

‘Advancing Health Professionals’ Knowledge of Liver Disease’

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PREFACE

This critical appraisal is original and contains independent work and co-authored works by the author, Gerri Mortimore.

The contribution of the author is acknowledged in attribution forms in the appendices.

Table 1: List of included published works

1. Casey, G. , Nortcliffe S., Sharpe, P. and Buggy, D. (2006) 'Perioperative Nimodipine and Postoperative Analgesia', <i>Anesthesia & Analgesia</i> , 102(2), pp.504-508. doi: 10.1213/01.ane.0000194448.37407.6a.
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Abstract

Background: Over the last 50 years, mortality and morbidity from liver disease has increased and is a global health concern (Global Burden of Disease, 2020). In the United Kingdom, within this time frame, liver mortality has risen by 500% in the under 65-year age group (British Liver Trust, 2019). Treating and caring for patients with liver disease is complex, therefore it is imperative to educate health care professionals regarding the different types of liver conditions, the treatments and care required to support patients.

Aims: The critical appraisal spans over 14 years of research and will examine 19 publications which details the impact of the author's research on their academic journey, from a student nurse to the present day; underpinned by Benner's (1984) five stage theoretical framework. This appraisal demonstrates how the impact of the author's research, nursing practice and published papers is advancing health professionals' knowledge of liver disease within national and international arenas. It additionally evidences how the research has improved standards of medical and nursing care for patients receiving treatment for liver disease and establish how, by listening and responding to patient experiences, guided the research and assisted in the development of educational resources.

Methodology: The research chronologically encompassed positivist, interpretivist, and latterly pragmatic paradigms and utilised both quantitative and qualitative research methodologies. The research generated new knowledge regarding patients' lived experiences of haemochromatosis, generated data submitted to Parliament and highlighted the requirement for venesection guidelines.

Findings: The principal findings of the research demonstrated that there was a disparity of care across the British Isles, for people undergoing therapeutic venesection for haemochromatosis. This prompted the development of the venesection guidelines to standardise practice. A further finding demonstrated that less than 27,000 people were being treated for genetic haemochromatosis when the numbers should be nearer to 400,000 indicating that the condition is underdiagnosed. A further qualitative study highlighted that many General Practitioners take years to diagnose the condition, and some were unaware of its existence.

Impact: The author's expertise and research reputation, as evidenced by the collection of published research, has been sought by the National Institute of Health and Care Excellence (NICE) for the development of national guidelines and quality standards. The contribution from the author was recognised by NICE by the conferment of the title, NICE Expert. Research findings were presented to Parliament via an All-Party Parliamentary Group in 2020, to highlight the condition, genetic haemochromatosis and to lobby for increased awareness. The Venesection Best Practice Guide received Royal College of Nursing endorsement and was published as an eBook which has been downloaded by many countries, evidencing worldwide dissemination. This project won the National Patient Safety Learning Award in 2018 and in addition, the co-authors have been awarded winners of Nurse of the Year, 2021 by the British Journal of Nursing. This clearly demonstrates how the author has advanced health professionals' knowledge of liver disease by informing and influencing local, national, and international policy to improve or even transform lives for the better.

Chapter 1

1.1 Liver Disease

Liver disease is a worldwide issue (Global Burden of Disease [GBD], 2020) and recognised as a silent killer. Over the last 40 years, the United Kingdom (UK) has witnessed an exponential increase in liver disease mortality whereas death rates from other medical conditions such as: heart, respiratory disease and cancer have fallen, (Public Health England [PHE], 2020; British Liver Trust [BLT], 2019; Williams *et al.*, 2018; Williams, 2015; British Society of Gastroenterology [BSG], 2009).

Liver disease is recognised as the fifth leading cause of death worldwide and within the UK, is the third most common cause of premature death in the under 65-year age group (Public Health England [PHE], 2020; BLT, 2019; PHE, 2017; British Society of Gastroenterology [BSG], 2009) with death rates within this cohort group increasing by over 500% since the 1970's (BLT, 2019). These findings are supported by data published in 2015 by PHE and additionally state that over 600,000 people in the UK have some form of serious liver disease with over 60,000 diagnosed with liver cirrhosis. Further statistics published in the *Lancet* Standing Commission on Liver Disease in the UK report, emphasised this stark reality and added that liver disease will shortly overtake ischaemic heart disease regarding years of working life lost (Williams *et al.*, 2017).

Unfortunately, signs of liver disease are generally not apparent unless it has reached an advanced stage, evidenced by jaundice, ascites, oesophageal and gastric varices, all late signs of portal hypertension (Bacon, O'Grady, DiBisceglie, Lake, 2005). This is supported by research from the NIHR Southampton Biomedical Research Centre (2020) who established that 75% of people with liver cirrhosis were not diagnosed in primary care but in a hospital setting, when the disease had already progressed, and

treatment options were limited. Therefore, liver disease is acknowledged as the silent killer (BLT, 2021).

The main causes of liver disease are modifiable such as: alcohol related liver disease, fatty liver secondary to obesity, and viral hepatitis (PHE, 2020). However, there are other causes, such genetic haemochromatosis that tend to be overlooked.

1.2 Genetic Haemochromatosis

Over the last 20 years my research interest into liver disease has grown and developed with a specific focus upon genetic haemochromatosis. Genetic haemochromatosis is the **most common** genetic disorder affecting Caucasians in the UK, but people are not aware it exists (Haemochromatosis UK [HUK], 2020). It is an autosomal recessive disorder which requires a person to inherit one copy of a variant (mutated) gene from each parent to develop the condition. Inheriting two copies is termed homozygous or homozygote (Fitzsimons et al., 2018; European Association of the Study of the Liver [EASL] 2010). If only one copy is inherited, then that person is termed heterozygous, otherwise known as a “carrier” of the condition.

Haemochromatosis causes the body to absorb too much iron from the diet. Over time, the iron accumulates and is deposited throughout the organs of the body, including the skin, and joints. However, because the liver is the body’s main storage place for iron, any excess is deposited there, and liver disease usually precedes significant disease in other organs (**Mortimore**, 2017b; Bacon *et al.*, 2005). Due to the non-specific nature of early symptoms of haemochromatosis, diagnosis can be incorrectly diagnosed, missed, or delayed until more serious signs and symptoms have appeared, adding to the burden of serious liver disease.

