in relation to the information provided during the interviews, the literature review and any additional research following the interviews. Aspects in the development of the study such as; the use of focus groups; how the question guide was utilised; participant recruitment and a concern raised by a GP will also be discussed.

5.2 Study findings

5.2.1 Mental/cognitive impacts

Cognitive impacts were frequently reported across much of the literature (Steere 2001; Eikland *et al* 2011, Rebman *et al* 2017a; Bechtold *et al* 2017; Touradji *et al* 2019) and this study will define what this meant to participants. Participants acknowledged the difficulties experienced with word-finding and memory difficulties. Both were prevalent in day to day household and work activities, and they hindered participants when undertaking social activities. This cognitive symptomology was reported by participants diagnosed with Erythema migrans who were treated promptly with antibiotics and those who presented later and were diagnosed through serology. Conversely, participants were keen to propose that their memory problems may not be caused by Lyme disease and could be related to other factors particularly ageing. However, two participants aged 41 and 42 years respectively also described memory difficulties.

Finding the cognitive associated symptoms in the majority of participants irrespective of the timing of receiving treatment does not correlate with other studies. Bechtold *et al* (2017) found that ideally treated individuals with early Lyme disease demonstrated no objective evidence of cognitive impairments. Moreover, Keilp *et al* (2019) identified that cognitive dysfunction is detectable but more likely in those who are diagnosed later.

Depression was hypothesized to play a role in those reporting continuing symptoms (Aucott *et al* 2013; Rebman *et al* 2017a; Bechtold *et al* 2017), although less common when Lyme disease was identified and treated early. Only two participants in this study acknowledged their symptoms of depression; although not portrayed as an overwhelming impact. The absence of depression in the discussion could be related to participants not wanting to admit to having depression or participants did not recognise the relationship between depression and continuing symptoms.

The literature and current findings do not fully explain or negate in any way the subjective experience of cognitive changes reported. Participants within this study had other medical conditions that may or may not be contributing to the impacts discussed. In reality cognitive difficulties, chronic pain and fatigue are highly prevalent in the general population (Patrick *et al* 2015; Rebman *et al* 2017a). To enhance the findings of this study, a comparative study that looked at the presence of these symptoms in the general population as well as differentiating between the symptoms of co-morbid conditions and Lyme disease is required.

5.2.2 Physical impacts

In this study physical impacts were consistently acknowledged particularly in participants who reported continuing symptoms this corresponds with the findings of Aucott *et al* (2013); Wills *et al* (2016) and Rebman *et al* (2017a). There is evidence of limitations to general activity patterns and having to adjust hours of employment or in some participant's cases give up work. Many participants spoke about the restrictions the physical problems placed on their ability to take part in social activities such as dancing, walking, hill climbing.

However, in this study participants also spontaneously vocalised a determination to continue to lead a normal life and not allow symptoms to impact on their lives.

'*You have to be stubborn. Go part-time to have some quality of life'* (FG4P18).

'*You learn to live with and you learn to deal with (symptoms)'* (FG3P11).

The desire to lead a normal life is not identified in other studies. It is important to acknowledge this determination as opposed to the portrayal of a debilitating condition (Cameron *et al* 2014; Johnson *et al* 2014).

Fatigue was found to coexist with the physical impacts, echoing findings across studies (Chandra, Keilp and Fallon 2013; Weitzner *et al* 2015; Wills *et al* 2016, Wormser *et al* 2016; Weinstein *et al* 2018). The relentless feeling of fatigue was also identified by participants who considered that following treatment they had no further symptoms. This finding was corroborated by Aucott *et al* (2013) who found 20-45% of patients with Lyme disease who were diagnosed and treated early reported fatigue, pain or sleep disturbance six months later. In addition, Wormser *et al* (2016) suggested the incidence of fatigue correlated with a greater total of symptoms and that fatigue was 'likely to be a component in what has been referred to as the acute sickness response'.

Fatigue is complex and can be debilitating and clinicians need to understand the consequences for sufferers (Rebman *et al* 2017a). The lack of management options does prevent people seeking help one participant said:
'*You go to the doctor and you say you are feeling tired all the time well what are they supposed to do*' (FG3P11).

Acknowledging the consistent reporting of fatigue with Lyme disease (Rebman *et al* 2017a), indicates that it merits further study to advance the understanding of the impact of fatigue which is vital to improve outcomes for patients.

5.2.3 Social impacts

Symptomatic participants conferred the impact on relationships in families and a general lack of understanding from others. The invisibility of the illness and the unpredictable trajectory adds to the uncertainty for the patient and the family. Participants spoke about avoiding social encounters due to the cognitive impacts and the physical impacts of pain and fatigue removed participant's ability to join in family activities, exercise regimens and outdoor pursuits. These findings correlate with those of Rebman *et al* (2017a) in persons with continuing symptoms. However, the findings are in contrast to studies that consider Lyme disease to be 'mild and self-limiting' (Feder *et al* 2007), and studies that found the quality of life scores similar to those seen in the general population (Aucott *et al* 2013; Wormser *et al* 2015). Regardless this study suggests that a proportion of participants

experience altered quality of life therefore, it is important to gain understanding regarding the legitimacy of the illness for those who suffer from prolonged symptoms.

An unexpected apprehension not previously identified in quality of life studies was the fear of coming into contact with ticks and of contracting Lyme disease again. The Western Isles are renowned for the stunning landscapes, geology, wildlife and heritage and embracing these outdoor activities is an important aspect of living there. The suggestion that this fear could lead to people disengaging with the outdoors raises concerns. To avoid disengagement, it is imperative work is undertaken to educate the community on how to reduce the risk of tick bites, correct tick removal and the signs to indicate when to seek medical advice, as well as collaborating with others to reduce the burden of ticks in the environment.

5.2.4 Economic impacts

The participants provided evidence of amendments to work patterns and absences from work which in turn deliver reduced performance. In an area where increasingly high disease incidence is recorded this reduced performance could impact on the long-term workforce and in turn affect productivity. Participants who were self-employed acknowledged they were unable to work which reduces household income and ultimately leads to people requiring sickness/disability benefits.

It is beyond the scope of this study to calculate the economic costs with regard to direct medical costs, laboratory costs, antibiotic treatment and appointment costs. Nonetheless, in the cohort of participants in this study there is evidence that would indicate considerable use of these resources. A literature review by Mac, DaSilva and Sander (2019) discussed many studies that looked at economic costs in terms of paying for testing and treatments. In Scotland people are fortunate that testing and treatments are funded by the NHS. One participant spoke about seeking private treatment to great personal cost. This is part of the ongoing debate within Lyme disease. Some clinicians treat ongoing symptoms with long term, high dose antibiotics on the basis that the bacteria persist (Cameron *et al* 2014) as opposed to others that identify continuing symptoms exist with no evidence of persistent infection (Klemper *et al* 2001; Krupp *et al* 2003; Fallon *et al* 2008; Berende *et al* 2016; Di Domenico *et al* 2018).

This debate leaves the science of the persistence of Lyme disease and its associated symptoms as uncertain and evolving; with many physicians having conflicting opinions. Irrespective of this debate effective, cost-effective and compassionate management of people with Lyme disease is crucial to reduce costs and improve outcomes even in the absence of a definitive understanding of the pathophysiology of this post-treatment illness.

5.2.5 What helps participants

Other than antibiotic therapy there is no guidance of other treatment for Lyme disease. Two courses of antibiotics are recommended for patients with ongoing symptoms, followed by referral to a specialist service such as rheumatologist, cardiologist or neurologist depending on the symptoms presenting (NICE 2018). Two participants raised that they felt the specialist services did not know enough about Lyme disease, this could be a learning point for those developing Lyme disease guidance, current health professional resources are aimed at recognising and treating Lyme disease early. Lyme disease guidance should be developed for all disciplines within the specialities people could be referred to.

In the absence of further treatment patients are drawn to suggestions from the literature/social media or Lyme disease websites. Participants spoke about the use of turmeric, aromatherapy and saunas with no consensus regarding what worked. It was very much personal preference and ease of accessibility. Continuing to exercise appeared as a theme, yoga, low impact exercises, swimming and stretching were all mentioned. One participant said:

*'I exercise even though I've had problems' (*FG1P5).

The frequency with which physical problems related to pain, joint problems and reduced ability were mentioned and would suggest that encouraging people to undertake some low impact exercise would be practicable. D' Adamo *et al* (2015) did find that supervised low-intensity exercise was feasible. The participants recognised the validity of undertaking exercise insinuating that consideration should be given to referring patients with continuing symptoms for advice and support with regard to the most suitable exercises.

Participants also mentioned the importance of ‘mental’ stimulation; watching quiz shows and undertaking projects from beginning to end. It is acknowledged cognitive impairment impacts on functional ability (Chandra, Keilp and Fallon 2013). However, in the absence of any recognised therapeutic options future studies could evaluate the concepts identified for other conditions, such as those evidenced by Shimada *et al (*2019) where strategies successfully reversed the early cognitive difficulties associated with Alzheimer’s.

The literature discusses the contested illness aspect of Lyme and the similarity to other conditions (Rebman *et al* 2017a); there is no acknowledgement that study participants recognise this. Yet in this study participants were open to the fact that other factors could be responsible for their symptoms. More qualitative studies are required to document participant’s views, enabling an evaluation of how many sufferers recognise that Lyme disease may not be the cause of their symptoms.

5.3 Study strengths and limitations

The study examined patient-reported impacts of Lyme disease through a qualitative research methodology involving four focus groups with 18 participants. The focus groups generated descriptions of the impacts on participant’s lives based on personal experience. Using focus groups allowed a larger number of participants than would have been possible if one to one interview had been carried out. Throughout the groups the participants interacted; they asked questions of each other; exchanged anecdotes and commented on each other’s experience. The use of a focus group as suggested by Kitzinger (1995) benefited from the communication between participants to generate data. The appropriateness of the method was evident by the range of symptomology expressed across all groups.

Flick (2014) recommended the use of a diary to allow the researcher to reflect on the study and discussions. When reviewing the diary, it was noted that throughout the groups, participants readily spoke about symptoms of Lyme disease as opposed to impacts. In each group the researcher had to re-iterate to participants that the study was looking for information on the impacts/effects Lyme disease had on their lives. Participants found it much easier to relay symptoms and Rebman *et al* (2017b) suggest that purely medicalised understandings of illness are limited to physical signs and symptoms. Therefore, participants needed encouragement to view their discussion as a social construct to gain a broader understanding of the lived experience. The researcher was concerned that the terminology was not familiar to participants, by adding the word 'effects' appeared to resolve the issue.

The aim of this study was to gather narratives to contribute to the understanding of patient's experience and once the participants started to talk the researcher found that the question guide did not need to be adhered to rigidly, as the conversation flowed quite naturally, and each topic was discussed. Throughout the session the researcher reflected on the answers being given and prompted with sub-questions where certain aspects had not been discussed fully, this allowed participant discussions to lead the flow of conversation.

By designing the study to allow those with Erythema migrans or positive serology it was hoped to gain a perspective of how persons are impacted in the initial months or early years following diagnosis and treatment. Essentially one third (33%) of the participants in this study following receipt of antibiotics declared no continuing symptoms. Generally, in studies 80-100% of Lyme disease patients would not have persistent symptoms (Marques 2008). Therefore; it is acknowledged this study did attract more people with ongoing symptoms. However, this is the first study of its kind in the Western Isles and hesitancy to come forward could be a factor especially in asymptomatic people. Likewise, the self-selective nature of recruitment that was adopted offers a bias towards participants that are likely to have more symptoms. A suggestion for a future study could enrol all Lyme disease cases diagnosed in a calendar year, repeated over a few years. This would clarify how many people declare continuing symptoms.

With all the permissions in place, the researcher proceeded to advertise for study participants. As agreed, posters were distributed, seven days after the poster was distributed the researcher received an email from a local GP expressing concerns. The concerns were around the approval and study methodology and the influence the study could have on patients. In response to the concerns the researcher explained the process involved in gaining ethical approval and the engagement that the researcher had with the local GP committee and local senior medical advisors. The researcher also relayed the decision of GP sub-committee regarding confirmation of diagnosis. The researcher offered to meet with the GP for further discussions, an offer that was declined. The GP accepted the researcher's response and 'agreed to disagree'. Nevertheless, the GP did agree to confirm a diagnosis for any practice patients that volunteered.

Lyme disease is a controversial subject in politics and the media and having the opportunity to speak to patients and hear their views can help to improve the public understanding and knowledge on Lyme disease. A paper published by Eldin *et al* (2019) identifies the problems associated with the numerous pieces of information about Lyme disease emerging through media outlets. This information can be critical of guidance documents and the diagnosis and treatment methods used. The release of the information is thought to increase patients' expectations and arouse suspicion of the actions of practitioners

There is acknowledgement of the impact the information available on Lyme disease has on influencing patient's perception particularly on the severity of the illness (Eikland *et al* 2011). Two comments were made within the groups that would suggest participants were expecting to be debilitated by Lyme disease.

'I had flu-like symptoms for a while I took the antibiotic and I got away with it' (FG4P17).

'Not really a problem or a disabling condition' (FG2P7).

It is important that studies collate the incidence of those with continuing symptoms, representing these figures will help to dispel the myth that it is a debilitating illness for all whereas in reality approximately 10-20% of patients suffer continuing symptoms (Marques 2008; Rebman *et al* 2017a).

Although qualitative research findings are not concerned with generalisability (Creswell 2014) they can still be theoretically transferable (Silverman 2010). The sample size in qualitative research should be large enough to achieve variations in experiences and small enough to permit a deep analysis of the data. Eighteen people participated in this study, recruited voluntarily from a population with a high incidence of Lyme disease; this number appeared to achieve depth in the analysis. Each person's illness experience is unique, nevertheless, this study provides an important insight into some characteristics of those with Lyme disease. The findings provide a snapshot of the impact and draw attention to how some people with Lyme disease may be affected which in turn has important implications for management advice.

A limitation to the findings is co-morbidities, 13 participants had co-morbidities. Eight participants had pre-existing conditions of such a diverse nature that the researcher felt that naming the conditions would make the participant identifiable. Flick (2014), recommends the researcher must ensure participant confidentiality when writing up the findings. Five participants had conditions developed since the diagnosis and could be related to Lyme disease such as arthritis and cardiac problems. Comparatively, Wills *et al* (2016) found patients with co-morbidities were significantly more likely to report long-term subjective symptoms. Yet, the eight participants relayed that the symptoms they were describing were not present before their Lyme disease diagnosis and justified their attribution of Lyme disease as the cause. However, given that Wills *et al* (2016) recognised that lower quality of life measures was recorded when co-morbid conditions were present it would be imperative that any future studies should consider the impact of co-morbidities when evaluating patients with Lyme disease who have continuing symptoms.

Chapter 6: Conclusion

6.1 Introduction

The prognosis and impact of continuing symptoms on quality of life in people with Lyme disease are subject to debate. The findings of this study give an overall endorsement that early recognition of Erythema migrans and treatment positively impacts on the outcomes and these individuals can recover well and experience fewer symptoms. However, it is clear that there are also individuals who continue to suffer and express functional decline.

The study results demonstrate a range of impacts associated with a diagnosis of Lyme disease. The fatigue reported which impacts on physical, mental, economic and social aspects of nearly all participants irrespective of the stage of diagnosis is identifiable. The cognitive impact of word-finding and memory problems were reported mostly by participants whose Lyme disease was diagnosed later and has therefore impacted on their normal activities. These results determine there is a reduction in quality of life particularly in those with late Lyme disease and the antibiotic treatment does not resolve their symptoms.

Irrespectively, study participants expressed a determination to retain a normal life, this determination is not mentioned in the literature. But it is essential for those newly diagnosed with Lyme disease to hear this view expressed by people who have had the disease. The representation of a debilitating condition for all is misleading and delivers widespread public expectation.

6.2 Implications for practice

Patients and the general population have different insights into Lyme disease and there is a wide range of illness trajectories, thus clinicians may have difficulty understanding the patients' experience. Patients' perceptions are multidimensional, multifaceted and heterogenous in nature and there is a percentage of patients who do not recover quickly.

6.3 Recommendations

6.3.1 For future research

The number of participants without prolonged symptoms did not reflect the 80-90% findings in other studies (Marques 2008; Rebman *et al* 2017). This could be due to the fact that people may not have come forward as they thought only those with symptoms were required. However, a future study of all newly diagnosed cases of Lyme disease would help to clarify the true incidence of those with continuing symptoms.

To compare the presence of the symptoms; particularly the cognitive symptoms described by the participants and to truly relate them to Lyme disease would require a comparative study with those in the general population without Lyme disease. The distinct nature of the Western Isles would make this an ideal population on which to undertake this type of study.

The consistent reporting of fatigue and the lack of management options would suggest that it merits further study and the knowledge gained could be used to improve outcomes for patients. The researcher hopes the findings of this study will generate interest and funding opportunities to look at the impacts in greater detail.

6.3.2 For the NHS

As the number of cases of Lyme disease increases, the future economic impact of Lyme disease would be expected to increase. Therefore, further research and priority should be placed on preventative interventions. A case study could be performed to gather evidence from patients attending with Erythema migrans, the analyses could include; tick exposure, precautions taken to avoid ticks, the method used for tick removal and what prompted attendance at GP. This could be undertaken as a pilot project with one GP practice initially.

Participants spoke about the benefits to continuing to exercise and they did this with no formal guidance. A recommendation is that when patients continue to suffer symptoms a referral is made to an appropriate health professional for advice and guidance on low impact exercises, this could help to maintain a patients vitality and assist with improving their long term outcome.

Given the concern the cognitive impacts cause the participants, studies could be undertaken to examine the benefits of continuing with targeted activities as recommended by Shimada *et al* (2019); who identified the reversal from mild cognitive to normal cognitive function in Alzheimer's patients. The reversal was associated with lifestyle activities such as driving a car, reading books or newspapers, participating in hobbies or sports activities, and gardening.

6.4 Dissemination of findings

The research findings from this study will be disseminated through NHS networks and the Scottish Health Protection Network 'Lyme Borreliosis' group. There are plans in place to submit an abstract of the findings to the 'Lyme and tick-borne disease research in the UK' conference in November 2019. The researcher will also prepare an article for publishing in peer-reviewed journals.