Once diagnosed the mainstay of treatment is the therapeutic removal of blood, approximately 450mls, known as venesection (Francis, **Mortimore** and HUK, 2020; Fitzsimons *et al.*, 2018; EASL, 2010). In the de-ironing phase, as iron levels are brought down to normal levels, venesection can occur weekly or fortnightly for many weeks, months or years depending on initial ferritin levels. Once the iron has been successfully removed and ferritin levels brought down to within normal levels then patients are in maintenance and venesections are then required approximately every two to four months for the rest of their lives (Fitzsimons *et al.*, 2018; EASL, 2010).

There are other rarer types of iron overload but Type 1 genetic haemochromatosis is the most common and has been passed down through the Northern European bloodline especially Celtic, Picts and Viking. Research reveals that 1:113 people in Scotland and Ireland have the disease and 1:150 in England and Wales (HUK, 2020; Pilling *et al.*, 2019). This is interesting to note, as in an article authored by **Mortimore** (2017b) only two years earlier, cited the American Association of the Study of Liver Disease guidelines on haemochromatosis which suggested that the numbers affected were less, at around 1:200 (Bacon *et al.*, 2011).

In 2019, research undertaken by the University of Exeter Biobank established that within the UK over 380,000 people have haemochromatosis. However, after obtaining information from NHS hospitals under the Freedom of Information (FOI) Act, (2000) it was apparent that only around 20,000 people were being treated within NHS Trusts (**Mortimore** and McClements, 2020). Even if this number was optimistically doubled to account for the NHS Trusts that did not respond to the FOI, this is a serious underestimate. This ultimately will have a profound long-term medical and financial consequences to the NHS, as undiagnosed patients may develop complications of liver disease. In view of this fact, the findings from my research culminated in a

presentation to an All-Party Parliamentary Group in Westminster to lobby Government for calls to action to tackle this issue (**Mortimore** and McClements, 2020a) (Chapter 3).

1.3 Responding to the educational needs of health care practitioners

The complex nature of liver disease morbidity and mortality denote the requirement of educating health care professionals (HCPs) regarding liver disease; its causes, complications, and treatment, to help improve the quality of care provided to patients and carers. This was acknowledged in 2013, when the Department of Health (DOH) in conjunction with the Royal College of Nursing (RCN) developed a competence framework for nurses and allied health professionals dealing with adults and young people with liver disease (RCN, 2013). This framework made clear the expectation that all HCPs should remain up to date; to keep abreast of skills and knowledge in the ever-evolving field of healthcare and liver disease, thereby ensuring that information or advice given to patients and carers is evidence based (Nursing and Midwifery Council [NMC], 2018). Despite an expectation from national drivers regarding liver disease education (BLT, 2019; Williams *et al.*, 2017; PHE, 2017) it is surprising to find that there is a paucity of liver educational courses being delivered nationally. This point was raised in my publication in the Gastrointestinal Nursing journal, titled, “*Advanced liver training: where are the courses?*” (**Mortimore**, 2016a), with an acknowledgement that reading relevant journals and attending conferences, is often the easiest, most convenient, and cost-effective way HCPs can keep up to date. This continuing professional development for HCPs is prerequisite for professional revalidation by the General Medical Council (GMC) and the NMC and helps to improve the safety and quality of care provided for patients and the public (GMC 2020; NMC 2019).

Since 2006, I have published numerous articles regarding liver disease with the aim to advance health professionals knowledge. My expertise within the field of liver disease has been recognised with requests to speak at national conferences, author further articles and become a peer reviewer for nursing journals. It has also led to invites from pharmaceutical companies to offer advice for potential research studies in patients with liver cancer and contribute to teaching modules for nurses (Chapter 4).

1.4 Research and audit

Audit, research and clinical trials are an everyday part of the National Health Service (NHS) and any robust research project relies on the ability to collect high quality data and to analyse it correctly. High quality data, in terms of validity and reliability, can inform and enhance evidence-based decisions and aid learning. Moreover, the evidence-based medicine (EBM) that we practise today, is attributable to past research. EBM requires the assimilation of high-quality research evidence along with clinical experience, expertise and patients' values and experiences (Strauss *et al.*, 2019). Thus, research assists the NHS in its future healthcare, although it is recognised that a large proportion of health research is not only clinical trials, but information based.

In a systematic review of the literature in a publication titled, "*Towards Noninvasive Detection of Oesophageal Varices*" (Rye, *et al.*, 2012) we compared the standard endoscopy for the diagnosis of oesophageal varices in cirrhotic patients with clinical, biochemical, and radiological investigations. We concluded that these investigations were currently not accurate enough and potentially could miss the diagnosis of large varices and suggested that further research was required. This review has been cited

numerous times (appendix 1) thereby demonstrating that this article has been used as evidence in further research, thereby contributing to EBM.

Within this appraisal I will evidence how collecting data in the form of homogenous purposeful sampling (Braun and Clarke, 2013; Palinkas, *et al.*, 2013) significantly contributed to audit and research studies. The findings of these studies resulted in changes to medical and nursing practise which enhanced the hepatology service and directly improved patient care.

1.5 Patient and public involvement in research

Within research, it is expected that there will be patient and public involvement (PPI) to make the research process more effective and representative of the patients' needs (BSG 2018). PPI is key to undertaking any research and applying for research funding and increasingly recognised that the patient voice drives policy areas (Clempson, 2016).

Over recent years, the NHS, BSG, National Institute for Health and Care Excellence (NICE), National Institute for Health Research (NIHR) and pharmaceutical companies have become increasingly patient focussed, as they recognise the benefits of patient engagement to improve the quality of the research evidence (Pharmerit, 2020; NIHR, 2020; NHS, 2020; NICE, 2013). For example, all pharmaceutical company clinical trials have Patient Related Outcome Measures tools (Austin, *et al.*, 2019; Kingsley and Patel, 2017) to assist in the understanding of the degree of disease severity (Mokkink, *et al.*, 2010). NHS Ethics committees, where all pharmaceutical and local research studies must apply to, actively examine any research proposal that directly or indirectly relates to patients, and question whether patients were involved in the study design.

NICE involve patients when devising national guidelines and acknowledges that including them, “*adds value to the discussions of the independent committees and working groups that develop NICE guidance*” (NICE, 2013, pg. 2). Thus, the patient voice is essential as it assists in shaping the research, the guidelines, and the policies of the future.

On a personal level, over the decades I have witnessed a paradigm shift from doctors paternalistically dictating to patients, to the present day, where patients are becoming actively involved in their treatment. Nurses, on the other hand, have always been recognised as the patient advocate, and this advocacy, in the form of empathy, patient protection and being the patients’ voice, facilitates effective nursing care (Nsiah, Siakwa and Ninnoni, 2019; Davoodvand, Abbaszadeh and Ahmadi, 2016).

This thesis will evidence how listening to patient experiences and needs guided research and audit studies and assisted in the development of educational publications, all of which have advanced HCPs and patient’s knowledge of liver disease.

1.6 Aims and purpose of this thesis

This PhD by publication encompasses many years of academic research into liver disease which has generated new knowledge and offered guidance to health professionals, patients, and their carers nationally and internationally.

The aims of this critical appraisal are to demonstrate:

- the impact of my research, nursing practice and published papers in advancing health professionals’ knowledge of liver disease within national and international arenas

- that my research has improved standards of medical and nursing care in patients receiving treatment for liver disease
- listening and responding to patient experiences guides research and assists in the development of educational resources
- the impact of my research contribution and how this has influenced my professional standing

The first three aims follow-on from each other in a continuing cycle and could be described as part of a feedback loop to advance health professionals' knowledge (figure 1).

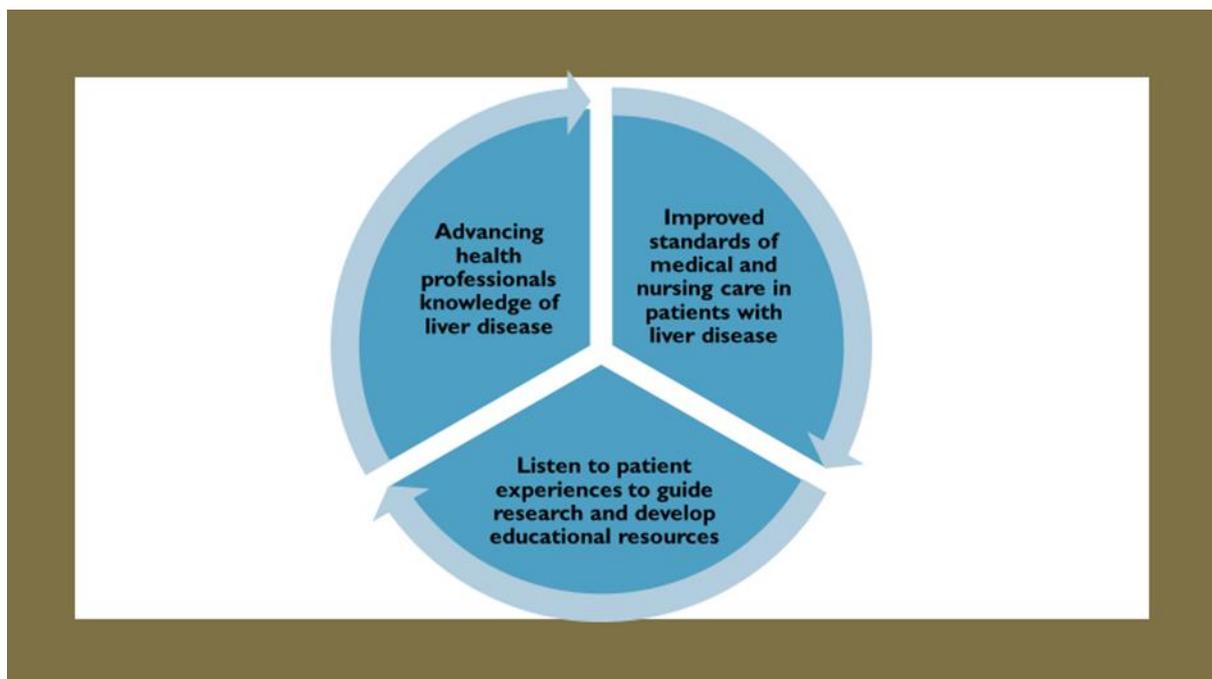


Figure 1: Aims of thesis as a continuous cycle

1.7 Three themes of the thesis:

This thesis is categorised through three themes and underpinned by Benner's *Novice to Expert* theoretical framework (1984), which was adapted from the *Dreyfus Model of Skill Acquisition* (Dreyfus and Dreyfus, 1980). Embedded within this critical appraisal I

reflect on my levels of clinical and research expertise: novice, advanced beginner, competent, proficient, and expert (Benner, 1984).

1.7.1 Underpinning theoretical framework and female icons:

Benner's 1984 framework has been applied by other health professions and has been extensively cited over the decades, the latest being Murphy and **Mortimore**, (2020); Hoover, *et al.*, (2020); Thomas and Kellgren (2017); McHugh and Lake (2010); Lyneham, Parkinson and Denholm (2008); Evans and Donnelly (2006); Meretoja, Isoaho, and Leino-Kilpi (2004). When Benner's theoretical framework was published in 1984, I was a student nurse and I distinctly remember the feeling of inadequacy as a novice nurse, working in my first ward, which was then called psychogeriatrics and my second ward in acute general medicine. However, this thesis will demonstrate that over time, as my knowledge and experience increased, I not only attained Benner's (1984) five levels of competence but surpassed them, to become an advanced expert and an internationally recognised researcher and policy influencer (**Mortimore**, Reynolds, Forman, Brannigan and Mitchell, 2021), (figure 2). Hence, applying Benner's (1984) framework aptly reflects my personal journey and is fully aligned to addressing the research journey explored in this thesis.

My research chronologically encompassed positivist, interpretivist, and latterly pragmatic paradigms, although on reflection, I feel I align more closely with the Pragmatic theorists/philosophers and in particular to Jane Adams. Much of her work was overlooked and associated with her male contemporaries such John Dewey, William James and George Mead (Stanford Encyclopaedia of Philosophy, 2018). This resonates with my own experience as a novice researcher, which I will expand on in Chapter 2. It is only relatively recently that Jane Addams extensive collection of

authored works has come to light, mainly thanks to feminist historians and philosophers, and these works clearly denote her intellect and progressive, pragmatic thinking (Stanford Encyclopaedia of Philosophy, 2018; Haight and Bidwell, 2016; Shields, 2006).

Although I admire Jane Adams, there is another important female icon that I deeply respect and that is Florence Nightingale. Although Florence was recognised as a statistician, with this work falling under the positivist paradigm, I would argue that she was one of the greatest female pragmatists before her time. Although most people associate her with the Crimean war; where she worked tirelessly to care for wounded British soldiers and improve cleanliness, sanitation, little focus has been given to her approach to health care in Derbyshire.