Chapter 7: References

Ali, A., Vitulano, L., Lee, R., Weiss, T. R., & Colson, E. R. (2014) 'Experiences of Patients identifying with chronic Lyme disease in the healthcare system: A qualitative study'. *BMC Family Practice* [online]*15* (79). Available from < https://bmcfampract.biomedcentral.com/articles/10.1186/1471-2296-15-79> [19 March 2019]

Anker, A.E., Reinhart, A.R. and Feeley, T.H. (2011) 'Health information seeking: A review of measures and methods'. *Patient Education and Counselling* 82(3), 346-354

Aronowitz, R.A. (1991) 'Lyme disease: The social construction of a new disease and its social consequences'. *Milbank Quarterly* 69, 79-112

Aucott, J., Morrison, C., Munoz, B., Rowe, P.C., Schwarzwalder, A. and West, S.K., (2009) 'Diagnostic challenges of early Lyme disease: Lessons from a community case series'. *BMC Infectious Diseases* [online] **9** (79). Available from < https://doi.org/10.1186/1471-2334-9-79> [28 June 2019]

Aucott, J., Seifter, A. and Rebman, A.W. (2012) 'Probable late lyme disease: a variant manifestation of untreated *Borrelia burgdorferi* infection'. *BMC Infectious Diseases* [online] 12(173). Available from < https://doi.org/10.1186/1471-2334-12-173> [28 June 2019]Aucott, J. N., Rebman, A. W., Crowder, L. A., & Kortte, K. B. (2013). Post- treatment Lyme disease syndrome symptomatology and the impact on life functioning: Is there something here?. *Quality of Life Research 22*, 75–84

Baker, P.J. (2019) 'Is it possible to make a Correct Diagnosis of Lyme Disease on Symptoms Alone? Review of Key Issues and Public Health Implications' *The American Journal of Medicine* [online]. Available from < https://doi.org/10.1016/j.amjmed.2019.04.001>[17 May 2019]

Bakken, L.L. (2002) 'Role and Experience and Context in Learning to Diagnose Lyme Disease'. *The Journal of Continuing Education in the Health Professions* 22, 131-141

Ballantyne, C. (2008) 'The chronic debate over Lyme disease'. *Nature Medicine* 14, 1135-1139

Barbour, A.G. (2015) *Lyme Disease Why its Spreading, How It makes you sick, and What to Do about It.* Baltimore: John Hopkins University Press

Bechtold, K. T., Rebman A. W.Crowder L. A. Johnson-Greene, D. & Aucott, J. N. (2017) 'Standardized symptom measurement of individuals with early Lyme disease over time'. *Archives of Clinical Neuropsychology* 32, 129-141

Berende, A., ter Hofstede, H.J.M., Vos, F.J., van Middendrop, H., Vogelaar, M.L., Tromp, M.,van den Hoogan, F.H., Donders, A.R.T., Evers, A.W.M., and Kulberg, B.J.(2016) 'Randomized trial of longer-term therapy for symptoms Attributed to Lyme Disease'. *New England Journal of Medicine* 374, 1209-1220

Berende, A., Nieuwenhuis, L., ter Hofstede, H.J.M., Vos, F.J., Vogelaar, M.L., Tromp, M., van Middendorp, H., Donders, A.R.T., Evers, A.W.M., Kulberg, B.J. Adano, E.M.M. (2018) *Cost-effectiveness of longer-term versus shorter-term provision of antibiotics in patients with persistent symptoms attributed to Lyme disease* [online]. Available from< https://doi.org/10.1371/journal.pone.0195260> [13 May 2019]

Berg, B. and Lune, H. (2012) *Qualitative Research for the Social Sciences* 8th Edition. Boston MA: Pearson Internationals Edition.

Berglund, J., Eitrem, R., Ornstein, K., Lindberg, A., Ringer, A., Elmrud, H., Carlsson, M., Runehagen, A., Svanborg, C. and Norrby, R. (1995) 'An epidemiological study of Lyme disease in southern Sweden'. *New England Journal of Medicine* 333, 1319-1327

Borgermans, L., Goderis,G., Vandevoorde,J and Devroey D (2014) 'Relevance of Chronic Lyme Disease to Family Medicine as a Complex Multidimensional Chronic Disease Construct: A Systematic Review'. International Journal of Family Medicine [online]. Available from < http://dx.doi.org/10.1155/2014/138016>[16 May 2019]

Bowling, A. (1996) 'The effects of illness on quality of life: findings from a survey of households in Great Britain'. *Journal of Epidemiology and Community Health* 50, 149-155

Bowling, A. (2009) *Research Methods in Health: Investigating Health and Health Services* 2nd Edition. Buckingham: Open University Press

Bowling, A. (2014) *Research Methods in Health: Investigating Health and Health Services* 4th Edition. Maidenhead: Open University Press.

Brett, M.E., Hinkley, A.F., Zeilinski-Gutierrez, E.C. and Mead, P.S. (2014) 'U.S. Healthcare providers' experience with Lyme and other tick-borne diseases'. *Ticks and Tick-Borne Diseases* 5(4), 404-408

British Infection Association (2011) 'The epidemiology, prevention, investigation and treatment of Lyme borreliosis in United Kingdom patients: a position statement by the British Infection Association'. *Journal of Infection* 62(5), 329-338

Brown, P. and Zavestoski, S. (2004) 'Social movements in health'. *Sociology of Health and Illness* 26(6), 679-694

Bruce, C.D. (2007) 'Questions arising about emergence, data collection, and its interaction with analysis in a grounded theory study'. *International Journal of Qualitative Methods* 6 (1), 51-68

Brunton, G., Sutcliffe, K. Hinds, K., Khatwa, M., Burchett, H., Dickson, K., Rees, R., Rojas- Garcia, A., Stokes, G., Harden, M., Stansfield, C., Sowden, A. and Thomas, J. (2017) *Stakeholder experiences of the diagnosis of Lyme disease: A systematic review*. London: The Department of Health Reviews Facility

Busija, L., Tan, J. and Sanders, K.M. (2017) 'Associations between illness duration and health-related quality of life in specified mental and physical chronic health conditions: results from a population-based survey'. *Quality of Life Research* 26, 2671-2681

Cameron, D.J., Johnson, L.B. and Maloney, E.L. (2014) 'Evidence assessments and guideline recommendations in Lyme disease: the clinical management of known tick bites, erythema migrans rashes and persistent disease'. *Expert Review of Anti-Infective Therapy* 12(9), 1103-1135

Cerar, D., Cerar, T., Ruzic-Sabljic, E., Wormser, G.P and Strle, F. (2010) 'Subjective symptoms after treatment of early Lyme disease'. *American Journal of Medicine* 123, 79-86

Chandra, A.M, Keilp, J.G. and Fallon, B.A. (2013) 'Correlates of perceived health-related quality of life in post-treatment Lyme encephalopathy'. *Psychosomatics* 54(6), 552-9

Chenail, R.J. (2011) 'How to Conduct Qualitative Research on Patients Experience'. *The Qualitative Report* 16(4), 1172-1189

Clark, K.L., Leydet, B.F. and Threlkeld, C. (2014) 'Geographical and genospecies distribution of *Borrelia burgdorferi* sensu lato DNA detected in humans in the USA'. *Journal of Medical Microbiology* 63, 674-684

CNR *Borrelia*' Centre National de Reference-*Borrelia* (2019) *Borrelia burgdorferi* Spirochete [photograph]. Strasbourg, 24 February 2019

Creswell, J.W. (2014) *Research Design: Qualitative, quantitative and mixed methods approaches* 4th edition. London: Sage Publications

Creswell, J.W. and Creswell, J.D. (2018) *Research Design: Qualitative, quantitative and mixed methods approaches* 5th edition. London: Sage Publications

Creswell, J.W. and Plano-Clark, V.L. (2017) *Designing and Conducting Mixed Methods Research 3rd Edition.* California: Sage Publications

Crowder, L.A., Yedlin, V.A., Weinstein, E.R., Kortte, K.B. and Aucott, J.N. (2014) 'Lyme disease and post-treatment Lyme disease syndrome: the neglected disease in our own backyard'. *Public Health* [online] *128*(9), 784-791. Available from < DOI: 10.1016/j.puhe.2014.06.016> [19 June 2019]

D'adamo, C.R., Mcmillin, C.R., Chen, K.W., Lucas, E.K. and Berman, B.M. (2015) 'Supervised Resistance Exercise for Patients with Persistent Symptoms of Lyme Disease' *Medicine & Science in Sports & Exercise* 47(11), 2291-2298

Davies, G. and Nichter, M. (2015) 'The Lyme wars: the effects of bio-ommunicability, gender and epistemic politics on health activation and Lyme science'. In *Diagnostic controversy: Cultural perspectives on competing knowledge in healthcare.* ed. by Smith-Morris, C. New York: Routledge, 215-246

Delong, A.K., Blossom, B., Maloney, E.L. and Phillips, S.E. (2012) 'Antibiotic retreatment of Lyme disease in patients with persistent symptoms: a biostatistical review of randomized, placebo-controlled, clinical trials'. *Contemporary Clinical Trials* 33(6), 1132-1142

Denzin, N.K. and Lincoln, Y.S. (2011) 'Introduction: The Discipline and Practice of Qualitative Research'. In *The Sage Handbook of Qualitative Research*. ed. by Denzin, N.K. and Lincoln, Y.S. California: Sage Publications, 1-20.

Denzin, N.K. and Lincoln, Y.S. (2013) 'The Discipline and Practice of Qualitative Research'. In *Strategies of Qualitative Inquiry*. ed. by Denzin, N.K. and Lincoln, Y.S. United States of America: Sage Publications, 1-44

Dersch. R. (2018) 'Lyme Neuroborreliosis: A European Perspective'. In *Lyme disease An Evidence-based Approach*. ed. by Halperin J.J. London: CAB International

Dersch, R., Sarnes, A.A., Maul, M., Hottenrott, T., Baumgartner, A., Rauer, S. and Stich, O. (2015) 'Quality of life, fatigue, depression and cognitive impairment in Lyme neuroborreliosis'. *Journal of Neurology* 262, 2572-2577

Di Domenico, E.G., Cavallo, I., Bordignon, V., D'Agosto,G., Pontone,M., Trento, E., Gallo, M.T., Prignano, G., Pimpinelli, F.,Toma, L., and Ensoli, F.(2018) 'The Emerging Role of Microbial Biofilm in Lyme Neuroborreliosis' *Frontiers in Neurology* [online]. Available from< doi: 10.3389/fneur.2018.01048> [10 March 2019]

Dilaria.C.,Hockenberry-Eaton, M.,Malbach, E. And Rivero, T. (1994) 'Focus groups: an interview method for nursing research'. *Journal of Neuroscience Nursing* 26(3), 175-180

Dubrey, S., Bhatia, A., Woodham, S. and Rakowicz, W. (2014)' Lyme disease in the United Kingdom'. *Postgraduate Medical Journal* 90(1059), 33-42.

Eikeland, R., Mygland, Å., Herlofson, K. and Ljøstad, U. (2011) 'European neuroborreliosis: quality of life 30 months after treatment'. *Acta Neurologica Scandinavica* 124(5),349–354

Eldin, C., Raffetin, A., Bouiller. K., Hansmann, Y., Roblot, F., Raoult, D. and Parola, P. (2019) 'Review of European and American guidelines for the diagnosis of Lyme borreliosis'. *Medicine et Maladies Infectieuses* 49(2), 121-132

Eliassen, K.E., Hjetland,R., Reiso,H., Lindbæk, M. and Tschudi-Madsen, H. (2017) 'Symptom load and general function among patients with erythema migrans: a prospective study with a 1-year follow-up after antibiotic treatment in Norwegian general practice'. *Scandinavian Journal of Primary Health Care* 35 (1), 75-83

European Centre for Disease Prevention and Control. CDC. (2016) '*Tick maps: tick species-distribution maps* [online]. Available from <http://ecdc.europa.eu/en/healthtopics/vectors/vector-maps/Pages/VBORNET-aps-tick-species.aspx>[18 May 2016].

Fallon, B.A., Keilp, J.G., Corbera, K.M., Petkova, E., Britton, C.B., Dwyer, E., Slavov, I., Cheng, J., Bodkin, J., Nelson, D.R. and Sackeim, H.A (2008) 'A randomized, placebo-controlled trial of repeated IV antibiotic therapy for Lyme Encephalopathy'. *Neurology* 70(13),992–1003

Fallon, B.A., Petkova, E., Keilp, J.G.and Britton, C.B. (2012) 'A reappraisal of the U.S. Clinical trials of post-treatment Lyme disease syndrome'. The *Open Neurology Journal* 6,79–87

Feder, H.M., Johnson, B.J., O'Connell, S., Shapiro, E.D., Steere, A.C., Wormser, G.P. and Zemel, L. (2007) 'A critical appraisal of "chronic Lyme disease'. *New England Journal of Medicine* 357, 1422-1430

Flick, U. (2006) *An Introduction to Qualitative Research*. Thousand Oaks, California: Sage

Flick, U. (2009) *An Introduction to Qualitative Research* 4th edition. California: Sage Publications Ltd

Flick, U. (2014) *An Introduction to Qualitative Research* 5th edition. London: Sage Publications Ltd

Flyvbjerg, B. (2011) 'Case study'. In *The Sage Handbook of Qualitative Research*. ed.by. Denzin, N.K. and Lincoln, Y.S. California: Sage Publications,301-316

Fontana, A. and Frey, J.H. (2008) 'The Interview: From Neutral Stance to Political Involvement' In *Collecting and Interpreting Qualitative Materials*. ed.by Denzin, N.K. and Lincoln, Y.S. California: Sage Publications,115-160

Gale, N.K., Heath, G., Cameron, E., Rashid, S. and Redwood, S. (2013) 'Using the framework method for the analysis of qualitative data in multi-disciplinary health research'. *BMC Medical Research Methodology*[online] 13,117. Available from < doi:10.1186/1471-2288-13-117> [19 December 2018]

Geebelen, L. Lernout, T., Kamba-Mukadi, B., Saegeman, V., Sprong, H., Van Gucht, S., Beutels, P., Speybroeck, N. and Tersago, K. (2017) 'The HUMTICK study: protocol for a prospective cohort study on post treatment Lyme disease syndrome and the disease and cost burden of Lyme borreliosis in Belgium'. *Archives of Public Health* 75(42), [online]. Available from <DOI 10.1186/s13690-017-0202-z> [4 December 2018]

Gelling, L. (1999) 'Ethical Principles in Healthcare Research'. *Nursing Standard* 13, (36), 39-42

Gelling, L. (2015) '*Ethical principles underpinning high quality research'* [online blog]. Available from <https://clinfield.com/ethical-principles-underpinning-high-quality-research/> [15 December 2018]

Gerrish, K. and Lacey, A. (2010) *The research process in nursing* 6th Edition. Oxford: Blackwell Publishing

Gill, P, Stewart, K., Treasure, E. and Chadwick, B (2008) 'Methods of data Collection in Qualitative Research: Interviews and Focus Groups'. *British Dental Journal*. Vol 204(6),291-295[online]. Available at: <https://www.nature.com/articles/bdj.2008.192>[15 December 2018]

Guba, E.G. and Lincoln. Y.S. (1994) 'Competing paradigms in qualitative Research*'*. In *Handbook of Qualitative Research*. ed.by Denzin, N.K. and Lincoln, Y.S. California: Sage Publications,105-17

Guest, G., MacQueen, K.M. and Namey, E.E. (2012) *Applied Thematic Analysis*. California: Sage Publications

Haddad,E ., Chabane,K., Jaureguiberry,S., Monsel,S., Pourcher,V.,and Caumes,E. (2018) 'Holistic Approach in Patients With Presumed Lyme Borreliosis Leads to Less Than 10% of Confirmation and More Than 80% of Antibiotic Failures'. *Clinical Infectious Diseases*, 68(12), 2060-2066

Halperin, J.J., Baker, P. and Wormser, G.P. (2013) 'Common Misconceptions about Lyme Disease' *The American Journal of Medicine* [online]. Available from <http://dx.doi.org/10.1016/j.amjmed.2012.10.008> [12 April 2018]

Halperin, J.J. (2014) 'Lyme Disease: Neurology, Neurobiology, and Behavior'. *Clinical Infectious Diseases* 58 (9), 1267–1272

Health Protection Scotland (2017a) *HPS Weekly Report* [online]. Available from< https://www.hps.scot.nhs.uk/media/1115/weekly-report-1742.pdf> [12 April 2019]

Health Protection Scotland (2017b) '*Tick and Lyme disease poster'* [online]. Available from<file:///C:/Users/macinni/Downloads/2_tick-lyme-disease-poster-20170810.pdf> [24 April 2019]

Health Research Authority (2018) *GDPR Guidance for researchers and study co-ordinators* [online]. Available from < https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/> [18 March 2019]

Henry, B., Crabtree, A., Roth, D., Blackman, D. and Morshed, M. (2012) 'Lyme disease: knowledge, beliefs, and practices of physicians in a low endemic area'. *Canadian Family Physician* [online] 58, e289-295. Available from< https://www.ncbi.nlm.nih.gov/pubmed/22734172> [18 April 2019]

Hickie, I., Davenport, T., Wakefield, D., Vollmer-Conna, U., Cameron, B., Vernon, S.D, Reeves, W.C. and Lloyd, A. (2006) 'Post-infective and chronic fatigue syndromes precipitated by viral and non-viral pathogens: prospective cohort study' *British Medical Journal* [online] 333 (7568), 575. Available from <https://www.ncbi.nlm.nih.gov/pubmed/16950834> [12 April 2019]

Hill, D. and Holmes, T. (2015) 'Provider knowledge, attitudes and practices regarding Lyme disease in Arkansas'. *Journal of Community Health* 40, 339-346

Hofhuis, A., Herremans, T., Notermans, D.W., Sprong, H., Fonville, M., Joke, W.B., van der Giessen, van Pelt, W. (2013) 'A prospective study among patients presenting at the general practitioner with a tick bite or erythema migrans in The Netherlands'. *PLoS One* [online]. 8 (5), e64361. Available from <doi: 10.1371/journal.pone.0064361> [20 June 2019]