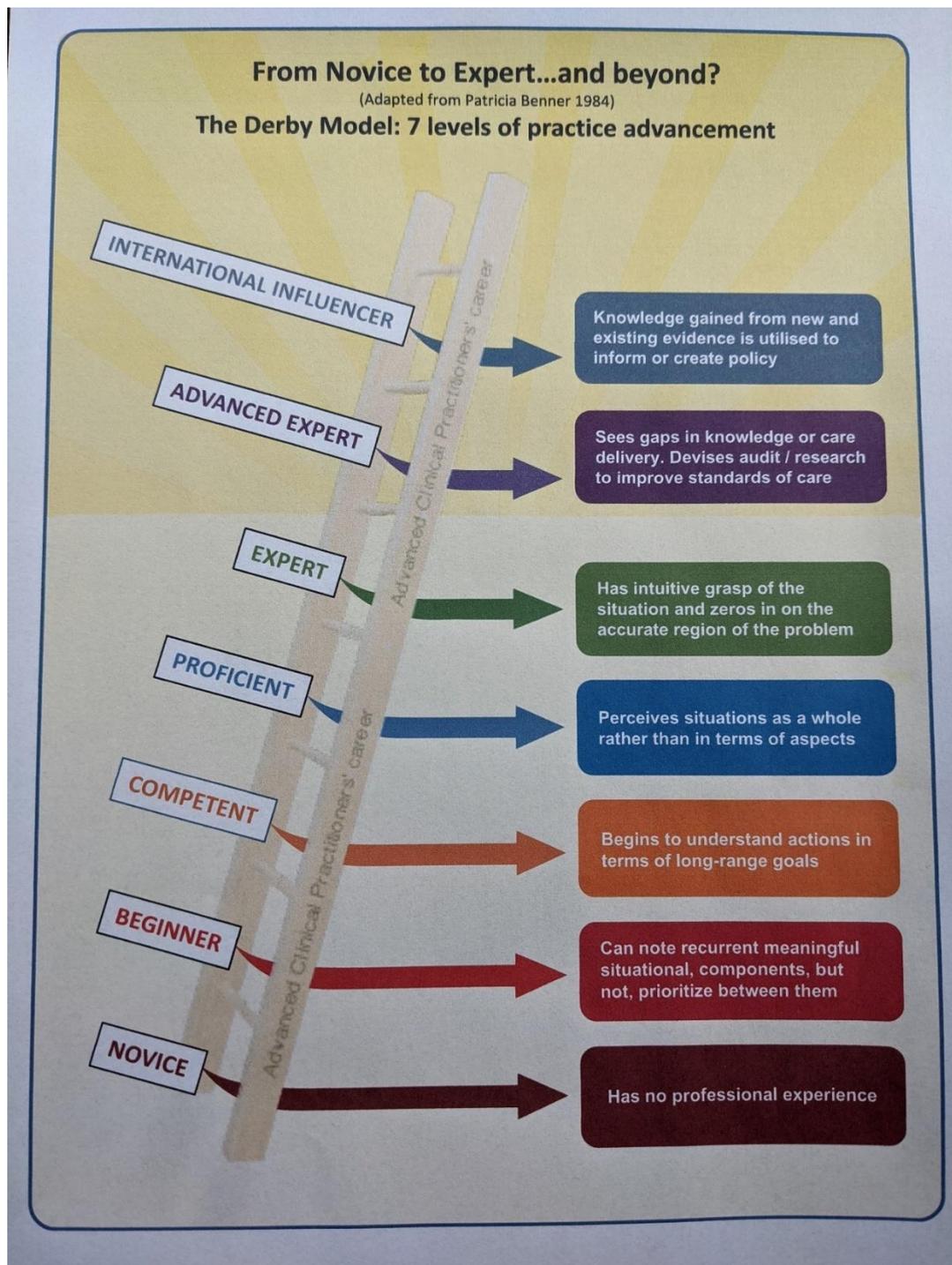


Figure 2: Derby Model: 7 levels of practice advancement (Mortimore, Reynolds, Forman, Brannigan and Mitchell, 2021)

Florence went against her wealthy family's wishes to become a nurse and arguably set up the first district nursing service in Derbyshire. She termed these nursing roles

as health missionaries (Middleton-Smith, 2020). Florence visited what she termed the “poorly poor”, gifting them food and ensuring that they were cared for. Moreover, she spoke with local and London doctors to discuss and diagnose patients under her care, paid to support several families for many years, bought a waterbed for one of her patients and sent another down to London to be treated, which again she financed. In addition, she ordered numerous public health interventions to prevent the spread of disease, writing letters chronicling the dangers of living next to, or above a cesspool, warning about the potential of the water being contaminated by sewage (Middleton-Smith, 2020). This clearly demonstrates Florence’s pragmatic approach, akin to Addams, using her wealth, intellect and status to improve the health and care of marginalised people in Derbyshire.

1.7.2 Theme 1: Nurse practitioner and researcher: from novice to expert

In chapter two, I provide a chronological evidence base of how my nursing and research experience developed from a novice to an advanced beginner, progressing through to a competent nurse researcher; recognising and collecting data that could potentially be utilised for audit and research purposes, through to a proficient researcher and expert nurse, where I recognised which data could contribute to research that would make a difference to patient care. It will evidence how I perceived gaps in health care knowledge, devised and led audit and research studies thereby demonstrating, in reference to Benner (1984), that I attained expert researcher status.

1.7.3 Theme 2: An influencer of national policy

In chapter 3, I evidence how my extensive knowledge of liver disease and the nursing care required to look after this cohort of patients was recognised by NICE and my expertise utilised to inform national clinical guidelines and Quality Standards. Additionally, this chapter demonstrates how my research into genetic haemochromatosis identified the lack of standardised venesection practice within the UK. Authoring of venesection guidelines, endorsed by the Royal College of Nursing (RCN), led to implementation of the guidelines as nursing guidance for the UK and has assisted in standardising nursing care nationally and internationally (Francis, **Mortimore** and HUK, 2020). This research played a significant role in demonstrating my transition into the expert level of competence (Benner, 1984).

Further exploration using my qualitative research study (**Mortimore** and Woodward, 2019) into genetic haemochromatosis, along with published articles regarding this subject and Venesection guideline (Francis, **Mortimore** and HUK, 2020) contributed towards an invitation to become a member of an All Party, Parliamentary Group in Genetic Haemochromatosis, thus, informing policy at a Government level. All these contributions evidence my expert status as a nurse, academic and researcher, and provided a platform to raise liver disease awareness to HCPs and increase the profile of the University of Derby.

1.7.4 Theme 3: An academic nurse practitioner and expert researcher delivering best practice in the clinical setting.

Chapter four demonstrates how, as an academic and nurse practitioner, my published articles have assisted in the advancement of HCPs' knowledge of liver disease and influenced my career and academic decisions. Moreover, it demonstrates how my publications have successfully increased my research reputation, as evidenced by my ResearchGate score which is 25.92 (appendix 2).

This chapter explores how my wealth of publications has led to invitations to speak at national conferences and local and national BBC radio interviews, all of which contributed to successful applications for funding to continue with research projects. It will additionally evidence how my research reputation drew the attention of international pharmaceutical companies who requested my services to act as a consultant advisor on several research and teaching projects, and how I continue to receive requests by editors to publish in national journals thereby increasing knowledge dissemination. This knowledge and expertise are currently used to educate HCPs undertaking their MSc in Advanced Clinical Practice.

My contribution to national and international policy and research supports the PhD by publication route. The aims will be achieved through the presentation of nineteen publications to create a coherent study that evidences the development, synthesis, and dissemination of my research into liver disease listed on pages 6-8.

Chapter 2: Theme 1 - Nurse practitioner and researcher: from novice to expert

2.1: Nursing and research journey

This chapter will reflect on my nursing and research career, commencing as a novice nurse and researcher in the 1980's and 1990's respectively, where I did not fully appreciate that patients' knowledge, concerns, needs or educational requirements could help shape research hypotheses, or that these early research experiences would form the basis of my research philosophy. Additionally, this chapter will explore my first publication, what this meant to me and how it ignited my interest in research. As my insight into research developed, I recognised the value of data which I utilised for audit purposes and the findings of which, changed practice at the local hospital Trust. As my expertise grew, I recognised gaps in health care knowledge which enabled me to devise and lead on my own audit and research projects to advance understanding but most importantly improve the care delivered to patients.

On reflection of my nursing career commencing in 1982, as a novice student nurse, I realise how my career, research, personal life, and environmental experience augmented my own knowledge base. According to Knowles, *et al.*, (2015), a learner requires to be motivated, the greater this determination, the greater the depth of learning.

2.2 Novice researcher

My desire and curiosity for knowledge and skills for use in clinical practice (Knowles, *et al.*, 2015) paved the way to learn new skills and in the late 1990's, I assisted in biological research undertaking: Enzyme Linked Immunosorbent Assay (ELISA) to measure levels of cytokines and preparing human liver for slide fixation and staining for microscopic examination. This meant I had to go into the operation room to collect

the freshly removed liver, to weigh and then prepare for staining. This was unusual work for nurses to undertake and although I considered myself a “proficient nurse”, according to Benner’s Novice to Expert (1984) concept, I was a “novice” in terms of my research experience (figure 2). This was evidenced by the fact that although the laboratory work was pivotal to the research projects, and as there were only three people undertaking the laboratory work; the first and second author and myself, I was not included as an author on the final published research articles. At that time this did not cause me concern. I was happy to undertake the tasks I had been given as the doctor’s nurse assistant and as a nurse, I did not expect my name to be placed on published medical research. Only now, on reflection, I appreciate that this oversight should not have occurred. From an epistemological perspective, “I didn’t know what I didn’t know.” Philosophers such as Rorty (1979), consider that epistemology is pivotal to science as it offers a vantage point from which we can evaluate our claims to knowledge. My acceptance of the then “status quo” of nurse handmaiden to the medics (Summers, 2010), identified my lack of critical thinking and from an epistemological perspective, I could not be expected to develop or produce change as evidenced by the Dreyfus and Dreyfus (1980) and the works of Benner (1984).

2.3 Reflection

Reflecting on my novice approach to research, Korthagen (2004) states that reflection is vital for personal development and helps develop clinical reasoning and critical thinking. Smith, Brown, and Crookes, (2015) concur and additionally add that reflection allows the person to analyse the evidence and in so doing, creates new knowledge and experience. Creating this new knowledge is one of the corner stones behind the learning theory of Malcolm Knowles, *The Four Principles of Andragogy*, (Knowles, et al., 2015).

Reflection is actively encouraged amongst health care professionals and there are many reflective models on which to base a reflective account (Kolb, 2015, Driscoll, 1994; Gibbs, 2008, 1988). With regards to nurses, reflection is now a crucial and mandatory element of their three-yearly revalidation with the Nursing and Midwifery Council (NMC, 2019). It was through reflection on my career, that I realised that it would be advantageous to undertake a university degree, in line with all newly trained nurses who qualified with either a degree or diploma. In 2004, I was successfully awarded a BA (Hons) in Health Studies.

2.3.1 Professional impact

In 2002, I was appointed to a senior H-grade position as a lead Clinical Nurse Specialist working in hepatology and my success was attributable to my prior experiential learning (Kolb, 2015) and the fact I was undertaking a degree. Being awarded H grade status was an acknowledgement that I had entered the fifth and final stage of Benner's (1984) framework of expert nurse status (figure 2).

2.4 First publication

In 2006, in recognition of my extensive input into anaesthetic research projects from 1998 to 2002, I was placed as first author on the published research findings titled, "*Perioperative Nimodipine and Postoperative Analgesia*" (**Casey [Mortimore nee Casey]** *et al.*, 2006). The hypothesis of this research was that Nimodipine, a calcium channel blocker would enhance the antinociceptive properties of Morphine therefore, prescribing patients nimodipine pre- and post-operatively would reduce overall pain. This would be confirmed by improved pain scores and a reduction in overall post-operative Morphine consumption. Interestingly, the findings demonstrated that although there were no significant differences in pain scores between the groups prescribed Nimodipine and those that were not, for those that were prescribed

Nimodipine there was increased Morphine consumption after 12 hours. This suggested that in patients receiving knee replacement surgery Nimodipine had no additional analgesic effect and, in contrast to the hypothesis, may inhibit the analgesic effect of Morphine.

According to Sandercock, (2012) research findings suggesting no effect or opposite effect are deemed negative results and according to Dwan, *et al.*, (2013) and Fanelli, (2012) negative results appear to be not published; estimated to be approximately 50% of all published articles, or selectively published thereby introducing bias towards specific aspects of the study. Smith (2006) argued that the editorial peer review process is strongly biased against 'negative studies' and is the reason why researchers do not publish their findings. Selectively publishing can cause huge issues in relation to evidence-based medicine, as HCP's and policymakers making decisions on treatment and/or writing guidelines based on flawed evidence could cause serious harm. In comparison, the benefits of publishing results that contradict the hypothesis can help other researchers to adapt their research methods to increase their chances of success (Mlinarić, *et al.*, 2017).