Hofhuis, A., Harms, M., van den Wijingaard, C., Sprong, H. and van Pelt, W. (2015) 'Continuing increase of tick bites and Lyme disease between 1994-2009'. *Ticks and Tick-Borne Diseases* 6, 69-74

Holloway, I. (2005) *Qualitative research in health care*. Berkshire: Open University Press

Holloway, I. and Wheeler, S. (2010) *Qualitative research in nursing and health care.* Oxford: Wiley-Blackwell

Jayasekara, R.S. (2012) 'Focus groups in nursing research: methodological perspectives'. *Nursing Outlook* 60(6), 411-416

John Hopkins Medicine (2018) 'Severe and lingering symptoms occur in some after treatment for Lyme disease'. *ScienceDaily*[online]. Available from www.sciencedaily.com/releases/2018/02/180201104612.htm [02 August 2019]

Johnson, M. and Feder, H.M. Jr (2010) 'Chronic Lyme disease: a survey of Connecticut primary care physicians'. *Journal of Pediatrics* 157(6), 1025–1029

Johnson, L., Wilcox, S., Mankoff, J. and Stricker, R.B. (2014) 'Severity of chronic Lyme disease compared to other chronic conditions: a quality of life survey' *PeerJ* [online] 2:322. Available from < https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3976119/> [08 May 2019]

Kalish, R.A., Kaplan, R.F., Taylor, E., Jones-Woodward,L., Workman, K. and Steere, A.C. (2001) 'Evaluation of Study Patients with Lyme Disease, 10–20-Year Follow-up'. *The Journal of Infectious Diseases* 183(3), 453–460

Keilp, J.G., Corbera, K., Gorlyn, M., Oquendo, M.A., Mann, J.J. and Fallon, B.A. (2019) 'Neurocognition in Post-Treatment Lyme Disease and Major Depressive Disorder'. *Archives of Clinical Neuropsychology.* 1(34) (4), 466-480

Keodel, U., Fingerle, V. and Walter-Pfister, H. (2015) 'Lyme epidemiology, diagnosis and management'. *Nature reviews and Neurology* [online] Available from < https://www.ncbi.nlm.nih.gov/pubmed/26215621> [05 April 2018]

Keodal, U. and Pfister, H-W. (2017) 'Lyme neuroborreliosis'. *Current Opinion Infectious Diseases* 30, 101-107

Kitzinger, J. (1995) 'Focus group research: using group dynamics to explore perceptions, experiences and understandings'. In *Qualitative Research in Health Care*. ed. Holloway, I. Maidenhead: Open University Press, 56-70

Klempner, M.S., Hu, L.T., Evans, J., Schmid, C.H., Johnson, G.M.,Trevino. R.P.,Norton, D., Levy, L., Wall, D., McCall, J., Kosinski, M., and Weinstein, A.(2001) 'Two controlled trials of antibiotic treatment in patients with persistent symptoms and a history of Lyme disease'. *New England Journal of Medicine* 345(2), 85-92

Klempner, M.S., Baker, P.J., Shapiro, E.D., Marques, A., Dattwyler, R.J., Halperin, J.J., Wormser, G.P. (2013) 'Treatment trials for post-Lyme disease symptoms revisited'. *American Journal of Medicine* 126(8),665–669

Kowalski, T.J., Berth, W.L., Mathiason, M.A. and Agger, W.A. (2010) 'Oral antibiotic treatment and long-term outcomes of Lyme facial nerve palsy'. *Infection* 39, 239-245

Krupp, L.B., Hyman, L.G., Grimson, R., Krupp, L.B., Hyman, L.G., Grimson, R., Coyle, P.K.,Melville, P.,Ahnn, S.,Dattwyler, R.and Chandler, B. (2003) 'Study and treatment of post Lyme disease (STOP-LD): a randomized double masked clinical trial'. *Neurology* 60(12),1923–30

Lam, C.L. and Lauder, I.J. (2000) 'The impact of chronic disease on the health-related quality of life (HRQOL) of Chinese patients in primary care.' *Family Practice* 17(2), 59-166

Lindgren, E. and Jaenson, T.G. (2006) '*Lyme Borreliosis in Europe: Influences of Climate and Climate Change, Epidemiology, Ecology and Adaptation Measures'* [online]. Copenhagan; World Health Organization Europe. Available from < http://www.euro.who.int/__data/assets/pdf_file/0006/96819/E89522.pdf> [12 June 2019]

Liu, H., Cella, D., Gershon, R., Shen, J., Morales, L.S., Riley, W. and Hays, R.D., (2010) 'Representativeness of the patient-reported outcomes measurement information system internet panel'. *Journal of Clinical Epidemiology* 63,169–1178

Lyme Disease Action (2019) *Ixodes ricinus* tick [image]. Available from <https://www.lymediseaseaction.org.uk/about-ticks/uk-tick-images/> [28 April 2019]

Mac, S., da Silva, S.R. and Sander,B. (2019) 'The economic burden of Lyme disease and the cost-effectiveness of Lyme disease interventions: A scoping review' *PLos One* [online] 14 (1). Available from <e0210280. doi: 10.1371/journal.pone.0210280. eCollection 2019.> [28 June 2019]

Marques, A. (2008). Chronic Lyme disease: A review. *Infectious Disease Clinics of North America* [online] *22*, 341–360. Available from < https://www.ncbi.nlm.nih.gov/pubmed/18452806> [12 December 2018]

Marzec, N.S., Nelson, C., Waldron, P.R., Blackburn, B.G., Hosain, S., Greenhow, T., Green, G.M., Lomen-Hoerth, C., Golden, M. and Mead, P.S. (2017) 'Serious bacterial infections acquired during treatment of patients given a diagnosis of chronic Lyme disease-United States' *Morbidity and Mortality Weekly Report* 66, 607-609

Maxwell, J. (2005) Qualitative Research Design: An interactive approach. 2nd Ed, *Applied Social Research series*, Vol 42, London: Sage

McNamara, C. (1999). General Guidelines for Conducting Interviews, Authenticity Consulting LLC [online]. Available from< http://www.managementhelp.org/evaluatn/intrview.htm> [13 December 2018]

Mead, P.S. (2018) 'Global Epidemiology of *Borrelia burgdorferi* Infections'. In *Lyme disease An Evidence-based Approach*. ed. By. Halperin J.J. London: CAB International, 76-93

Mielck, A., Vogelmann, M., Leidl, R. (2014) 'Health-related quality of life and socioeconomic status: inequalities among adults with a chronic disease' *Health Quality of Life Outcomes*[online] 12(58). Available from < https://hqlo.biomedcentral.com/articles/10.1186/1477-7525-12-58> [18 July 2019]

Miller, D.L and Creswell, J.W (2007) *Applying Qualitative Research: A practical Guidebook.* California: Sage Publications

Mygland, A., Ljostad, U., Fingerle, V., Rupprecht, T., Schmutzhard, E. and Steiner, I. (2010) 'European Federation of Neurological Sciences (EFNS) guidelines on the diagnosis and management of European Lyme neuroborreliosis'. *European Journal of Neurology* 17, 8-16

Nadelman, R.B. and Wormser, G.P. (1998) 'Lyme borreliosis'. *The Lancet* 352, 557-565

National Institute for Health and Care Excellence (2018) *Lyme disease NICE Guideline [NG95]* [online]. Available from < https://www.nice.org.uk/guidance/ng95>[16 October 2018]

NHS Western Isles (2018) '*The 'Tick'-ing time bomb. The incidence of Lyme disease in the Outer Hebrides* (2010-2017)'. In Conference poster at 5 Nations Health Protection Conference. Held 23-24 April 2018 in Belfast

Nowakowski, J., Nadelman, R.B., Sell, R., McKenna, D., Cavaliere, L.F., Holmgren, D., Gaidici, A. and Wormser, G.P. (2003) 'Long-term follow-up of patients with culture-confirmed Lyme disease'. *The American Journal of Medicine* 115(2),91–96

Nursing and Midwifery Council (2018) *The Code Professional standards of practice and behaviour for nurses, midwives and nursing associates* [online]. Available from < https://www.nmc.org.uk/standards/code/> [26 April 2019]

Obel, N., Dessau, O.N., Krogfelt, K.A., Bodilsen, J., Anderson, N.S., Moller, J.K., Roed, C., Omland, L.H., Christiansen, C.B., Ellermann-Eriksen, S., Bangsborg,J.M., Hansen,K, Benfield,T.L,J Rothman,K.J, Sørensen, H.T, Andersen,C, Lebech,A.M (2018) 'Long term survival, health, social functioning and education in patients with European Lyme Borreliosis: nationwide population-based cohort study' *British Medical Journal* [online] 361. Available from < http://dx.doi.org/10.1136/bmj.k1998> [10 March 2019]

Oksi, J., Nikoskelainen, J., Hiekkanen, H., Lauhio, A., Peltomaa, M., Pitaranta, A.,Nyman, D., Granlund, H., Carlsson, S.A., Seppälä, I., Valtonen, V. and Viljanen, M. (2007) 'Duration of antibiotic treatment in disseminated Lyme borreliosis: a double-blind, randomized, placebo-controlled, multicenter clinical study' *European Journal of Clinical Microbiology and Infectious Diseases* 26(8),571-81

Padilla-Diaz, M. (2015) 'Phenomenology in Educational Qualitative Research: Philosophy as Science or Philosophical Science?'. *International Journal of Educational Excellence* 1(2), 101-110

Parsons, T. (1951) *The Social System.* Illinois: The Free Press

Patrick, D.M., Miller, R.R., Gardy, J.L., Parker, S.M., Morshed, M.G., Steiner, T.S., Singer, J., Shojania, K., Tang, P., Mattman, A., Sirrs, S, Reid, W.D., Phillips, P., Avina-Zubieta, A., Reynolds, J., Wong, H., Bested, A., Hyams, I., Ng, B, Blaney, G., Spinelli, J., Isaac-Renton. J., Hoang,L., Krajden, M. and McCabe, M. (2015) 'Lyme disease diagnosed by alternative methods: a phenotype similar to that of chronic fatigue syndrome'. *Clinical Infectious Disease* 61, 1084-1091

Patton, M.Q. (1990) *Qualitative evaluation and research methods* 2nd Edition. California: Sage

Patton, M.Q. (2002) Two Decades of Developments in Qualitative Inquiry *A Personal, Experiential Perspective*[online]. Available from < http://journals.sagepub.com/doi/abs/10.1177/147332500200100363 6> [16 April 2019]

Pole, C. and Lampard, R. (2002) *Practical Social Investigation: Qualitative and Quantitative Methods of Social Research*. Harlow: Prentice Hall.

Pope, C., Zeibland, S. and Mayes, N. (2000) 'Analysing qualitative data'. *British Medical Journal* 32, 114-116

Priem, S., Munkelt, K., Franz, J.K., Schneider, U., Werner, T., Burmester, G.R. and Krause, A. (2003) 'Epidemiology and therapy of Lyme arthritis and other manifestations of Lyme borreliosis in Germany: results of a nationwide survey'. *Zeitschrift fur Rheumatologie* 62, 450-458

Public Health Act (2016) *Guidance on Part 2 - Notifiable Diseases, Notifiable Organisms and Health Risk States*[online]. Available from <https://www2.gov.scot/Topics/Health/Policy/Public-Health-Act/Implementation/Guidance/Guidance-Part2> [19 June 2019]

Public Health England (2016) *Ticks and your health: Information about tick bite risks And prevention* [online]. Available from< https://www.gov.uk/government/publications/tick-bite-risks-and-prevention-of-lyme-disease> [12 December 2018]

Rebman, A.W. Bechtold, K.T., Yang. T., Mihm, E.A., Soloski, M.J. Novak, C.B. and Aucott, J.N. (2017a) 'The Clinical, Symptom, and Quality-of-Life Characterisation of a Well-Defined Group of Patients with Post treatment Lyme Disease Syndrome'. *Frontiers in Medicine* [online] 4:224. Available from: <http://doi:10.3389/fmed.2017.00224> [7 December 2018]

Rebman, A. W., Aucott, J., Weinstein, E. R., Kortte, K. B., Smith, K., & Leonard, L. (2017b) 'Living in Limbo: Contested Narratives of Patients with Chronic Symptoms Following Lyme Disease'. *Qualitative Health Research 27*(4), 534-546

Ritchie, J. and Spencer, L. (1994) 'Qualitative data analysis for applied policy research'. In *Analysing qualitative data.* ed.by Bryman, A. and Burgess, R.G. London: Routledge,173-194

Ritchie, J., Lewis, J., McNaughton- Nicholls, C. and Ormston, R. (2014) *Qualitative Research Practice* 2nd edition. London: Sage

Rizzoli, A., Hautte, H.C., Carpi, G., Vourc, H.G., Neteler, M. and Rosa, R. (2011) 'Lyme borreliosis in Europe'. *Eurosurveillance* 16, 1-8

Royal College of Nursing (2004) *Research ethics. RCN guidelines*. RCN: London

Sharareh, N., Sabounchi, N.S., Roome, A., Spathis, R. and Garruto, R.M. (2017) 'Model-based risk assessment and public health analysis to prevent Lyme disease'. *Royal Society Open Science*[online]. Available from http://dx.doi.org/10.1098/rsos.170841 [19 April 2018]

Shimada, H., Doi, T., Lee, S. and Makizako. H. (2019) 'Reversible predictors of reversion from mild cognitive impairment to normal cognition: a 4-year longitudinal study'. *Alzheimer's Research & Therapy* [online] 11:24. Available from <https://alzres.biomedcentral.com/articles/10.1186/s13195-019-0480-5> [21 July 2019]

Silverman, D. (2010) *Doing qualitative research* 3rd Edition. London: Sage Publications Ltd

Sosnowski, R., Kulpa, M., Zietalewicz, U.,Wolski, J.K., Nowakowski, R.,Bakula, R. and Demkow, T. (2017) 'Basic Issues Concerning Health-Related Quality of Life'. *Central European Journal of Urology* 70(2), 206-211

Spencer, L., Ritchie, J., Ormston, R., O'Connor, W. and Barnard, M. (2014) 'Analysis: Principles and Processes'. In *Qualitative Research Practice*. ed. by Ritchie, J., Lewis, J., McNaughton-Nicholls, C. and Ormston, R. London: Sage, 269-294

Sperber, K. and Dattwyler, R.J. (2018) '*Borreliella*: Interactions with the Host Immune System'. In *Lyme disease An Evidence-based Approach*. ed. by Halperin J.J. London: CAB International, 45-57

Srivastava, P., and Hopwood, N. (2009) '*A Practical Iterative Framework for Qualitative Data Analysis' International Journal of Qualitative Methods* [online]. Available from <https://journals.sagepub.com/doi/full/10.1177/160940690900800107> [18 June 2019]

Stanek, G. and Strle, F. (2003) 'Lyme borreliosis'. *The Lancet* 362, 1639-1647

Stanek, G. and Strle, F. (2018) 'Lyme borreliosis- from tick bite to diagnosis and treatment' *FEMS Microbiological Review* [online]. Available from <http://doi.org/10.1093/fensre/fux047 > [4 June 2019]

Stanek, G., Wormser, G.P., Gray, J. and Strle, F. (2012) 'Lyme borreliosis'. *Lancet* 379, 461-473

Steere, A.C., Malawista, S.E., Hardin, J.A., Ruddy, S., Askenase, P.W., Andiman, W.A. (1977) 'Erythema chronicum migrans and Lyme arthritis: the enlarging clinical spectrum'. *Annals of Internal Medicine* 86, 685-698

Steere, A.C., Bartenhagen, N.H., Craft, J.E., Hutchinson, G.J. Newman, J.H., Rahn, D.W., Sigal, L.H., Spieler, P.N., Stenn, K.S. and Malawista, S.E. (1983) 'The early clinical manifestations of Lyme disease'. *Annals of Internal Medicine* 99, 76-82

Steere, A.C. (2001) ‘Lyme disease’. *New England Journal of Medicine* 345(2),115–125

Steere, A.C., Strle, F., Wormerser, G.P., Hu, L.T., Branda, J.A., Hovius, J.W., Li, X. and Mead, P.S. (2016) ‘Lyme borreliosis’. *Nature Reviews Disease Primers* [online] 2, 16090. Available from<http://DOI:10.1038/NRDP.2216.90.> [4 December 2018]

Strle, F., Shin, J.J., Glickstein, L.J. and Steere, A.C. (2012) ‘Association of a Toll-like receptor 1 polymorphism with heightened Th1 inflammatory responses and antibiotic-refractory Lyme arthritis’. *Arthritis and Rheumatism* 64, 1497-1507

Strle, F. and Stanek, G. (2009) ‘Clinical manifestations and diagnosis of Lyme Borreliosis’. *Current Problems in Dermatology* 37, 51-110

Strle, F. Stanek, G and Strle, K. (2018) Lyme Borreliosis: The European Perspective In *Lyme disease An Evidence-based Approach*. ed. by Halperin J.J. London: CAB International, 124-138

Sykes, R.A. and Makiello, P. (2017) ‘An estimate of Lyme borreliosis incidence in Western Europe’. *Journal of Public Health- Oxford Academic* 39(1), 74-81

Thomas, D.R. (2006) ‘A general inductive approach for analysing qualitative evaluation data’. *American Journal of Evaluation* 27, 237-246

Thomas, D.R. and Hodges, I.D. (2010) *Designing and managing your research project: Core knowledge for social and health researchers.* London: Sage

Touradji, P., Aucott, J.N., Yang, T., Rebman, A.W. and Bechtold, K.T. (2019) ‘Cognitive Decline in Post-treatment Lyme Disease Syndrome’. *Archives of Clinical Neuropsychology* 34(4), 455–465

Traynor, M (2015) ‘Focus group research’. *Nursing Standard* 29(37), 44-48

Vahdat, S., Hamzehgardeshi, L., Hessam, S., and Hamzehgardeshi, Z. (2014) ‘Patient involvement in health care decision making: a review’. *Iran Red Crescent Medical Journal* [online]16(1): e12454. Available from < doi:10.5812/ircmj.12454> [18 December 2018]

Vandenesch, A., Turbelin, C., Couturier, E., Arena, C., Jaulhac, B., Ferquel, E., Choumet, V., Saugeon, C., Coffinieres, E., Blanchon, T., Vaillant, V. and Hanslik, T. (2014) ‘Incidence and hospitalisation rates of Lyme borreliosis, France, 2004-2012’. *Eurosurveillance* [online] 19(20883). Available at <https://www.ncbi.nlm.nih.gov/pubmed/25188613> [4 December 2018]

van den Wijingaard, C.C., Hofhuis, A., Simoes, M., Rood, E., van Pelt, W., Zeller, H. and van Bortel, W. (2017) 'Surveillance perspective on Lyme borreliosis across the European Union and European Economic Area'. *Eurosurveillance* [online] 22(27) pii30569. Available from < http://DOI:10.2807/1560-7917.ES.2017.22.27.30569> [4 December 2018]

von Allmen, R.S., Weiss, S., Tevaearai, H.T., Kuemmerli, C., Tinner, C., Carrel, T.P., Schmidli, J. and Dick, F. (2015) 'Completeness of Follow-Up Determines Validity of Study Findings: Results of a Prospective Repeated Measures Cohort Study'. *PLoS ONE* [online]10(10): e0140817. Available from <doi:10.1371/journal.pone.0140817> [18 December 2018]

Vrijmoeth, H.D.,Ursinus,J., Harms,M.G., Zomer,T.P., Gauw,S.A., Tulen,A.D., Kremer,K., Sprong,H., Knoop,H.,Vermeeren,Y.M., Van Kooten,B., Joosten,L.A.B., Kullberg,B.J., Hovius, J.W.R., and van den Wijngaard C.C.(2019) 'Prevalence and determinants of persistent symptoms after treatment for Lyme borreliosis: study protocol for an observational, prospective cohort study (LymeProspect)'. *BMC Infectious Diseases* [online]19:324. Available from < https://doi.org/10.1186/s12879-019-3949-8> [4 December 2018]

Watson, R., McKenna, H., Cowman, S. and Keadyet, J. (2008) *Nursing Research: Designs and Methods.* Edinburgh: Churchill Livingston

Weinstein, E.R., Rebman, A.W., Auctott, J.N., Johnson-Greene, D. and Bechtold, K.T. (2018) 'Sleep quality in well-defined Lyme disease: a clinical cohort study in Maryland'. *Sleep Research Society* 41(5),1-8

Weitzner, E., McKenna, D.,Nowakowski, J., Scavarda, C., Dornbush, R., Bittaker, S., Cooper, D., Nadelman, R.B., Visintainer, P., Schwartz, I. and Wormser, P. (2015) 'Long term assessment of post treatment symptoms in patients with culture-confirmed early Lyme disease'. *Clinical Infectious Diseases* 61, 1800-1806

Wienecke. R., Zochling, R., Neubert, U., Schlupen, E.M., Meurer, M. and Volkenandt, M. (1994) 'Molecular subtyping of *Borrelia burgdorferi* in erythema migrans and acrodermatitis chronic atrophicans'. *Journal of Investigative Dermatology* 103, 18-22

Wilking, H. and Stark, K. (2014) 'Trends in Surveillance data of human Lyme borreliosis from six federal states in eastern Germany, 2009-2012'. *Ticks and Tick-borne Disease* 5, 219-224

Wills, A.B., Spaulding, A. B., Adjemian, J., Prevots, D.R., Turk, S.P., Williams, C. and Marques, A. (2016) 'Long-term Follow-up of Patients With Lyme Disease: Longitudinal Analysis of Clinical and Quality-of-life Measures'. *Clinical Infectious Diseases* 62(12), 1546-1551

Winterkorn, J.M.S., (1990) 'Lyme disease: Neurologic and Ophthalmic Manifestations'. *Survey of Ophthalmology* [online] 35(3). Available from < https://www.sciencedirect.com/science/article/pii/003962579090089E> [01 August 2019]

World Health Organization (WHO) (2014) Antimicrobial resistance: global report on surveillance[online].Available from < https://www.who.int/drugresistance/documents/surveillancereport/en/> [3 September 2018]

World Health Organization (WHO) 1997 (2016) '*WHO Measuring Quality of Life*. [online]. Available from <https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/> [03September2018]

Wormser, G.P., Ramanathan, R., Nowakowski, J., McKenna, D., Holmgren, D., Visintainer, P., Dornbush, R., Singh, B. and Nadelman, R.B. (2003) 'Duration of antibiotic therapy for early Lyme disease. A randomised, double-blind, placebo-controlled trial'. *Annals of Internal Medicine* 138(9), 697-704

Wormser, G.P., Dattwyler, R.J., Shapiro, E.D., Halperin, J.J., Steere, A.C., Klempner, M.S.,Krause, P.J., Bakken, J.S., Strle, F., Stanek, G., Bockenstedt, L., Fish, D.,Dumler, J.S. and Nadelman, R.B. (2006) 'The clinical assessment, treatment, and prevention of Lyme disease, human granulocytic Anaplasmosis, and Babesiosis: clinical practice guidelines by the Infectious Diseases Society of America'. *Clinical Infectious Diseases* 43, 1089–134

Wormser, G.P., Weitzner, E., Mckenna, D., Nadelman, R.B,Scavarda, C.,Molla, I., Dornbush, R.,,Visintainer, P. and Nowakowski, J.(2015) 'Long-term Assessment of Health-Related Quality of Life in Patients With Culture-Confirmed Early Lyme Disease'. *Clinical Infectious Diseases* 61(2), 244-247

Wormser, G.P., Sudhindra, P., Lopez, E., Patel, L., Rezai, S., Brumbaugh, A.D.D, Mckenna, D., Scavarda, C., Shapiro, E.D., Karmen, C.L. and Visintainer, P. (2016) 'Fatigue in patients with erythema migrans'. *Diagnostic Microbiology and Infectious Disease* 86, 322-326

Yin, R.K. (2003) *Case study research: design and methods* 3rd Edition. London: Sage Publications Ltd

Chapter 8: Appendices

Appendix 1: Focus group question guide

Where have you been exposed to ticks?	Was the tick exposure that led to your Lyme disease diagnosis in the Western Isles? If yes where was the location? Postcode if you know it? If no: Where was your tick exposure?
Describe your general health? Explain why you chose 1-5?	If it was a scale ranging 1. Very good 2. Good 3. Fair 4. Bad 5. Very bad
Is there any pattern	Daily pattern Weekly pattern Seasonal pattern
In the last six months have you been limited in what you usually do?	1. Severely limited 2. Limited but not severely 3. Not limited at all
How did you feel?	How was your mood How was your sleep How was your concentration
How does Lyme disease impact on your physical activity?	Did you do all the things you normally would?
How does Lyme disease impact on your Work? Employment or general housework etc...	Did you have absences from paid work?
How does Lyme disease impact on your leisure activity?	
How does Lyme disease impact on your Social activity?	Your family life?
How does Lyme disease impact on your child care?	
How does Lyme disease impact on your relationships/family?	
What has helped? Have you any management advice for others?	Coping strategies Potential help and support

Appendix 2: Participant Information sheet

Participant Information Sheet

Study Title: The impact on quality of life since the diagnosis of Lyme disease from the participant's point of view.

IRAS ID: 254643 **UHI ID:**

My name is [redacted] and I am a student at the University of the Highlands and Islands (UHI). I also work for NHS Western Isles as a [redacted]. As part of my MSc Infection Prevention & Control I am undertaking a research project to investigate the impact on quality of life since a diagnosis of Lyme disease from the participant's point of view. I am the researcher for the study.

You are being invited to take part in this research study. Before you decide whether you wish to participate in this research it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information. Alternatively, you may contact my research supervisor Dr Rachel Erskine at Lews Castle College UHI. Contact details are listed at the end of this sheet. Please take time to decide whether you wish to take part. Thank you for taking the time to read this information sheet and considering taking part in this study.

What is the purpose of this study?

Lyme disease is the most common tick-borne disease with clinical presentations that range from acute to chronic illness. Lyme disease is on the increase worldwide and the Western Isles have been identified as a 'hot spot' with one of the highest levels in the UK. There is a substantial amount of literature that provides evidence of the effect of Lyme disease on patients but a very limited number of studies that look at the impact Lyme disease has on the lives of patients. This research is being undertaken to address this knowledge gap by exploring the impact on quality of life since the diagnosis of Lyme disease from the participant's point of view.

Patients who have been diagnosed with Lyme disease are being invited onto this study. The diagnosis of Lyme disease can be either through an Erythema Migrans rash or positive

Borrelia serology. Your permission will be sought to confirm your Lyme disease diagnosis with your GP. Your GP will be asked to confirm that you had Lyme disease (see question 8-11 on the consent form). Your GP will not be asked for any other information. You are being given this information sheet as you responded to the advert calling for volunteers to participate.

Who has reviewed this study?

The East of Scotland Research Ethics Service REC 2, which has responsibility for scrutinising all proposals for medical research on humans, has examined the proposal and has raised no objections from the point of view of research ethics. It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from University of Highlands and Islands and NHS Western Isles Research and Development officer whose role it is to check that research is properly conducted and the interests of those taking part are adequately protected.

Do I have to take part?

Participation in the study is voluntary. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw from participation in the study at any time and without giving a reason. If you do not want to take part in the study, it will not impact on your future healthcare management.

What will happen to me if I take part?

If you fulfil the Lyme disease diagnosis criteria and you agree to take part, you will be invited to attend one focus group meeting. Focus groups will be held on Barra at Barra Children's Centre (week 1 (dates will be confirmed before the PIS is issued)), Uist at Claddach Kirkibost Centre (week 2), Harris at Tarbert Hotel (week 3) and Lewis at the Bridge Centre (week 4). The focus group meetings will last approximately one hour. All the focus group meetings across the Islands will take place over three months.

What will the focus group involve?

You will take part in one focus group only, the one nearest to you. There will be 4-12 participants in each focus group, all participants will have responded to the advert and will have had a diagnosis of Lyme disease. The focus group will be a facilitated session where all participants will have the opportunity to speak about their own experience of living with Lyme disease. Prior to the commencement of each focus group all those present will discuss the ground rules of the session. The focus group will include discussion on the importance

of group confidentiality, participants will want assurance that anything they mention will not be spoken about out-with the focus group.

The researcher will be facilitating the group and has a list of prompt questions to ask the group. The questions are about the experience of living with Lyme disease including the physical, mental, social and economic impacts Lyme disease has had on you. A benefit to participating in a focus group is that it will give you the opportunity to meet others with Lyme disease and hear how they are managing their illness. Participants should also be aware that the researcher is not able to make any suggestions for medical care or treatment. If any of the participants wish to seek guidance the researcher has included details for Lyme disease UK, a support group for people with Lyme disease. The details are on this sheet in the section 'other agencies'.

Participant and researcher safety

If at any point during the focus group, you feel uncomfortable, if you find it difficult to participate, do not like speaking in front of others or change your mind about taking part you can stop the discussion and you are free to withdraw.

If any of the participants bring up anything that is of a confidential or sensitive nature the researcher will stop the discussion and advise that this focus group is not the appropriate place for such a discussion. The researcher will speak to the participant and advise them to see their GP and offer information on suitable counselling services.

If any of the participants raise any issues of concern the researcher will speak to the participant and advise that they will have to discuss the concern with their research supervisor or the participants GP.

Recording the group discussion?

The group discussion will be taped using a digital audio recorder. Following the group discussion, the researcher will transcribe the recording and use the data collected to support the information for a master's research dissertation. The recordings and the transcribed papers will be kept in a locked filing cabinet at the researchers place of employment. Access to this data is limited to the researcher and the academic supervisor. The tapes and data will be kept until the successful completion of the master's dissertation, once a verified result that the dissertation has passed has been received all the data will be destroyed. This will complete your involvement with this research study.

What will happen to the results of the research study?

The information collected will be analysed and used in my dissertation. Some quotes from the group dialogue will be used, however your name will not be used, and it will not be possible for readers to identify the participants. The dissertation will be submitted to UHI as part of a master's degree in Infection Prevention and Control. The results of the study may also be presented at a conference or published in a peer reviewed health care journal. Full electronic copies of the dissertation will be made freely available to you on request.

Consent:

Consent will be obtained prior to interviews taking place. When you contact to express an interest in participating the researcher will send you information and the consent form. The researcher will arrange to meet with you to answer any questions you may have and to receive your completed consent form. A consent document will be signed and a copy stored with the researcher and a copy given to you as the participant. The researcher will ensure personal details are transferred to an ID number ensuring anonymity.

Advantages to participating

There will be no direct advantage to you for participating in this research. The findings will add to the current knowledge on the impact Lyme disease has on the quality of life of people who have it in the Western Isles.

Disadvantages to participating

There are no anticipated disadvantages to participating in this study although please feel free to get in touch to discuss anything that you are concerned about in advance.

Confidentiality, data protection and anonymity:

All the information you share within the interview including your name and other details personal to yourself will be kept confidential. Only the researcher and research supervisor will see focus group transcript. It will not be shared with anyone else. In addition, the interview transcript will be anonymised so it will not be possible to identify the participants. Your name will not appear in any research papers produced as a result of this research. Individual anonymised quotes may be used to illustrate the research findings in research papers and reports. All information will be collected and stored within the requirements of the Data Protection Act (2018).

What happens if there is a problem?

Please discuss any problems with me or my supervisor. Our contact details are given at the bottom of this letter.

If you are not happy with any aspect of your involvement with the study you may submit a complaint through the NHS complaints procedure. The following link will take you to the NHS Western Isles site and provides information on the complaints procedure.

Link to complaints procedure:

https://www.wihb.scot.nhs.uk/edocman/misc/NHS%20Western%20Isles%20Customer%20Facing%20CHP%20V1%20Final-1.pdf

You may also contact the NHS Western Isles Complaints officer; Mr R MacKay

37 South Beach Street, Stornoway, Isle of Lewis. Tel 01851702997.

If you would like to seek advice from an Independent person who has knowledge of the study but is not directly involved you can contact Dr Maggie Watts, Director of Public Health, NHS Western Isles, 37 South Beach Street, Stornoway, Isle of Lewis, HS1 2BB. Tel 01851 708033.

Other agencies

If you feel you would benefit from speaking about any issues that have arisen from this process you can contact Breathing Space on 0800 83 85 87 or you can visit their website on www.breathingspace.scot/

Lyme disease UK patient support and advice: http://lymediseaseuk.com/

Expenses and payments:

No payment will be offered for your participation.

What happens now?

Please feel free to discuss this letter with your family and friends. If, after consideration, you would like to take part in this study please contact me or my research supervisor using one of the contact routes listed below.

Researcher:	Research Supervisor:
[redacted] 05017797@uhi.ac.uk [redacted]	Dr Rachel Erskine Email: Rachel.erskine@uhi.ac.uk Tel: 01851 770491

Thank you for taking the time to read this sheet.

Appendix 3: Consent form

CONSENT FORM

Study title: What is the impact on quality of life for those who have had Lyme disease in the Western Isles of Scotland?

IRAS ID: 254643 **UHI ID:**

	Please initial box
Participant Identification number for this study	
1. I confirm that I have read and understand the patient information sheet dated 12/03/2019 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	
3. I understand that data collected during the study will be looked at by individuals from The University of the Highlands and Islands where it is relevant to my taking part in this research. I give permission for these individuals to have access to the data.	
4. I agree to anonymised quotes from my interview being used in any research output (e.g. academic articles, professional papers, conference presentations) from this study.	
5. I understand that my name will not appear in any reports, articles or presentations.	
6. I agree to an audio recording of the interview for research purposes and accuracy.	
7. I agree to take part in the above-named study.	

8. My Lyme disease diagnosis was confirmed by (tick which applies) • An Erythema Migrans rash ☐ • A positive *borrelia* serology result ☐	
9. Which location will you be attending? (Tick which applies) Barra ☐ Uist ☐ Harris ☐ Lewis ☐	

Name of participant:
Signature: Date

Name of person taking consent

Signature: Date

If you wish to clarify anything required on the form, please contact the researcher.

Researcher contact details: [redacted]
[redacted] 05017797@uhi.ac.uk

PARTICIPANT: PLEASE COMPLETE QUESTION 10 ON THE PAGE 3 AND THEN HAND PAGE 3 INTO YOUR GP PRACTICE.

GP confirmation sheet

Study title: What is the impact on quality of life for those who have had Lyme disease in the Western Isles of Scotland?

Question 10: Participant to complete

I consent to my GP giving information to confirm my Lyme disease diagnosis.

Participant name:

Participant date of birth:

Participant address:

Participant signature: Date:

Participant: Following completion of Question 10- this form is given to your GP practice
For the purposes of this study the researcher requires confirmation that the patient has had a diagnosis of Lyme disease.

Question 11: GP to complete

The above-named patient had a Lyme disease diagnosis **YES/NO** **(delete as appropriate)**

The Lyme disease diagnosis was confirmed by (please tick which applies)

- **Erythema migrans**

- **Positive borrelia serology**

GP signature: **Date of signing:**

GP: Please return the completed page to the researcher:

[redacted]05017797@uhi.ac.uk

Appendix 4: Research proposal

University of the Highlands and Islands
Oilthigh na Gàidhealtachd agus nan Eilean

MA Health & Wellbeing & MSc Infection Prevention & Control

Dissertation Proposal

Please complete your dissertation proposal using the sub-headings shown below for guidance.

Name: [redacted]

Student Number: 05017797

Programme of Study: Msc Infection Prevention and Control

Research Question

What is the impact on quality of life for those who had Lyme disease in the Western Isles of Scotland?

Working title of Dissertation

Quality of Life Experiences of Lyme disease in the Western Isles of Scotland.

Lyme disease is the most common tick-borne disease in America and Northern Europe, with clinical presentations that range from acute to chronic illness (Stanek and Strle 2017). Geebelen *et al* (2017) found that despite the recommended antibiotic treatment a proportion of patients with Lyme disease report persisting non-specific symptoms of such severity that they influence the patient's daily life. There is an array of literature detailing the effects of Lyme disease, with most of it coming from America and more recently Northern Europe however, of these studies there are minimal studies that look at the impact of the disease. In addition, there is very limited research on Lyme disease from the patient's perspective undertaken in the United Kingdom or Scotland. There is an increase in the incidence being reported worldwide which highlights that this is a disease that merits further investigation.