2.4.1 Professional and Research Impact

My lack of appreciation regarding the significance of being a published author highlighted my advanced beginner (Benner, 1984) understanding to research. At the time, although delighted of having my first publication, it did not occur to me that we may be advancing that field of research (Kelly, Sadeghieh, Adeli, 2014; Rawat and Meena, 2014). To date this article, "*Perioperative Nimodipine and Postoperative Analgesia*" has been cited sixteen times (**Casey *et al.*, 2006**) in national and international journals thereby evidencing worldwide dissemination (appendix 1).

Although this article was not related to liver disease, the publication ignited my interest and enthusiasm for academic research. This article was pivotal, as it heralded a paradigm shift (Kuhn, 2012) in the nascent inception of my critical thinking and gave me the inspiration to expand my nursing and medical knowledge and the confidence to write articles for publication in peer reviewed journals, showcasing my expert knowledge in the field of liver disease. Moreover, it taught me that if the findings contradicted the hypothesis, it is still important to publish and disseminate, to aid other researchers in that field.

2.5 Data collection

In the 1990s and early 2000, academic nurse research was not high on the nursing or local National Health Service (NHS) agenda, although attempts were being made to redress the balance (DOH, 2012; UKCRC, 2007). These reports clearly outlined the barriers for nurses trying to undertake research such as: *“clinical workloads..., an anti-academic culture in the nursing profession..... lone working, poor appraisal systems and very limited education and training opportunities”*. In addition, the report noted that *“nurse researchers were unlikely to be supported by academic departments of nursing, if the work was under the command of other health professionals”* (UKCRC, 2007, pg. 17, 18). Instead, based on my expert knowledge I developed an appreciation of how knowledge could be developed, or noted gaps in knowledge that could be investigated to benefit patients, carers and HCPs and I commenced collecting relevant data for potential audit and research. This is supported by Cottrell (2017, P4) who states that *“advances in knowledge and professional practice are made through recognising where improvements can be made to what has gone before.”* In relation to nursing, skills through experience, are a prerequisite for becoming an expert nurse as reflected in Dreyfus and Dreyfus (1980) and Benner (1984) writings.

Collecting data sets was attributable to my desire and curiosity for knowledge and skills for use in clinical practice (Knowles et al., 2015). The collated data was pivotal in the following research Rye *et al.*, (2016); Rye, *et al.*, (2012); White, *et al.*, (2011); Li, *et al.*, (2006a, 2006b).

The data was utilised in the prospective audits (Li *et al.*, 2006a, 2006b) examining liver biopsy practice, related adverse events and patient usage of post-operative analgesia. The findings were published in the *Journal of Hepatology* which in 2019, had an impact factor of 20.582.

2.5.1 Purposive sampling

Data gathering is crucial in research and in the prospective audits Li *et al.*, (2006a, 2006b), and in the retrospective study, White, *et al.*, (2011) purposive sampling techniques, a form of non-probability sample was chosen (Etikan, Musa and Alkass, 2016). These patients were specifically selected because they were either undergoing a liver biopsy or they were homozygous for the H63D variant of haemochromatosis. According to Patton (2014) focussing on the similarity of the participants allows researchers to generalise the findings from the evidence gathered. However, it could be argued that by using homogenous purposive sampling it is too subjective and there is an element of researcher bias in choosing specific subjects for the study (Braun and Clarke, 2013). (Please see Chapter 4.1, for additional comments regarding the Li *et al.*, 2006a, 2006b, White, *et al.*, 2011 and Rye *et al.*, 2012 publication authorship).

2.5.2 Professional impact

The recognition of where improvements could be made to patient care, also known as critical thinking (Kuhn 2012), allowed me to deliberate what data could be collected, as evidenced in the above studies, which had a positive impact on patient care. Reflecting on Benner's (1984) theoretical model this evidences that professionally I

transitioned through the competent stage and was now proficient with regards to research (figure 2).

2.5.3 Research impact

These audits were published in eminent international journals for worldwide dissemination thereby contributing to the body of research and evidence-based medicine. Additionally, they were presented at the annual British Society of Gastroenterology meeting allowing dissemination of the research thus increasing my academic reputation.

This research changed medical practice and improved patient care within the University Hospitals of Derby and Burton Foundation Trust (UHDBFT). The prospective audit of liver biopsies by Li *et al.*, (2006a, 2006b) noted a reluctance by radiologists to use a wider bore liver biopsy needle because of the possibility of adverse events such as haemorrhage (O'Neil Machado, 2011). The findings of this research revealed that not only did the larger bore needle provide superior histological samples for analysis, but the smaller gauge needle gave samples that were often inadequate for assessment. This meant that some patients required a further liver biopsy to confirm a diagnosis which increased their risk of complications. In addition, it was reasonably postulated by some medics that using a larger gauge biopsy needle would cause increased postoperative discomfort and adverse events compared to using the smaller gauge needle. In contrast, the audit revealed that there was no statistical difference between the two groups regarding post-operative pain or adverse events. These findings changed radiology practice in UHDBFT, who now opt to use the larger gauge needle, giving improved histological samples and reducing the risk of additional biopsies to the patient.

In the White, *et al.*, (2011) study we examined patients who were diagnosed as H63D homozygotes over a 4-year period. H63D homozygotes for genetic haemochromatosis are noted to carry a small risk of developing iron overload compared to C282Y homozygotes. Therefore, H63D homozygotes are often not given long term medical follow up (Kelley *et al.*, 2014; EASL, 2010) and in France, H63D genotyping is not requested (Fitzsimons *et al.*, 2018).

The findings revealed that 38% of H63D homozygote patients were histologically proven to have iron overload on liver biopsy. The study concluded that iron overload is still encountered in clinical practice and not related to an increase in ferritin due to an acute reactant phase and should therefore not be discounted. The results of the study led the hepatology unit to advise that all H63D homozygote patients, who do not require immediate venesection, to donate blood via the blood transfusion service and have ferritin and transferrin saturation levels checked yearly to two yearly by their general practitioner, with suggested referral back to secondary care if ferritin levels or transferrin saturation levels increase despite blood donation. This was in contrast to advice given in EASL (2010) haemochromatosis guideline.