The World Health Organisation (WHO) considers quality of life to comprise the dimensions of mental and physical health, social functioning, performance of roles in life and general well-being (WHO 1997). Essentially, quality of life according to this model is defined as the extent to which an individual makes use of the opportunities that life brings. The symptoms of chronic illness and the associated functional limitations have the potential to adversely impact health related quality of life in affected individuals (Bowling 1996, Busija, Tan and Sanders 2017). This study into the impact of the disease will allow for evaluation of the actual burden on those with Lyme disease.

This qualitative research while considering quality of life will explore the physical, emotional and social impacts of Lyme disease on the lives of patients living in the Western Isles (WI) of Scotland. The study aims to develop understanding on how Lyme disease impacts on an individuals' ability to function and what if any strategies they use to manage any incapacity. The study findings will then form recommendations for future research and treatment interventions if applicable.

Rationale behind Dissertation

Lyme disease is the result of an infection caused by the *Borrelia burgdorferi* bacteria, the bacteria is commonly found in ticks and people develop the disease following a bite from an infected tick (Public Health England (PHE) 2016). An early sign of the infection is an Erythema Migrans (EM) or 'bulls-eye' rash (Wormser *et al* 2006), and late Lyme disease is usually diagnosed when patients attend with symptoms such as fatigue, malaise, headache, myalgia and arthralgia (Stanek and Strle 2017) and subsequently Lyme disease is confirmed serologically (Dubrey *et al* 2014). If untreated dissemination of bacteria to other tissues can occur (Dessau *et al* 1998, van den Wijngaard *et al* 2017) leading to persistent clinical complications, these can include skin, neurological, cardiac, musco-skeletal and ocular manifestations (Weitzner *et al* 2015). It is well established that incurable illness such as cancer has a detrimental impact on quality of life (Lam and Lauder 2000), however less is known about the trajectories of illnesses such as Lyme disease.

The increasing levels of Lyme disease being reported in the Western Isles has stimulated the author to undertake this study, with the opinion that documenting patients experience will lead to a better understanding of living with the condition.

Aim:

The study aim is to investigate the impact on quality of life since the diagnosis of Lyme disease from the participant's point of view.

Objectives:

- To explore participant's experiences of living with Lyme disease.
- Identify the physical, mental, social and economic impacts on participants in the study.
- To analyse the data received to form conclusions relating to the quality of life of participants in the Western Isles and develop hypotheses for further research.

An exploratory qualitative, phenomenological approach will be utilised within the study, qualitative to gain from exploring and understanding the meanings participants assign to their problem (Denzin and Lincoln 2011) and phenomenological, to identify the lived experience of the participants. Yin (2003:13) recommends an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clear. Qualitative studies are useful when previous literature is limited, and this study lends itself to an interpretative constructivist view of the world, which will involve the exploration of the phenomenon to understand what it means to people. Qualitative research is predominately inductive in nature, with the researcher building up information and forming general themes enabling generation of meaning from study data (Bowling 2009). Silverman (2010) recognised as a strength the researcher's capacity as a tool within the research process, allowing the researcher to understand participant's experiences reflexively. The in-depth interview elicits the participant's construction of reality, not the researcher's assumptions, with the conversation provoking the release of specific information (Jayasekara 2012). Active participation in focus groups and interviews as opposed to completed questionnaires also gives the researcher the opportunity for probing and clarification of meanings (Holloway 2005). However, the inductive nature of qualitative research has been recognised as a limiting factor by Denzin and Lincoln (2011), where it was suggested that researchers cannot accept their personal biases thus findings of studies become ungeneralisable. Yet generalisability is not the aim of qualitative research but the fit (Lincoln and Guba 1985). Flick (2009) suggests limitations to generalisability are in direct association to the small sample size that will be utilised in this study.

Furthermore; Flick (2009) identified that exploratory studies inductively generated data which could be used to develop theory. There is no current theory of the impact on quality of life associated with Lyme disease therefore it can only be understood through social constructions and interactions with patients, making this an appropriate study to gain information on the impact of Lyme disease on quality of life.

Methods likely to Use:

Purposive sampling will be used to recruit participants, through an advert sent to General Practitioners (GP) who will share the advert with patients that are known as having been diagnosed with Lyme disease. An advert will be sent to the local 'Events' newspaper, and local web-based news services 'Hebrides news' and 'welovestornoway' as well as the recently set up Lyme disease support groups across the Western Isles. The advert will be in circulation for six weeks, an end date for applications will be included. The GP practices in the Western Isles and the support group organiser will be given information packs about the study; the pack will include copies of the advert; the participant information sheet and the consent form. When potential participants contact the researcher, the detail included on the participant information sheet will be discussed with them. The potential participant will be asked if they fulfil the criteria of having had a Lyme disease diagnosis. The criteria which fulfils a Lyme disease diagnosis is based on NICE guidelines published in 2018 which state 'diagnose Lyme disease in people with erythema migrans, a red rash that increases in size and may have central clearing' or 'use a combination of clinical presentation and laboratory testing to guide diagnosis in people without erythema migrans'. The potential participant will be informed that the diagnosis will require to be confirmed by their GP; the researcher will arrange to meet with the participant prior to the focus group to have a discussion ensuring the patient can give informed consent. The researcher will discuss the focus group process, answer any questions and receive the completed consent form from the participant. The consent form includes a question which when completed will confirm that the participant is agreeing for a GP to verify their diagnosis. The researcher will then give page 3 of the consent form to the participants GP. The GP completes question 11, where they are asked to confirm the participant's diagnosis and the GP is asked to return the form to the researcher. When the GP confirms that the participant fulfils one of the Lyme disease diagnosis criteria the participant will be invited to participate in the study. On the day the participant attends the focus group, the researcher will discuss their completed form with each participant to clarify that they are happy with the information provided.

The study has the support of the Director of Public Health, the Medical Director and the GP sub-group in the Western Isles, these contacts will encourage practices to support the study. Also, information packs will be sent to the practices along with the poster to ensure they have information available if any of the patients ask them any questions about the study.

The data will be collected using focus groups, increasingly in health care focus groups are used (Gill *et al* 2008), the purpose of using focus groups in qualitative research is to collect data on the knowledge, attitudes, and experiences of participants through group interaction (Dilaria *et al* 1994), using this method facilitates a narrative of shared experiences, fosters group comfort and cohesion, and improves the quality of group interaction (Traynor 2015). The optimal size for a focus group is between four and 12 participants, which creates a large enough group to facilitate discussion without inhibiting balanced participation (Jayesakara 2012). Therefore, the researcher is hoping to recruit a minimum number of four participants in each focus group and will accommodate up to twelve at each group. The study will take place over three months and the researcher will base focus groups in locations closest to the participant's residence therefore limiting inconvenience and travel. It is foreseen that focus groups will be arranged on the four main Islands in the Western Isles, this is dependent on volunteering participants. The meetings will be held on Barra at Barra Children's Centre (week 1), Uist at Claddach Kirkibost Centre (week 2), Harris at Tarbert Hotel (week 3) and Lewis at the Bridge Centre (week 4). The locations have been selected as they are all accessible by public transport. The groups will be arranged for one a week until completed to allow the researcher time to transcribe the data.

Given that the Western Isles have seen approximately 30-40 cases of Lyme disease every year since 2010 (NHS Western Isles 2018) the researcher is confident of achieving the minimum number of participants. Kidd and Parshall (2000) suggested that the findings of focus groups can be further improved by conducting multiple groups. In the event of the number of respondents exceeding the maximum number required for four focus groups, further focus group sessions will be arranged at the most appropriate venue. The group sessions will be recorded to ensure an accurate record of each participant's perspective and the data will be transcribed verbatim to accurately record the conversations.

The groups will be arranged once a week until all four sessions have been completed, planning one meeting a week will allow the researcher time to transcribe the data in a timely manner. If the number of participants exceeds 48 further sessions will be arranged on a weekly basis.

The focus groups will be led by a facilitator who will use an interview guide with semi structured open questions which are built upon from the literature review (Maxwell 2005, Kitzinger 1995). Flick (2006) recognised that regular reflection on the questions is an important aspect in the process, therefore the questions will remain fluid as theories may emerge and extra exploration is required (Berg and Lune 2012). The semi structured method being used will allow a more open conversation (Flick 2014), employing flexibility and responsiveness throughout the process allows for the integration of participant suggestions (Phoenix *et al* 2018), this will also be the more appropriate method if sensitive data is divulged and a more sympathetic approach is required. Information on support available will be offered to the participants if it is required.

Written, informed consent will be secured from all the participants prior to the focus groups, it will also be highlighted that they can withdraw at any time. Participants will be offered the dates and times of the focus groups and they can select the most appropriate for them to attend. The researcher will be facilitating the group and ensure that the participants are comfortable with the situation before proceeding. Approval will be sought from the participants to confirm the use of a recording device and written notes may also be taken.

In this study the data collection does not set out to test hypotheses, but to gather information and this stance will be maintained in data analysis. Gerrish and Lacey (2010) advise organising the data in a logical manner, accordingly framework analysis will be utilised to provide clear rationale for any themes identified. Framework analysis involves transcription of the data which allows for familiarisation, developing the thematic framework, indexing and sorting, charting, mapping and interpretation (Green and Thorgood 2009). A framework method is will also offer the ability to compare the data by themes and across different participant perspectives (Gale *et al* 2013) and as Ritchie and Spencer (1994) identified the method will aid a novice researcher to make sense of the data.

Problems that could be encountered are a lack of volunteers for focus group participation; if that is the case an amendment to the data collection method could be required. To avoid any biases the researcher would have to remain aware and provide reflexivity to enlighten the reader to such bias throughout the process.

In order to carry out this study it will be necessary to seek relevant ethical approval. The researcher has considered the mitigation of the seven ethical principles which form the founding philosophy for decision making in research (Gelling 1999). Each principle is closely linked but they will now be considered within the context of the proposed research.

Beneficence

This is the requirement to benefit the patient. The research has the potential to demonstrate to participants strategies used by others to help them cope, as well as the feeling of validation when they hear others speak of their experiences.

Non-maleficence

Ensuring the patient comes to no harm; according to the Nursing and Midwifery Council (NMC) code of conduct, 'a nurse must be aware of, and reduce as far as possible, any potential for harm' (NMC 2015). This would be exercised by keeping participants fully informed, seeking their consent throughout the process and reminding them that they can withdraw at any time.

Fidelity

The participant information sheet will be used to ensure the participant is fully informed, aware of the risks and give clear agreement on the role of the researcher and the participant, which are vital elements in building a trusting relationship.

Justice

The compromised health status due to illness will make all participants vulnerable and the researcher will remind those attending that anyone can withdraw at any time. Holding small focus groups will help participants that could feel intimidated by large groups.

Veracity

Any changes to activities throughout the research process will not occur without the participants consent. A copy of the final dissertation will be made available for the participants to read if they request it.

Confidentiality

Participant anonymity will be protected by removing identifying details and ensure the use of pseudonyms. As this is qualitative research and thick descriptions and quotes will be utilised to aid the credibility of findings, and participants will be made aware of this and the

opportunity to view selected quotes prior to submission will be offered. Digital recordings and transcribed data will be stored within a locked filing cabinet; with all digital recordings being erased after the dissertation has been completed. All computerised data will be password protected, no personal data of participants will be stored on computer and storage of data will be in line with the Data Protection Act 2018 (Health Research Authority 2018).

Respect for Autonomy

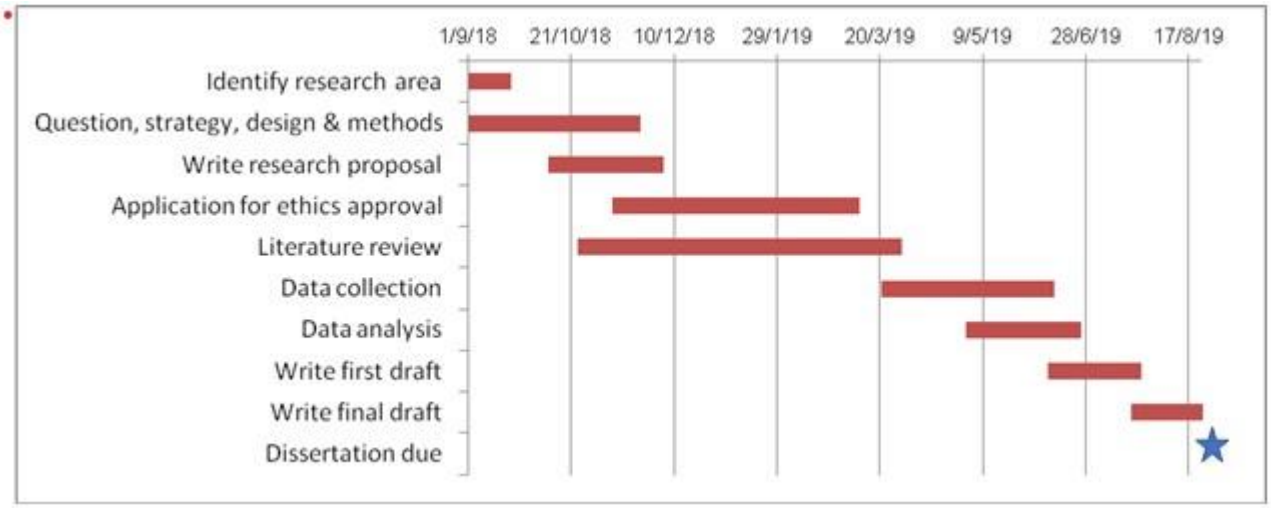
This concept covers participants understanding of what they have committed to and remaining free from influences by others. To minimise this risk participants will be given an information sheet and given the opportunity to volunteer to participate, with the reminder that they can remove themselves from the group at any time.

The study would require NHS board research and development approval and the North Research Ethics Service (NREC) which is required for research in the Highlands and Islands. Both require completion of the Integrated Research Application System (IRAS) an online form, this gives a checklist of the documents that would be required. Formal approval would also be required from the University of the Highlands and Highlands (UHI) Ethics committee.

Work Schedule

As the research and dissertation will be completed while working full time and taking six weeks out of the schedule to travel on a 'Churchill Fellowship', planning the workload is essential. I was awarded a 'Churchill Fellowship' in 2018; my project involves visiting America, Canada and France to gather evidence on programs and actions being taken with regard to ticks and Lyme disease, particularly looking at the areas of prevention and awareness raising, environmental and land management and to observe and learn from the models of healthcare provision available for people living with Lyme disease. The first phase of my travel begins on the 14th October until 15th November 2018; the second phase is for two weeks in February 2019. I will not be using any of the information gained from people I meet on my travels within this master's Research study. I have to write and publish a report for the Winston Churchill Memorial Trust on completion of my trips. The report will include information from the literature review I will undertake as part of the master's research. I will not be using any of the information I gain from the participants of the focus groups within the Churchill report. I will not be publishing my Churchill report until after the submission and grading of my dissertation has taken place.

A basic Gantt chart outlines the estimated time allocated to carry out each component of the research study, into which I have allowed time for my travelling.



References Cited and Indicative Bibliography

Berg, B. and Lune, H. 2012 '*Qualitative Research for the Social Sciences'*. 8th Edition. Boston, MA: Pearson Internationals Edition.

Bowling, A. (1996) 'The effects of illness on quality of life: findings from a survey of households in Great Britain'. *Journal of Epidemiology and Community Health* 50, 149-155.

Bowling, A. (2009) '*Research Methods in Health: Investigating Health and Health Services*'. (3rd Edition). Maidenhead, Open University Press.

Busija, L., Tan, J. and Sanders, K.M. (2017) 'Associations between illness duration and health-related quality of life in specified mental and physical chronic health conditions: results from a population-based survey'. *Quality of Life Research* 26, 2671-2681

Denzin, N.K. and Lincoln, Y.S. (2011) 'Introduction: The Discipline and Practice of Qualitative Research' In *The Sage Handbook of Qualitative Research*. ed.by. Denzin, N.K. and Lincoln, Y.S. California: Sage Publications, 1-20.

Dessau, O.N., Krogfelt, K.A., Bodilsen, J., Anderson, N.S., Moller, J.K., Roed, C., Omland, L.H., Christiansen, C.B., Ellermann-Eriksen, S., Bangsborg,J.M., Hansen,K, Benfield,T.L,J Rothman,K.J, Sørensen, H.T, Andersen,C, Lebech,A.M (1998). Long term survival, health, social functioning and education in patients with European Lyme Borreliosis: nationwide population-based cohort study. *British Medical Journal,*361.

Dilaria.C.,Hockenberry-Eaton, M.,Malbach, E. And Rivero, T. (1994) 'Focus groups: an interview method for nursing research'. *Journal of Neuroscience Nursing*,26(3), 175-180.

Dubrey, S., Bhatia, A., Woodham, S. and Rakowicz, W. (2014)' Lyme disease in the United Kingdom'. *Postgraduate Medical Journal* 90(1059), 33-42.

Flick, U. (2006) *An Introduction to Qualitative Research*. Thousand Oaks, California: Sage

Flick, U. (2009) *An Introduction to Qualitative Research* 4th edition. California: Sage Publications Ltd

Flick, U. (2014) *An introduction to qualitative research*. 5th Edition. Thousand Oaks, CA: Sage.

Gale, N.K., Heath, G., Cameron, E., Rashid, S. and Redwood, S. (2013) Using the framework method for the analysis of qualitative data in multi-disciplinary health research'. *BMC Medical Research Methodology*[online] 13,117. Available from < doi:10.1186/1471-2288-13-117> [19 September 2018]

Geebelen, L. Lernout, T., Kamba-Mukadi, B., Saegeman, V., Sprong, H., Van Gucht, S., Beutels, P., Speybroeck, N. and Tersago, K. (2017) 'The HUMTICK study:protocol for a prospective cohort study on post treatment Lyme disease syndrome and the disease and cost burden of Lyme borreliosis in Belgium'. *Archives of Public Health* 75(42), [online]. Available from <DOI 10.1186/s13690-017-0202-z> [15 September 2018]

Gelling, L. (1999) 'Ethical principles in healthcare research'. *Nursing Standard* 13(36) 9-42

Gerrish, K. and Lacey, A. (2010) *The research process in nursing* 6th Edition. Oxford: Blackwell Publishing

Gill, P, Stewart, K., Treasure, E. and Chadwick, B (2008) 'Methods of data Collection in Qualitative Research: Interviews and Focus Groups'. *British Dental Journal*. Vol 204(6) pp 291-295 [online] Available at: <https://www.nature.com/articles/bdj.2008.192> [15 September 2018]

Green, J. and Thorgood, N. (2009) *Qualitative Methods for Health Research*. London: Sage Publications, pp. 198–203

Health Research Authority (2018) GDPR Guidance [online]. Available from <https://www,hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance>[16 September 2018]

Holloway, I. (2005) *Qualitative research in health care*. Berkshire: Open University Press

Jayasekara, R.S. (2012) 'Focus groups in nursing research: methodological perspectives'. *Nursing Outlook* 60(6), 411-416

Kidd, P.S. and Parshall, M.B. (2000) 'Getting the focus and the group: enhancing analytical rigor in focus group research'. *Qualitative Health Research*10, 293-308

Kitzinger, J. (1995) 'Qualitative Research: Introducing focus groups' *British Medical Journal* 311 [online] Available from <https://doi.org/10.1136/bmj.311.7000.299> [15 September 2018]

Lam, C.L. and Lauder, I.J. (2000) 'The impact of chronic disease on the health- related quality of life (HRQOL) of Chinese patients in primary care. Family Practice 17(2), 159-166

Lincoln, Y.S. and Guba, E.G (1985) Naturalistic Inquiry. Beverly Hills, California: Sage Publications

Maxwell, J. (2005) 'Qualitative Research Design: An interactive approach. 2nd Ed, *Applied Social Research series*, Vol 42, London: Sage

NHS Western Isles (2018) Conference poster: 5 Nations Health Protection Conference 23-24 April 2018 Belfast. The 'Tick'- ing time bomb. The incidence of Lyme disease in the Outer Hebrides (2010-2017).

Nursing and Midwifery Council (NMC) (2015) '*The Code: Professional standards of practice and behaviour for nurses and midwives*'. NMC : London

Phoenix, M.,Nguyen, T., Gentles, S.J.,VanderKaay, S., Cross, A. and Nguyen, L.(2018) 'Using qualitative research perspectives to inform patient engagement in research'. *Research Involvement and Engagement* 4,20

Public Health England (2016) *Ticks and your health: Information about tick bite risks and prevention* [online]. Available from < https://www.gov.uk/government/publications/tick-bite-risks-and-prevention-of-lyme-disease> [19 September 2018]

Ritchie, J. & Spencer, L. 1994. Qualitative data analysis for applied policy research by Jane Ritchie and Liz Spencer in A. Bryman and R. G. Burgess [eds.] '*Analysing qualitative data'*, (pp.173-194). London: Routledge.

Silverman, D. (2010) *Doing qualitative research* 3rd Edition. London: Sage Publications Ltd

Stanek G. and Strle, F. (2017) 'Lyme borreliosis-from tick bite to diagnosis and treatment'.*Federation of European Microbiological Societies Microbiological Reviews* [online] Available from< https://academic.oup.com/femsre/advance-article-abstract/doi/10.1093/femare/fux047/4904097> [15 September 2018]

Traynor, M (2015) 'Focus group research'. *Nursing Standard* 29(37), 44-48

Van den Wijngaard, C.C., Hofhuis, A., Simoes, M., Rood, E., van Pelt, W., Zeller, H., Van Bortel, W. (2017) 'Surveillance perspective on Lyme borreliosis across the European Union and European Economic Area. Euro-Surveillance[online] Available from< http://www.eurosurveillance.org/content/10.2807/1560-7917.ES.2017.22.27.30569> [14September 2018]

Weitzner, E., McKenna, D.,Nowakowski, J., Scavarda, C., Dornbush, R., Bittaker, S., Cooper, D., Nadelman, R.B., Visintainer, P., Schwartz, I. and Wormser, P. (2015) 'Long term assessment of post treatment symptoms in patients with culture-confirmed early Lyme disease'. *Clinical Infectious Diseases* 61, 1800-1806

World Health Organization (WHO) 1997 (2016) ‘WHO Measuring Quality of Life. [online]. Available from: <http://www.who. int/mental_health/media/68.pdf> [03September2018]

Wormser, G.P., Dattwyler, R.J., Shapiro, E.D., Halperin, J.J., Steere, A.C., Klempner, M.S.,Krause, P.J., Bakken, J.S., Strle, F., Stanek, G., Bockenstedt, L., Fish, D.,Dumler, J.S. and Nadelman, R.B. (2006) ‘The clinical assessment, treatment, and prevention of Lyme disease, human granulocytic Anaplasmosis, and Babesiosis: clinical practice guidelines by the Infectious Diseases Society of America’. *Clinical Infectious Diseases* 43,1089–134

Yin, R.K. (2003) *Case study research: design and methods* 3rd Edition. London: Sage Publications Ltd

Appendix 5: REC favourable outcome letter

East of Scotland Research Ethics Service (EoSRES)

Tayside medical Science Centre
Residency Block Level 3
George Pirie Way
Ninewells Hospital and Medical School
Dundee DD1 9SY

[redacted]

Date: 19 March 2019
Your Ref: LR/19/ES/0003
Enquiries to: Mrs Lorraine Reilly
Our Ref:
Direct Line: 01382 383878
Email: eosres.tayside@nhs.net

Dear [redacted]

Study Title:	**What is the impact on quality of life for those who had Lyme disease in the Western Isles of Scotland?**
REC reference number:	**19/ES/0003**
Protocol number:	**65283/18/01**
IRAS project ID	**254643**

Thank you for your letter of 12 March 2019, responding to the Committee's request for further information on the above research and submitting revised documentation.
The further information has been considered on behalf of the Committee by the Chair.
We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion
On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion
The REC favourable opinion is subject to the following conditions being met prior to the start of the study.
Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.
Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

19/ES/0003 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project. Yours sincerely

L Reilly

Pp **Mrs Samantha Downie**
Chair
Email: eosres.tayside@nhs.net
Enclosures: "After ethical review – guidance for researchers"
Copy to: Dr. Rachel Erskine, Lews Castle College UHI & Inverness College UHI Mr Martin Malcolm, NHS Western Isles

disability confident EMPLOYER

1

Appendix 6: NHS Western Isles Research and Development approval

Bòrd SSN nan Eilean Siar
Western Isles NHS Board

Public Health Department

37 South Beach
Stornoway
Western Isles HS1 2BB
Telephone 01851 702997
Fax 01851 704405
http://www.wihb.scot.nhs.uk

NHS
Eileanan Siar
Western Isles

[redacted]

Date: 09 May 2019
Your Ref:
Our Ref: 138

Enquiries to: Martin Malcolm
Extension: 3042
Direct Line: 01851 708042
E-mail: martin.malcolm@nhs.net

Dear [redacted]

Management Approval for Non-Commercial Research Project Amendment

MREC Ref: **19/ES/0003**
NRS Ref: **N/A**
Project title: **What is the impact on quality of life for those who had Lyme disease in the Western Isles of Scotland?**

Amendment No.
Amendment Date:

I apologise for the delay but having received documents relating to the above amendment to your study I confirm R&D management approval for the above amendment on behalf of Western Isles NHS.

Please advise myself and R&D Manager, NHS Highland on any future changes to the project such as protocol amendments, recruitment, funding, personnel or resource input required by NHS Western Isles.

Please inform the R&D Lead, Western Isles when the study is due to start and once completed. I wish you every success with your project and please don't hesitate to contact us should you require further assistance on NHS Western Isles R&D Management Approval.

Yours sincerely,

Martin Malcolm
R&D Lead, Head of Public Health Intelligence & Information Services, NHS Western Isles

cc Frances Hines, NHS Highland Research Office, Room S101, The Centre for Health Science, Old Perth Road, Inverness, IV2 3JH
Pamela Shand, Senior Administrator, NHS Research Scotland CC, Research and Development Office, Foresterhill House Annexe, Foresterhill, Aberdeen, AB25 2ZB

Appendix 7: UHI letter

University of the Highlands and Islands
Oilthigh na Gàidhealtachd agus nan Eilean

Chancellor:
HRH The Princess Royal
Seansalair:
A h-Àirdeachd Rioghail A' Bhana-phrionnsa Rioghail

Principal and Vice-Chancellor:
Professor Clive Mulholland BSc PhD CSci FIBMS SFHEA FRSA
Prionnsapal agus Iar Sheansalair:
An t-Àrd-Ollamh Clive Mulholland BSc PhD CSci FIBMS SFHEA FRSA

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E/Pd: eo@uhi.ac.uk
www.uhi.ac.uk

25th April 2019

[redacted]

Dear [redacted]

What is the impact on quality of life for those who had Lyme disease in the Western Isles of Scotland?.

I can confirm that your application for ethical approval (ref. no. OLETHSHE1559), in which you indicate that you have applied for NHS ethical approval, has been noted here at the Research Office of the University of the Highlands & Islands.

Best wishes,

Fiona Leiper
Research Ethics Officer

Appendix 8: Transcript of focus group 1

Focus group 1 recording 1

R-Okay so thank you very much for coming so I think just so just to help me when I'm transcribing we'll just a quick round the table so that I'll be able to relate the voices so I'll try my best to see – it may not be possible.
So I have a question guide so the first few are really easy ones just to get you into the frame of talking and you can just ignore these things that are recording. So you are obviously all here because you have Lyme's disease. To have Lyme's disease you've obviously been exposed to ticks at some point because that is how Lyme's disease is transmitted.
Can you remember where your tick exposure was that lead to your first Lyme disease diagnosis?
P4 -I would say no, I can't remember. I'm bitten on a frequent basis so it could have been anytime.
R –west where in Uist
P4 – on the croft, Drysdale
R – perfect but you just can't date it
P1 –cant date it.
R – okay
P6 – what was the question?
R – so your obviously here because you have Lyme's disease so you've been exposed to ticks somewhere, do you have any idea where your tick exposure was.
P6 -I get about 10 bites since I can remember so no
R – where you live in Uist?
P6 – where I live in Uist I can remember about 10 years ago I was camping on an island and I came back covered on ticks but I don't think I picked it up then because I don't think I had symptoms after that because that was a long time ago but where I live I have a lot of shrubbery and I love shrubbery and you walk by and they jump on you and you pick 'em off
R – so you get lots of ticks all the time
P6 – I get lots and lots of ticks yeah about 10 a week.
P2 – um, I do remember yeah my tick because I've just looked at the form it was in 2002 it was in the peat moors up in Ness, Lewis and I haven't had many tick bites since because I've been pretty paranoid about them to be honest since that happened
P1 -Em I didn't see the tick, I was at work and I had an itchy leg so I pulled up my trouser leg and I had about 12 separate dots on my leg which the next day went into a massive wheal/wheel? I actually think, my thought is, that I had a cat at the time and although my landlord had a dog that went up way into the moors around my house I reckon my cat got it off the dog and rubbed it. Because I was very, very careful I was mindful of it then I used to go climbing and walking with boots tucked in and things. But its where a cat would rub against your leg so I reckon the cat brought it in to me but I never saw a tick at all.
R – but definitely in Uist?
P1 – definitely in Uist. Poor cat had to get tested as well and I had to pay £15 to get the cat tested down in Liverpool+--
R – and?
P6– it came back negative
P5 -I don't know, I don't know at all. I never saw a tick but it's interesting I didn't have anything that a rash but sometime after, a few months after it suddenly occurred to me from here to here and from here to here on both arms they had been a bit pinky/red and I'd thought it's the sun. so im seeing is that I got it from the garden and it is February I think it happened, ill get back to that, but you know the flippin plants that get all the dead bits underneath particularly germaniums and carcosmias and stuff and it had all been lying for

the winter you know and I'd been pulling it up with my arms but I didn't actually have anything you know there was no tick no tick at all and I'd been doing that in February but obviously what then happened. But P1 has said about spots and I noticed much later that I had these, sort of I don't know if they were spots but these sorts of wee lumps brown/around on this arm and I also had them on this leg that was also slightly. There was no tick no sign of a tick. now I've just, thought about this a few weeks ago but its now just clearing up but I mean it's been here now since last summer and its still but it is now just clearing up but no tick what so ever
R - so you never saw it, but it could have bitten you
P5 -it could have done but the only other thing is, 14 years ago, was it 14 I cant remember, not in Uist but in Japan I was bitten by an insect but I didn't know at the time but I came back and I realised I was going to go back to Edinburgh but I was really ill on the plane they had to get medical stuff had to go to a clinic in Frankfurt off the plane and I came back with this leg that was bright blue and three times the size of this one and the doctor said och its fine just take paracetamol but in actual fact I ended up really ill couldn't get out of bed really sick all the time and I ended up in that hospital with drips. Now I don't know of that was a mosquito bite I mean I pulled it out, at my daughters, I pulled it out and saw 2 wee wings sticking out of my ankle but it was never, I don't know what happened and I don't know if it was a mosquito or what it was or whether it could have carried something but I have actually had quite a lot on and off ill health since then but not quite not, since February I've been particularly very ill but that's kind of a really difficult side of the story that I have you know and I don't and I didn't get tested. But I asked to get tested FOR Lyme disease
R- so there was a gap
P5 -yes of about 6 months before I got tested. I was really ill
R – and remind me when was Japan and when was the lymes disease test
P5 – two thousand and, I'm trying to think the age passes you by, it could have been 2012 or 2014 I just cant remember – I mean I could actually get that date because I know we were at a conference
R – and then when was your lyme's serology positive
P5 -ay, that was a year, a year past October
R – so October 2017
P5 -No 2018, yep October 2018. It would have been February 2018 that I think I started getting symptoms/ill garden
P5-So it was from then that I was really really ill with symptoms , I know your going to ask about them later, so that's my story kind of a
R – it's a mixed picture but you have definitely in the middle of all of that had positive serology. Okay, so P3 your tick exposure
P3 – eh, it must have been in the garden
R – in Uist
P3- yeah in uist. In 2010 and when I was given antibiotics it was maybe only for 2 weeks at the time if it was even 2
R – it would have been the guidance changed in 2018 to three weeks so it would have been 2 then.
P3 – yeah
R – did you notice any difference in the antibiotics from when you had 2 weeks to when you've had 3 weeks more recently
P3 -shakes head
R – no
P3 -no it just takes longer to remember to take but hahaha
R– yes and there are not easy tablets to take
P3 – oh! But they go across and them they get stuck yeah I know they are not easy
R - so everyone has been exposed to ticks in Uist

P2 - except me in Lewis
R- oh well apart from Lewis, in the Western Isles, sorry!
R – okay so this is another quick question How would you describe your general health today? Okay so 1 being very good 2 being good 3 is fair 4 is bad 5 is very bad maybe not today maybe in the last month how would you describe your general health so we will go around in a different way this time
P6 – do you mean your general health apart from your Lyme's symptoms or do you mean your general health
R – well if, just your general health. Is your Lyme affecting your general health at this moment
P3 – some days are worse than others
R - there's no pattern to it
R3 -no no no pattern, I blame the weather
P6 -it comes like waves, a couple of days and then its better again
2 -yes!
P6 -well I mean in terms of general health I just had my check up and um Marie Currie said you're so healthy everything is perfect and I said okay fine and I am but I have joint problems and fatigue – muscle fatigue that I think come from Lyme, post-Lyme so I cant quite answer your question with a number its either 1 or 2
R – well you don't need to answer with a number then but generally the fact that it comes in waves
P6 – yes and the fact that I don't have anything else, in other words I had a really enthusiastic report from the practise nurse
R– well how about comparing to before Lyme, can you compare it to before you had Lyme disease to now
P6 – well its clearly worse, I wouldn't say health but my comfort is worse. I don't quite view it as a health problem it's a pain problem. And a stiffness problem so I dont feel its impacting on my health but it certainly impacts on my mobility
P1-have you seen a pattern to your waves?
P6-like you I don't think so no but I've been kind of watching and somedays I think oh! Everything's great so much better and then other days ughawoo
R – 3 week pattern?
P1 - there was a definite 3 week pattern for me when I was at my worst – with every three weeks I was just a bit worse
P2 -do you think it could have been at all , I'm not suggesting
P6 -are you still in that pattern
P1- probably not I I mean
R – its okay
P1– oh ive forgotten where I was going
R– that s okay, Melanie (3) you were going to say
P2 -sorry what I was going to say and I don't mean this question like are you sure its not just your hormones, obviously its not just your hormones im just wondering if when you say three weeks could there be any hormonal impact making it worse on top of that. Do you think there was?
P1 - em well we looked into it at the time and quite a lot of the research was saying that there is a three week sort of
P2 -that its not nothing to do with hormones
P6-the lymes research suggests that
P2-oh okay
P1- I used to keep a diary a uh symptom diary and along with that I probably kept a menstrual diary and from my memory there was nothing
(Lots of mumbling about connections)