2.6 Advanced Clinical Practitioner

Benner's nursing theory (1984) proposes that over time, with experiential learning and appropriate education, nurses develop expert skills and understanding of patient care. This is evidenced within my own personal journey. After completing my MSc in 2010, and Leadership and Management course in 2011, my role as a nurse specialist developed further into an advanced clinical practitioner (ACP). Advanced clinical practice is defined by Health Education England (HEE) as "*... a level of practice characterised by a high degree of autonomy and complex decision making.....underpinned by a master's level award.....*" (HEE, 2017; pg. 8).

After hearing multiple accounts of poor experiences from patients undergoing therapeutic paracentesis, I recognised the requirement to improve the service and patient care offered to this group of patients. After approval from the hospital audit department, I devised my own audit and employed the findings to author a business case for a nurse-led paracentesis service.

The business case proposed that if my nursing team undertook the paracentesis procedure rather than junior doctors, it would improve the patient journey and potentially save the Trust tens of thousands of pounds a year in inpatient overnight stays, save doctors time, and allow patients if medically fit to be discharged on the same day. This business case was presented to the senior management of the local Trust and approval was immediately given to set up and manage a nurse led paracentesis service after appropriate training.

2.6.1 Professional Impact

Cottrell's (2017) acknowledges that recognising where improvements are required, advances knowledge and practice. LoBiondo-Wood, Haber and Titler, (2019) concur, and supported by reports from Titler, (2014) and Strauss *et al.*, (2019) who state that the thoughtful use of current evidence combined with clinical experience and patient ideals, where appropriate, can guide health care decisions. It has been further recognised by Lunenburg, (2010), that any individual who initiates and manages change within an organisation is known as a 'change agent'. Orchestrating and managing the paracentesis service to benefit the service users, based on collated evidence, clearly demonstrates that I was a 'change agent', a leader and highlighted my critical thinking, aptitude, and interest to improve evidence-based practice thereby evidencing not just expert nurse status (Benner, 1984) but working at an advanced

expert level (figure 2) demonstrating all four pillars of advanced practice: clinical, leadership, research and education (HEE, 2017).

2.7 Reviewing the literature

Healthcare decisions for patients should be informed by the best available research evidence (LoBiondo-Wood, Haber and Titler, 2019; Strauss, *et al.*, 2014) and this integration of the best available evidence, clinical expertise and patient values is termed evidence-based medicine (EBM). To ensure that EBM is delivered to a high standard, it is necessary for HCPs to keep abreast of new clinical evidence. According to Aveyard, Payne, and Preston (2016) and Gopalakrishnan and Ganeshkumar (2014), reading clinical guidelines and systematic reviews are a robust approach to assuring this practice.

In the review article titled, “*Towards non-invasive detection of oesophageal varices*” (Rye, *et al.*, 2012) a review of the literature was undertaken to examine and compare non-invasive ways to detect oesophageal varices, as opposed to the Gold standard of oesophago-gastro-duodenoscopy (OGD) in cirrhotic patients (Tripathi, *et al.*, 2015). The review reflected on the dependability of different screening tests. Current guidelines recommend that all cirrhotic patients are screened for varices at diagnosis and followed-up either annually, or two to three yearly depending on size of varices and requirement for prophylactic medical treatment (EASL, 2018).

Routine surveillance causes a huge burden on endoscopy units and regular OGD’s in some patients, can have a detrimental effect on compliance (Garcia-Tsao, *et al.*, 2007; Merli, Nicolini, Angeloni, 2003). Moreover, Rye *et al.*, (2012) acknowledged the variable inter-observer reliability for agreeing the presence and grading of the size of oesophageal varices at endoscopy and this was demonstrated by a large variation in Kappa values. This was an important observation, as reliability and validity are used

to evaluate the quality, accuracy and trustworthiness of research processes and findings, in order to avoid misleading those that wish to utilise the research (Roberts, Priest and Traynor, 2006).

The clinical review by Rye *et al.*, (2012) concluded that despite the availability of clinical, radiological, and novel biochemical markers as a non-invasive means to diagnose varices, none were accurate enough to avoid endoscopy. Therefore, this review resulted in the confirmation that endoscopy remains the Gold standard screening tool for diagnosing varices despite its recognised limitations such as the cost to the NHS and unpleasantness for the patients.

2.7.1 Research Impact

This review assimilated and summarised the best available evidence which, according to Aveyard, Payne and Preston (2016) makes it valuable. Although this article did not highlight a non-invasive test comparable to OGD it did recommend that further research into this area was required. Since its publication, it has been cited forty times in national, European, and international medical journals evidencing the impact and quality of this review (appendix 2).

2.8. Non-invasive Diagnosis of Oesophageal Varices

Following on from the Rye *et al.*, (2012) review article, I was involved in further novel prospective medical research, investigating non-invasive means of diagnosing oesophageal varices measuring systemic haemodynamics by Finometry, compared with other non-invasive predictive scores (Rye, *et al.*, 2016). Although the aim was to assess if the Finometer, as a non-invasive means was accurate in predicting varices, it required all patients who consented into the trial to undergo invasive endoscopy and portal pressure measurements assessed by measurement of the hepatic venous pressure gradient. This necessitated puncture of the jugular vein and a catheter

inserted to pass through to the superior vena cava until it reached the hepatic vein of the liver.

In the Rye *et al.*, (2016) study, a Swan-Ganz catheter was required to pass through the heart to reach into the inferior vena cava then into the hepatic vein. Once in the hepatic vein, rather than one measurement being taken, a minimum of three hepatic wedge pressure readings were taken and averaged. This was crucial to the accuracy of the study and ensured the reliability and validity of the wedge pressure measurements.

According to Spieth, *et al.*, (2016) and Wunsch, Linde-Zwirble and Angus (2006), choosing the appropriate study design is pivotal to produce accurate data that can be translated into clinical practice. The Rye, *et al.*, (2016) study, the methodology and methods were clearly defined ensuring the research was reproducible, thereby improving its validity. However, it was acknowledged that larger studies were required to include patients independent of their prescribed medication and co-morbidities to validate the research findings.

Selecting the correct statistical method is of paramount importance in quantitative studies as the inappropriate use of statistical techniques may lead to erroneous conclusions, which would undermine the significance of the findings within a research study. These findings would not only be misleading but could be construed as unethical or lead to unethical practice (Ali and Bhaskar, 2016; Sprent, 2003). Therefore, the correct statistical analysis is part of the rigour in the validity and reliability of quantitative research studies. In the study undertaken by Rye, *et al.*, (2016) the support of the hospital statistician was requested.