P2 – I would say my general health, touch wood, is pretty good but I have um joint pain which comes in cycles and I just assumed, honestly, that it was to do with my hormones. You know I haven't thought about lyme's disease since 2002 when I had this diagnosis and the antibiotics and ive had joint pains all through my and im 53 now and ive oooh im exposing both my age and my maths but Ive had it a long time ago and I haven't really thought about it much but ive had joint pain that have got significantly worse other the last 3 or 4 years of menopause and now my hip pain wakes me up and drugs don't do it just you know they don't I can take whatever they give me and it just doesn't make it go away and when I have it definitely impacts my life but I have periods when I don't have it and I just assumed it was my eostrogen level going whooff you know as it does when you are going through the menopause it comes in big bursts trying to get pregnant you know I have got eggs I have I have .
Hahahah
P2-Throw them out and you know that's what i thought it was down to and I didn't know there was any association between joint pain and lymes – I never looked into it. So that's the long answer I think my general health is good my joint pain is getting worse and it definitely impacts me very negatively
R – but you've, there has been a 20-year-gap from your lymes disease diagnosis to now and you
P2 – not with that joint pain, ive had joint pain
P2– you've had joint pain all over, its just got worse
P1 – is it just joint pain or is it bone and muscle pain
P2 -I don't know what the difference is, not bone pain like here but it will be in a joint, my hip bone my knee and my ankles are where the pain is but also the things none of these things come to my head I always forget I get bizarre nerve pains, ive always had that well not always but since from my 20's and I always use to get one in my toe and I would get frightened that I would crash the car it woulds just come in my toe and it would be excruciatingly ridiculous like a couldn't stop reacting to it and it would only last for a short did you get that?
P6 -no no I was thinking of gout
P6– yeah well I know that sounds like a gout
P2 – yes and with the lifestyle I had kind of bought into that and I would get it in my fingers so I would get bizarre nerve pains um sporadically but shortlived and they don't really hold me back
R- they don't
P2 – and they might be nothing they might just be me being nervy
R – part of the problem in the literature with lyme disease and diagnosis is that the symptoms are very common like symptoms for other things and like your saying joint pains can come with menopause as you are aging you know there are other causes for things like that to em so it is one of the conflicting things that you read in the literature
P2 -and there is no nerve pain associated with …
R – emm well here we are talking to people here
P6 – in my case I would say not because I was free of joint pain since menopause until this happened so it was quite sudden I mean there were times were actually I could have perfectly well have had lyme back in the 90's without knowing it when I remember a period of my hips aching but then it went away and I was fine and that was after menopause anyway so its like it was very distinct that was the symptoms actually it was the hip pain and the fatigue that brought me to this surgery and maybe its time to test
R – general health.
P5 -well since last Friday my general health is absolutely fantastic according to the results of my bloods. Its not well it is good but that's been positive and I have to say its quite difficult for me in the last week I actually felt so much better than I felt for the, years really years but

emmmm but I would say that general its unpredictable its totally unpredictable. This business of a three week thing I cant really say this in a way because it took so long for me to get the docacycline I it was viral stuff really I was going up stairs on hands and knees I was frozen all the time I mean I didn't know I had lymes and emm you know I couldn't I couldn't walk up the the road I had to take my daughters arm in Edinburgh because I was so exhausted I couldn't you know I dont know why and that was before that antibiotic however it did relate very similarly symptoms to when I got bitten in Japan so ive had a bit of difficulty getting rid of it and generally my health did deteriorate em I couldn't do as much I didn't have the energy I wouldn't have any thought of I mean I think everybody feels you know to get the hoover out and clean the house is not exactly the most exciting thing in life you know but I mean it was like a process to actually do this at a time when I wasn't really wasn't really feeling that I wanted, that I could do it. But since I had the doxycycline I would say there was a cycle but I did take I did actually write stuff down I wouldn't necessarily be able to say it was three weekly you know what I mean but it never got better it was really really really so debilitating I mean I couldn't get out of my bed you know I mean I was just I cant even describe it I was just well you know im in my seventies now what do you do youre getting older so on and so forth but it wasn't that it wasn't that sort of thing you know. Emmm so in general I would say the cycle was there when it was very very when it was really bad but they were viral they were like viral symptoms that was the thing and the other thing that doesn't change with the three weeks would be like I cant remember things . I was going to the wrong cupboard to get stuff out of my kitchen and I knew it was the wrong cupboard but I was still going to this you know. I cant remember names like I would be able to name off everybodies name and address practically in the whole of uist now I cant even remember names for the odd faces that is better this week that has been better

R – so all of it has got better since the antibiotics, so youre saying that you were unable to do your housework not get out of bed

P5 - I still couldn't do that until really I still couldn't do that I'm getting out of bed its more really to me there last 4 weeks where I haven't felt exhausted. Im having to go to bed in the afternoon im so tired

P5- Em but things like my fingers go white my toes go white I am actually I really have to try hard to get that back and also I do have a – I wouldn't say it was joint I would say it was muscular that is all there these aren't as desperate symptoms as when the virus type I had bad bad symptoms then hearing and eye things.

R -I was just going to ask you, clarify what you mean by viral symptoms for me

P5 – I would say you know when you get a really bad flu and you actually think you know I think I um only actually had the flu once in my entire life but these were like a couldn't I could hardly lift my head my nose was running my eyes were running and em just so really unable to pick up anything just absolutely aching from head to foot and things that were really disturbing was my I had this dreadful buzzing in my ears and I couldn't sleep and everytime I put my head down my sinuses were running my ears were seriously buzzing and that was actually the first the first viral sort of stuff and that went on and other things as well I cant actually remember em and then I went to the doctor and they told me to take paracetamol whatever then at the sort of I didn't get better I was better than that I could get up you know and maybe for a few weeks or maybe for a few I don't know it wasn't even as much as that it all kind of blurs so then again I had really bad viruses but this time it was the same a wee bit of buzzing but not as much but I realised I couldn't read you know the tagline on the bottom of the news on the telly I couldn't read that it was all blurred all the time and then I started to have these things about not remembering you know things like not remembering I was supposed I was gonna say something I was gonna do something and I completely and utterly forget but the same cold type symptoms and I was frozen I couldn't get hot I was absolutely frozen all the time and like I was doing much exercises as you do but em that was the second that was the second one and em I went i went back them and I don't know

I think I just got the same answer about taking drugs. And the third time I was so absolutely fed up with it I thought whats the point in going back its not really doing anything for me em and it was the same type of symptoms but not the buzzing in the ears but all the flu-y all the stuff that you could imaging and I mean crawling up having to go uo the stairs on my hands my god and my knees were sore and I as I say I googled it and I looked and I mean if I did it now I would say ive had that that that that and that and I thought this is nonsense so I phoned the surgery and I said I want a lymes test
R and that's when you got
P5 -and it came back and I got the doxycycline and it nearly killed me, don't know which was worse the lymes or the doxy but I had it for 32 days
R– uhmm they cant give for longer
P5 -im always saying obviously it didn't do me good but I mean the symptoms are still going on until I mean there are still bits of them bits and pieces coming and going but em but these they were really dramatic symptoms and I say I always say I wrote all this out
R -no no thereare some good impacts there actually
P3 -do you think the warm weather helps a lot, yes
P5 - I think the sun does, they talk about vitamin D as their up topic you know I think the sun definitely you know going out into the and I think when the weather gets better but I think that's partly to do well maybe now that the rest of you have had it but I definitely think depression I think really makes you depressed and you don't why you're depressed and suddenly something hits you and your sitting with tears poUring down your face and your thinking goodness me I think the better you know I do think the better when the weathers got better regardless of the effects of vitamin d or whatever you know but you being able to go out in it em I do think yes I do think that but I think the depression is another thing that we are not really so sure of is that depression because we are feeling a bit fed up or is it actually an impact now I did notice that had slightly changed as well for me that I was actually feeling quite upbeat as im talking here blethering away but the point is that this is only just kind of recently and the other thing that ive found was your kids don't want you to be ill so there is a difficulty that their understanding of why you cant do the same things that you were able to do so like going to edinburgh or going swimming and running up and down a street and your dragging your feet and they think you know em the younger ones think that the older ones are a bit more sort of you know. But I think its really thinking my husband but its difficult for them to understand why this person has suddenly become this utterly useless old
P3– you look alright
P5 -I did I think I did look dreadful
P6 -I think one thing is quite funny well not funny about the the whole situation but the things you are reporting are tied up with menopause and getting old so it makes it a little bit harder to tease out symptoms because i know myself well you know Im tired well yeah im 76 why aren't I tired its perfectly normal
P5- the tiredness is something that's quite different from actually being so debilitated that youre actually unable to just naturally do tasks
P6-yeah when I say tired I meant tired in the sense that you'd have to think twice about going to the car from the house that's what I meant by tired
R– uhum… I have men in some of the groups too so I can balance
P6 - the ones who aren't having menopause that would be very useful
R– this is really good conversation but I want to give P4 the opportunity to talk about her general health, we started at P3 didn't we yes uhuh
P4– my general health is I would say good eh but I do have periods which was quite interesting chris brought up the periods where every three days 5 days where I am drained but I put it down to work I put it down to lots of different things lifestyle I put it down to that but there is this period where i have this fatigue and it passes I have it for 5 days and it goes

but generally im in good health so I got the antibiotics and that did make a big different to me because previous times of having that I hadn't been diagnosed and I had I felt as if I had to lead weights inside my legs I was literally dragging them along.
I was dragging and I thought what was wrong with me and I was going to spinning or exercise and had I done something to my legs had I hurt myself you know putting all these things through your head to find dia- what was wrong with me . Then I had a kidney infection so I got antibiotics for that and funnily enough I felt a wee bit better but then I got this rash on my neck. Not the circle just a rash on my neck and I went to the doctor with it and he said oh that's just a rash so that looks fine but it wasn't clearing then 1 of the creams he gave me cleared it and im quite good normal common cream will clear most things in me and nothing seemed to clear it so that was fine and I was having my shower and I happened to look in the mirror and I had this massive circle going right down to my arm and it still didn't click that I had the symptoms and I thought because this rash on my neck im going to the doctor. Went to the doctor he took one look at it and said you've got lymes don't panic where his exact words. You've got lymes don't panic. That's fine but after the antibiotics made a difference a huge bit of difference for me I felt so much better from having that but these symptoms of tiredness that you've been saying cant seem to calm yes I have I still have that I just thought it was me
P3 - I think that's the way we all are you just think its everybody
P4– well I had been to the doctors previously for symptoms of tiredness and just not feeling quite right, vague they were very vague not quite anything and I said I said to my doctor could I be tested and he said there was no point and I was miffed that he wasn't going to test me and I didn't realise why so after I got the antibiotics I definitely felt better bit I think I could've previously had it as well
P5– can I just another symptoms I noticed well I didn't notice a symptoms but I haven't got now I cant do any pas-de-bares I know this sounds really stupid but I used to dance all the time you know and I used to do pas-de-bares as a wee bit of an exercise ive no strength I cant actually lift my body off the floor like
R – and is that since lyme disease
P5 – definitely definitely I had no bother you no even when I wasn't im not I don't I was able to do it between being bitten by the the the Japanese whatever it was but its definitely definitely something that and it actually really quite took me aback you know and I couldn't actually jump I know it sounds really silly but I had no problem whatsoever but my body just feels as if its actually heavy and its really really heavy and fixed the I mean ive just lost that spring
P6 – that's kind of what you were saying
R – it is with the dead weights!
P6 – do you have weakness also do you feel your legs are weaker or just…
P4 – I wouldn't say I wouldn't say not now I seem to be fine at this moment in time but yeah previous they just felt so heavy but now I seem to be okay generally I would say my health is good, I've got good general health at this moment in time but previous I had all the symptoms
R – previous to the antibiotics
P4– previous to the antibiotic
P6 – did other people experience lack of strength sorry im just really curious
R – no it is its interesting that 2 of you are saying that
P2- No I don't remember noticing that
P5 -I mean actually with my background I know im a physio so exercise is you know my life you know and its not something I particularly did as a programme for me but you do do it you know you know em and I am deliberately I am actually sort of I found this heavy candle and I use it as a weight to try to get my you know I mean my arms I feel as it I could hardly

hold anything they were so heavy I don't have it that's why I thought ill have a go at trying to do a pas-de-bare you know but yes uh huh weakness is then it does come back
R – so its fluctuating
P5 – fluctuating yeah its really it does fluctuate I think for me mentally it is the fact you don't know if tomorrow I don't know if tomorrow I don't actually know if im gonna stop being feeling as good as im feeling today and that's really difficult because we go travel- we travel to the mainland quite a lot you know em and the thought of actually going and then not feeling like you can actually do anything and it could be something you know some grandchilds birthday or someones birthday whatever you know and you then ruin it for it ruins that part of your life your not going to get it back again because its been
P6– I I wonder about this getting back because I mean if you don't mind I have a sort of mental proposal which is I I I talk to my friends I feel like i have sort of a post-lyme syndrome im not sure I have it but I feel that maybe I wonder if the bacteria hasn't damaged things that may heal that's why I ask about the legs and the muscles and the joints and if in fact there is a possibility that there is simply physical damage that is done by this infestation and maybe you do gradually work it out do you have any comments on that
R – I do im not really supposed to have comments on things like this but because of my background reading and ive just had a visit from my host in america dr rob smith who is an infectious diseases doctor
P6 – which part of America
R – maine
P6 -okay
R – Portland maine and he sees patients with infectious diseases all the time and lyme disease particularly is his interest and he says that you can have post-treatment lyme disease 10% that's in the literature 10% of people can have post treatment lymes disease symptoms but he says most people will resolve that within 10 years so you are right
P6 – how many years
R – 10 years so there can be some residual and you would agree maybe even longer than 10 years you know but there can be symptoms
P6 -youre since when
P1 – 1999
R – hmm no bit these are really good and im getting some impacts of what your saying here but just remember it's the impacts of the symptoms that we are looking for, P1 where you going to speak
P1 – well did I get missed
R – did I sorry
P1 – emm uh hem
R– we can come back, general health difficulties
P1 – sorry I have word finding difficulties
R – that's a good thing to mention though
P1 – the the when im listening to you all I was starting to get upset remembering how bad I was cos at 1 point for months I was 22 hours a day in bed I could only get up for an hour in the morning and in the afternoon and I had all sorts of things bells palsy and the other thing in my mind when you were all saying is that after antibiotics you were better I didn't even have all these symptoms of a rash before the antibiotics all I had everything started going downhill after my treatment but in hindsight now my treatment wasn't long enough and wasnt enough antibiotics and I also went on to have IV antibiotics which I had three lots of three weeks of iv which was an experimental thing and they actually didn't make me any better but em if im saying what im like now em in comparison I would say im 80% better than at my worst however the things that really frustrate me are the ongoing always had a feeling of unreality that im not quite with things im not emotional I don't get upset I don't get happy im just a sort of flattened and ive had that for the 20 years emm ive also got residual memory

problems and word finding which gets worse when im tired emm but even you know speaking im starting to remember cos I can remember particularly 2 incidents one going around a corner coming from solas to lochmaddy there is a corner at the quarry there I can remember sitting in the car as a passenger and just I just remember the feeling it was early on in being ill of sitting in the passenger seat like this thinking this isn't life im just feeling totally out of it and the other thing I remember because I stayed in north uist then the occasional time in my hour when I was awake getting some make up on and going to the coop in my dream thinking id visit someone when I went there getting to the coop getting 5 things and being totally drained and going home and that was it never visiting anyone. So now im im getting my life back but I still have these awful things
P5 -as P1 is saying about word finding I mean thats a things that really sort of I don't my question is how much is it attacking my brain it may not be but that is a really serious issue to me much more than you know feeling that im tired you know and I I its really something that I mentally am trying to actually I watch every single programme I can possibly watch because ei don't need to I don't work anymore so so I mean I wouldn't be able to work that's another thing I would never have been able to keep my job if I had been emm I know I know I know I know I I you know I did think that if I had had these symptoms the first time with the Japanese one I was off for about 5 months with that but I did get better but I was never fully back to what I was but I was thinking if I had been working there is no way, no way, under any circumstances would I have been able to work but the mental thing is really more my questions of this what actually is happening about the mental problem because that is really really really serious I think because you don't know what is actually happening to your brain I cant can you know I can do arithmetic no bother you know its just about putting your fingers out but these to me are far more concerning than and not finding words
P1 – people don't realise I have the word finding difficulties especially family cos I actually , I don't know if you are doing this but I actually overtalk things I talk around if I cant remember the word in my mind for dustbin or something I would be rabbiting on you know the thing you put your rubbish in you know and a lot of people don't realise im having a problem in my head ive got that problem
P3– they say you don't your not finishing your sentence , I just cant remember the finish
(murmurs of agreement)
P1 – I get that all the time
P5 – and the other thing is suddenly you stand and you think what was I gonna do you know and that
P6 – ive had that since I was 20!
P5 - yeah but I think that's okay as long as it has been happening since you were 20 but I think if it just suddenly happened you know just a few months ago that's not something I was ever
(mumbling)
P5 – yeah and uh that these are really
P1– yeah and if you with someone, even here, if im meeting someone new I then have the embarrassment factor and it would actually makes the thing worse and you know their thinking what an idiot and that's going on in my head. So my confidence goes down
P5 – and you cant remember a name you've just been told and yeah you know and I was sitting here thinking what did she just say about that first bit I mean its alright I got them but its you you don't feel as sharp
MURMOURS OF AGREEMENT
R – that's a good way to describe it
P6-I just have been lucKy because I have just not had any mental symptoms that I can determine like I said I couldn't remember things when I was 20 it was purely purely very focused and very localised particular symptoms and it has affected me I mean ive had to change my decisions about what I can do on the croft because I simply cant get around and

I cant carry stuff the way I used to without without pain so um but mentally I think there hasn't been a particular change but physically ive had to make adjustments well I wont do that or okay can I find someone to work with me
R – so while we are talking about the mental do you want to say have you had any of these kind of
P2 – well I do suffer well ive put all my suffering in the last few years I mean it was a long time ago I remember 2002 when I had this tick bite and the lymes diagnosis so its been a long time so its difficult to know whoever said that so its difficult to know whats different to your hormones and I don have um mental um issues not emotional issues I don't feel depressed but I do have difficult and ive always had I my my career has been in communications ive stood up in front of thousands of people and made speeches and been in charge of directing conversations and ive been very very confident in my articulation but just recently I have felt, as part of the menopause i thought, a slackening off of my ability on that front but can I just ask a quick question and I know you don't want us asking questions but that you want to here from us
R – yes its not that I don't want questions I don't mind answering questions in my day job you see this is different
(incoherent mumbling)
P2 – it occurs to me that if I was pooh-poohing lines that I could say yes all of you could have had all of these things welcome to being a women of a certain age but then is suddenly it occurs to me how do, does anyone know if you've underlying, if you've lymes in your system and your symptoms of life you know whatever happens to you whatever I mean if you've got another illness like I don't know diabetes or arthritis or something different or just old age what does how do we know how much the the the existence of lymes in your low level symptoms that haven't bothered you before will impact all these other things coming on because living with menopause is so shit, excuse my French, because its hard I wouldn't have been able to work, I gave up my job because of my menopause basically I just couldn't do it and
R – I can help answer that question there is a difference from what you are saying to what kay and chris are saying and chrissie because their symptoms have been present from when their lyme was diagnosed they've been noticing they've been exhibiting, ill come to you yet jenny, I will come and ask you whereas yours there is a 20 year gap and you are only starting to feel that now so its much more likely yours will be to do with the menopause
P2 but how do we know that mines not 15% worse or 20% worse than that's not my question my question is if if lymes is in in tel tel ugh. Sadly im a lyme ridden menopausal woman and I cant articulate what I would like to tell you but how how do we that my symptoms aren't 20% worse because the lymes is in there
P6 – I think that's the mystery of
R – that's the mystery of lyme exactly
P2 – you make it sound so attractive when you say that
(loads of people talking over each other)
P6 – no no ive read a few papers I actually have some stuff I was sent from the continent in French and its interesting to see how different cultures perceive this but the problem is everywhere is that you cant tell
R – and the symptoms are so similar to so many other conditions but I would say that the pattern that these three women are describing its been there from the begining you know the the brain fog is documented so it would be more likely to be related to the lyme
P1 – I would say I easy menopause I would say I had no problems with that
P2 – maybe its because you were feeling so rubbish anyway
R – but were we're not belittling your symptoms either you know
(LOTS OF TALKING OVER)

R – if well cause you're referring to what is it still doing in your brain the the evidence will strongly suggest that if you've had the three weeks of doxycycline it will have killed the borrelia and the borrelia should not be having any impact
P5– can I just
R- but there are
P5– sorry just I I I understand that the problem I have with that is that I was told that if its not given within 24 hours the affect of the lymes will be much worse so I didn't have it for 4 months 5 months
P6 – I didn't have it for a year 18 months
R – lots of people didn't have it for a long time and maybe these are the people that exhibit more symptoms I have no answer to that
P5 – im not asking im just saying that what I was told
P6 – my theory is that all those little dead bodies lying around in your system probably takes a while to clear
R – bacterial debris is left with every bacterial episode you have from a urine infection to a chest infection to there is some debris left in your blood stream em and you know
P5 – if your in good health you wont get
R – that your body will fight it off yes
P5 – but what im saying is do we know by number what you know if the people who get it within 24 of the of the diagnosis do they have different or better you know results than those of us who actually haven't had it for months and its been you know
R – the 24 hour thing let me just ive never heard the 24 hour thing and ive not read the 24 hour thing. The 24 hour thing that ive heard of is tick attachment. If the tick is attached for 24 hours it is much more likely to put the borrelia into your blood stream that its got nothing to do with 24 hours to receive the antibiotics ive never read about this at all
P5 – I think maybe I misread this
R – but the longer the tick is attached the more likely process – if the tick is positive and attached for a longer period its more likely that the bacteria will be in your system I don't think there is anything ive never but that's not to say its not
(talking over)
P6 – all ive heard is if you've had undiagnosed lyme for a longer period of time its more
R – its hidden its hidden definitely
P6 – it does a better job of hiding itself
R – so we were talking about the cognitive symptoms the memory the word finding, P3 you've still got something to say on that but P4 have you cos everyone has, maybe you were finished I didn't think you had had long enough
P3-I cant remember
R – ahh its okay P4 did you have anything any experience of that
P4 – the only well the only you were talking about memory fog and I probably do have memory fog but again I put it down to age but it's the its when somebody says their name it's a complete its like I don't even hear it sometimes its odd its like ive lost the whole thing the whole name and ive missed it so I do have that I work on that when I get I work on these things
P6 – that different now than what it used to be
P4 – emm I never used to have that but then that's what worries me I don't think that's I think that's just me that's
P3 – you know I think a lot of us just put it down to age
P5-I actually am not
P6-Some of it must be
R - Some of it will be
(TALKING OVER/MUMBLING)
P3-Because that's what we say we don't think

P1-If you've got thyroid disease and rheumatoid arthritis youre not going to know which symptoms
(talking over)
P1-Ive got diabetes collegues
P5 – I don't have any
R– its hard to isolate but its looking at the pattern and the consistency of it I think
P1 – and also maybe knowing your own body knowing yourself whats right and whats wrong
P5 - see you've said this ladies name see I now can't remember
P2 - See I cant remember and I don't think ive got brain fog problems now apart from mem- and I can remember yours cos I knew you from previously but I cant remember and I cant remember any of your names
R – and that's quite a normal thing see see so there is an element of it
(talking over)
P2 – see if R had come in and said there is going to be a test at the end I mean we would all remember the names I mean that's just not what we are thinking right now I mean im no dismissing it but don't be alarmed if I cant remember your names
P5 – I never in my entire life would have that problem and im not just saying that
R – but I liked what you said about what you are trying to do to help with that is watching quiz shows using your brain and so we have ten minutes left if you want to finish at half past , yes so im getting some really good stuff but a little bit more impacts is that alright is that okay so ill just tell you we've just been covering just been dipping in and out of things but just if you wanted to consider physical how had it impacted on you physically I think you've said little bits you were saying about em you don't do as much on the croft
P6-well yeah my main impact has been physical yeah
R- so uhh explain it a little bit do you think
P6 – well it just means you have to make decIsions you know ohh I can go rushing off up the hill to talk to the cow or I can wait for the cow comes down to talk to me in a second because it would be a lot of effort to walk up that hill and I I think its good to keep pushing it because I I guess I had this theory where there has been damage done but there in theory if you don't getting lyme again you should be able to work through it therefore its like you said mentally its worth pushing yourself physically to a point on the other hand I mean if I go to the city and I walk on the pavement for a day im crippled um you know I just
P1 -I think there is a uhh a certain extent of that that is normality because we don't walk on hard pavements here I mean even before I got ill
R – where you like that
P6 – yes
P6 -yes and I was in Vermont recently with my brothers and I was walking around in the woods and I thought it was going to kill me because it was all uneven and I I felt much better you know so it seems to be a uhh and im not sure again you cant tell if its from the impact of the disease or if it was something that was happening anyway my problem is explicitly in my hips and thighs
P3- The bottom part!
P6 – but its not in my knees or my ankles
P3 – I have it in my hips and my ankles not in my knees
P6 -well I was interested in what you said about muscles because I uh in my case its uhh joints but also the large muscles and that impacts what you can do
R –physical impacts
P2 – I don't I don't think
R– and if you don't have any that okay
P2– well I do have physical impacts but I don't think they are to do with this because as you say there have been too much of a lack I do have very painful joints on and off that cycles that actually wake me up I wake up going ahhhhhh and ive also had my joints x-ray'd and

there is nothing wrong with them which makes me think well im not making it up so maybe it is a lyme-y but but I don't know
R – and it could be the muscles on the joints
P2 – my muscles are fine ive got sore ankles and sore hips and sore knees
R – and it wakes you up
P2 – how about ligaments
R – ligaments yeah it could be ligaments. It tends to be, if you're talking lyme borrelia it goes into joints more than muscles and ligaments
P2 - yeah well in my case yeah
P2 – I also get headaches but I think that's to do with the menopause as well it only just comes as my menopause has started and im still convinced – no one else in my family has had a bad menopause and im sure that that listening to you all speaking I bet that's why im having one
R – so things like how P6 is talking about not going to the cow waiting for the cow to come to her nothing like that that you wanted to comment on
P2 – yeah well pain impacts your life you know you do hobble about and get woken up in the night with it and its sore and its debilitating
P5-but if you've got increasing joint problems youll get weakness of your muscles regardless of itf you've got lymes or not so the answer is to key to do very very little non-impact exercise. Not to do to do a little bit daily
R– so a physio referral would be appropriate
P5 – yeah yeah or ive got a very physical life
P5 - Well not even that referral just that you know
R – keeping moving is important isn't it
P5 – not to think ive got this and I cant do. Don't be jumping just get out of your bed and do something
I didn't know Im determined not to get up
END OF RECORDING 1
START RECORDING 2
? – this is some really good stuff any other impact, physical impacts
P1– well before I got lymes I was really active in kayaking sea kayaking hill climbing dancing and everything very very active but all of that just stopped completely and that was the major impact. When you said about headaches the first time I got it one of the bad things was bad headaches all of the time but when it came back I didn't have any headaches and it it one of the big symptoms was breathlessness on exertion on even putting my socks on breathlessness e mem but I I youre all saying about lower but I was fritting all over it was fingers one day then knees the next day and one of the things I remember the worst was when I was driving the muscle in my forearms to drive along like this because it was just too sore the pain I mean I was on huge amounts of pain for years but ehh it didn't just wake me up I I sleep apparently I moaned when I was at my worst I was moaning in my sleep

- P2-Oh that's horrible
- R – the pain

P1– the pain colin would say that I was moaning away and I had no recollection of doing that another physical thing and em cos it wasn't so much joints it was my muscles and bones and joints I would have said were the least of the three but I ended up with a knee replacement 5 years ago which I don't put down to lyme I had an injury that was on my knee when I was much younger but I had a knee replacement less than 1% fail my knee failed within 7 months and I despite the fact that we did a whole lot of tests and I did private testing at the time of my revision knee emm and they all came back negative im still convinced lyme was at the back of it failing but it wasn't the initial reason for having it

R– physical impacts I think we got a few from you but is there anything else you wanted to add
P5 - I don't have a specific but my ankle was but the one THING that I did notice but trying to lift a shopping bag when it was bad that was I couldn't do I couldn't do that so I think you know that this is really just in general i think I was really sore and I would be waking up with the pain and my toes so bad that my toes would be waking me up and the other symptom id had which id never really had was cramp and that was excruciating
R – have you got a tick
P6 – yeah which bin do I use this in
R – that small one
Just in general
P2 – can we wait then if we are doing this because we are going to miss
P6 – have a demonstration here
R– the small end definitely underneath it
P2- we are going to miss what you are saying I think we are not paying attention if we are
P6 – I can always tell because I itch
P5 -it really was excruciating and I had no rhyme or reason to work out why my toes were terrible and I was so painful and of the pain that would probably be the most painful thing and but my toes and my fingers and them being white and they still do The other day that's what they were like
R– hmm is cramp something any of you have
MURMOURS OF NO
P4 – I get a lot of cramp, again I had a history of cramps so again not sure if its quite relevant sometimes it can belong to other things
P5 – I just think im lately so so cold so terribly cold. My body felt as if I would never warm up again and I never I never used to feel the cold and I never had my hands were cold or my feet were cold and this is something that really distress anyway
R -P3 physical impacts are you still able to garden and walk
P3 – I cant lift heavy things I cant do heavy things no. try and do everything else but you know but it has it has had an impact on my life
P2 – you got joint pain do you P3 what
P3 -yes, hips and ankles. The ankles are really bad but I cant remember when the what year they said I went to the doctor they sent me to a specialist and when I mentioned to them eh I had lymes he was very interested ehh because of ankles and stuff but never said that could've been the cause of it or anything. But there is no arthritis in the family or anything so its so I just think its had an effect on me you know you go to your bed at night thinking in the morning its easy to get up but I can hardly get my feet
P1– I used to worry I was in a hotel in brighton and there was a fire alarm and I would never be able to get up you know and I would lie awake thinking I was really stiff and what if I was in a hotel and there was a fire alarm
R – so stiff in the morning and slow to move
P3– shower I would go to the shower and massage them and that how I, I don't do it in the shower everyday but ever second day I
P5- ..increasing blood supply
P3 -so actually that was something to do massage the ankles and then id feel a lot lot better
R – good these are good things because you were saying about the brain how to keep it active so good some of the things you've done that help you so its good to record some of the things these things too so im im P4 will we go to you, so your house work your able to your generally able to, No at the beginning no but you were able to

P5 -all throughout no, I mean im not just making this up you know it really is something ive noticed and I had to have a cleaner and none of the children stay at home anymore so that was a bit of a bother
R- what about your
P6– I would say I get tired faster at almost anything whether its sweeping the floor or making the bed like that you just get tired faster
R – leisure activities you've been you know mentioning a little bit impacts do you still go spinning and to the gym
P4 -I still go spinning ive recently done some wall climbing ive recently done all of that but on the whole I am good I would say my fitness Is good for my age So ive no complaints like that but I do now I notice I don't do lots of things if I feel tired I just pull back to recover and once ive recovered im fine I start again its balancing act and you just I find I have to get it right and if you get it right im okay so if im good im good but if im feeling tired I just rest and wait until I wake up a wee bit then I go again but ive got good health
R – p3 leisure had it impacted on your leisure activities at all
P3 – well I still go walking but that's all I do
R – dancing because dancing was mentions
P3 – no I cant no there was skipping and I used to do about a hundred skips and I cant I cant
R– you cant because of your ankle
P3 -I can do 2 or 3 that's about it
P5 – I tried that the other day there the other day and I was thinking one of my granddaughters was up and I couldn't that's how I couldn't jump I couldn't lift myself up
P3 -I said to myself could you give me a hand with this, I cant I think I got 3
R – because of your legs feel too heavy or they feel weak or
P3– heavy? – heavy
P3- but I put it down to my weight
R - well no it shouldn't
P3 -well that's what I do I blame everything else anything other than
R -any other leisure impacts
P5 - I used to go swimming and I try to swim as much as I can and I noticed well I cant go and I cant go with the kids and I cant go when im away I cant do the things I cant climb hills I could hardly take a step from the path up the garden to the top. Oh the other thing that ive noticed sorry sorry my balance my balance is completely and utterly off its fine and then im leaning over and I suddenly feel as if im nose diving and ive got to stop myself and I thought that was because I was really really quite debilitated before when I was really really bad but its its its its continued now, today its not like that but its really quite scary because I feel as if im my especially when your kind of bending over in the garden and your going to pull a weed and you see yourself hitting the deck
R-is that something anyone else has noticed
P6 - I would say my balance is off but I dont think its balance I thinks its just my legs are weak so that I cant be if im stepping on uneven ground I have to just be careful because im not sure that ill be able to
P3 – yeah I think so to -I use a stick
P6- because I don't feel dizzy
P3 – no no
P5 – I cant stop myself I cant stop it
R – you described quite marked ear symptoms which would be maybe why you would have
P1 – what about em because I do remember hitting the door side as I went through them
R – spatial unawareness
P4 -yeah I do that but I thought it was me misjudging I do that quite frequently I try go through the door but im covered in bruises just banging in to things

R– P3 you said I have a stick in the garden did you always have a stick
P3 – no not really in the garden but if I go walking or even on the croft but I need it oh I would have to have it even just walking if you don't have a stick you are just watching every step
P5 – I actually balance myself with the whole when im moving something I have never never had to do before
R – you've given me some really interesting things to think about do you want to add anything else
P6 - I was going to add something that I'm probably not supposed to but you know you are talking about painkillers and everything but im afraid I've gone herbal and turmeric works for me it works very well it works like aspirin in works quickly I thought it was something you would have to take over time I know youre not supposed to be into those sort of terrible things
P3 – capsules?
P6– the the capsules of turmeric you buy them in the health food stores you buy them in the 400mg or something and I think its easier and ive been told not to take ibuprofen and I know all those things are really bad for your system and give you stomach upsets
R – and is turmeric an anti-inflammatory
P6– it's a rec- it's a I shouldn't quote the medical profession but one of the doctors said shes heard that turmeric might be something that you might want to look into or something
P2 – just to help me can I ask you what I take
P6 – yes you can buy them
R- itll just be a herbal google it
P2 – I know but there will be a thousand tumerics from 1 mg to 1000mg
P6 – seems to be standard 400mg it actually im very suspicious of this stuff because in Vermont everyone is into all this stuff but it actually
P1- I used aromatherapy, ive used aromatherapy I see on the mainland and she made me up stuff and certainly it helped a lot
P5 – I forgot this and actually it nearly killed me more than the lymes with the doxycycline I had the most absolutely utterly and horrendous indigestion and pain really pain I couldn't eat and I was doing exactly what I was told with the doxy I was standing up practically for half an hour nearly keeling over cos all I wanted to do was lie on my bed em and it went on
P1– at least they tell you that now they never told me
P6 -they told me fiercely and i was very careful about
P5– but anyway it went it really it carried on for ages and I was trying sort of and I didn't want to take and I wasn't particularly bothered with peppermint you know it didn't sort of do any good and so on and so forth and I did try to work at and my tongue was as brown and as thick and just awful and the pain it wasn't even it wasn't even up here it was in my oesophagus and no matter what I di I just couldn't get rid of it to the effect I was thinking god am I going to have to eat you know anyway this went on for quite a while-y and anyway it I I did kind of get rid of it but then for some reason with repeated symptoms it it it did come back and I had the most horrendous pain and I was violently sick violently projectile and I couldn't stop it and then it felt better so it went away it kind of went away again and then it came back again ohh and I thought I cant stand it I cant stand it and I was watching a programme on the television as I was cook from the island cooking and it was about chilies and it really obscure and I don't really like chilli and the upshot of this is they said its very very good if you've got problems with indigestion so I went to neillies and I bought a jar of chillies and actually I started eating lots of chillies and actually it had the most helpful effect of I wouldn't have believed that chilli I mean I do eat curries and stuff with chilli you know its not that but the fact that that this chilli that it and this is one of the things in south America and they sell these chillies and people were eating them whole quite good but I think that was so debilitating to be as unwell

R – ive never heard of that
P5 – something that was meant to make you better and I had dreaded taking them I actually dreaded it
R– it's the side effect the skin the skin as well
R -P2 im aware of the time for you its 39 minutes past 13.39
P3 -youre not meant to be out in the sun that right that's right
P3 -the first time no one warned me about it and I went red and I was wondering whats changed and then I read about it and that you had to keep covered up and ive just come off them a week ago and I think its affected my skin and my hands came up in blotches
R– its sunlight its sunlight your supposed to stay out of the sunlight and I think they are better at telling people that and it doesn't matter mean I mean even sitting in a window and the sun is on your skin that enough to mmake you react
R – have you any other things that you've used that have helped you so keeping moving keeping your brain active knowing when to slow down you know having to sit when you have to
P5 – I think ive exercised even all though ive had problems I think that's the thing keep going try not to let that take over your life and it doesn't need to be vigourous
P3 – what exercise would you do though you know
P5 -just just up and down with your toes when your watching telly keeping your circulation
P1 -I find tai chi the sitted tai chi in carinish I found that one the best thing because it felt that I was stretching that someone came and did pilates once and if someone came and did pilates here that would be I felt I needed to stretch the whole time
P6- I feel like im much more sensitive to getting sore and stiff but some of that is obviously age but I think its also maybe a change from the lyme and therefore you do also have to keep thinking about stretching and things I mean ive been going swimming
P5 -really gentle movement as well even just swinging and just which we should be doing anyway
P5 -but you know its just that sort of stuff people think you really need to power into exercise but that's not you know you don't have to do that
R – okay oi think ive kept you long enough unless you have anything else you want to say
END 18.37