The patient cohort groups were split into two groups. Group One, diagnosed with absent or small varices, N=18 and Group Two, who were diagnosed with medium to large varices, N=11. The OGD were undertaken by an experienced endoscopist who classified the size of the varices. The classifications were confirmed by a second clinician who observed the procedure to verify the results thus, increase reliability and validity and reduce bias. The differences between Groups One and Two were compared using a Mann-Whitney Test and associations between the variables was assessed by the Spearman correlation coefficient. The statistical analysis was undertaken using Analyse-It for Microsoft Excel (version 2.21). *P* values of less than 0.5 were considered statistically significant. Findings revealed that there were significant associations with Child Pugh score, cardiac output, cardiac index, hepatic venous pressure gradient and peripheral resistance with large oesophageal varices.

2.8.1 Research Limitations

Limitations of the study research were clearly articulated in the Rye, *et al.*, (2016), however, this was with hindsight, after study completion. The study acknowledged conditions that would affect systemic haemodynamics, such as the existence of hypertension or prescription medications, which occur frequently in the general population, but were excluded, potentially limiting the applicability of the test to a wider population, hence population bias (Gola, *et al.*, 2020; Pannucci and Wilkins, 2010). In addition, patients who consented underwent invasive procedures; they were required to have an additional endoscopy to confirm size of varices as well as undergo a neck vein puncture with the associated risks of haemorrhage and haematoma formation and the added risk of heart arrhythmias during the procedure. As only twenty-nine patients consented for the study it was acknowledged that larger prospective studies were required to validate the findings. However, the cost of the Finometer and finger

probes required to undertake beat-to-beat measurements as opposed to cheaper non-invasive tests may deter its widespread use across NHS Trusts.

2.8.2 Ethical considerations

The '*Non-invasive Diagnosis of Oesophageal Varices Using Systemic Haemodynamic Measurements by Finometry: Comparison with Other Non-invasive Predictive Scores*', Rye et al., (2016) study required patients who consented to participate to undergo invasive procedures as discussed in chapter 2.8. Any research study requires all potential risks to be explained to the participants and written, informed consent to be taken. All patients who consented to participate in this trial were fully aware of the invasive nature of a neck puncture, the possibility of developing cardiac arrhythmias or haematoma formations in the neck and the requirement of an additional OGD. It is widely acknowledged that informed consent requires patients to receive appropriate and accurate information regarding the study in a language that is easily understood for any potential participant and complies with data protection law (Dankar, Gergely, Dankar, 2019; Information Commissioner's Office 2018; Chan, *et al.*, 2017).

I was well known to the hepatology patients and well liked. An ethical consideration was that I had to ensure that my relationship with the patients did not unduly influence their decision to join the research trial. This was resolved by not allowing patients to sign up for the study immediately but instead were provided with an information sheet to share with their loved ones. After seven days, they were approached by a different researcher, given the opportunity to ask questions and if they were still willing to participate in the study, the consent form was signed.

All research studies undertaken within the Trust including the Rye *et al.*, 2016 had to apply through the Integrated Research Application System (IRAS), be approved by an

English research committee as well as be approved by the local hospital ethics committee before the research could commence.

2.8.3 Professional Impact

Personally, it was a privilege to be involved in pioneering medical research. I gained experience in the use Swan-Ganz catheters to obtain hepatic wedge pressures. My clinical expertise as a nurse and prescriber came to the fore when three patients developed supraventricular tachycardia and I prescribed and administered intravenous medication to correct this, after first initiating vasal vagal manoeuvres to slow down their heart rate (ACLS, 2020; Smith, 2012). Being pivotal in medical research studies demonstrated my development into a proficient researcher according to Benner's framework (1984) (figure 2) and instilled confidence to consider undertaking my own research study.

2.8.4 Research impact

The findings suggested that using Finometry could identify cirrhotic patients that do not require endoscopic surveillance for varices, thereby lessening the burden on endoscopy units. The results also suggested that Finometry had an improved diagnostic value than other non-invasive markers such as platelet count or Child-Pugh score; a scoring system to measure the severity of liver disease.

2.9 Genetic haemochromatosis: a qualitative exploration of patients' experience of diagnosis, treatment and management

My many years of treating patients with haemochromatosis allowed me to hear their personal stories of the time it took to be diagnosed with the condition and the anxiety that this diagnosis caused them, especially when informing other close family members. Listening to the patient voice was the primary reason that I undertook research to study patients lived experiences of being diagnosed with

haemochromatosis. Despite the prevalence of genetic haemochromatosis, only 1:5000 people are diagnosed with the condition in the UK (HUK, 2019; BLT, 2017). However, once diagnosed, treatment is lifelong. To date, there is a paucity of research examining patients' thoughts and experiences of being diagnosed with haemochromatosis and the effect this may have on their lives and immediate family.

2.9.1 Study design and methods

The aim of the study was to explore patient perceptions, perspective, and experiences of those living with genetic haemochromatosis; including how and when they were diagnosed. This was to ascertain how and when patients were first diagnosed with the condition, the effect of their diagnosis on their ontological security, their experience of living with the disease, the effect if any, on their family or loved ones as well as examining the patients' experience of receiving treatment.

Purposive sampling was employed to recruit participants from the local hospital. All participants volunteered after responding to a poster advertising the research study. Data was collected from twenty-four patients using semi-structured interviews, using broad themes. The interviews were recorded and transcribed verbatim. This was analysed using thematic analysis.

2.9.2 Emerging themes around diagnosis

Two themes emerged from the interview process around the participants diagnosis. The first was regarding the length of time it took for a diagnosis to be made and the second was the perceived lack of knowledge and information given about the condition from the GP. These findings were articulated in an academic poster (**Mortimore** and Woodward, 2019), (figure 3), and exhibited at the Royal College of GPs annual, three-day conference in 2019.

Background

- Genetic haemochromatosis (GH) is the most common inherited genetic disorder in Caucasians (Bacon et al. 2011), and commonly affects Northern Europeans, especially those with Celtic or Nordic descent, with a ratio of approximately 1:220 - 250 people (Fitzsimmons et al. 2018; Phatak et al., 2008). Despite the prevalence of GH only 1:5000 people are diagnosed with it (Haemochromatosis UK [HUK] 2019; British Liver Trust [BLT] 2017).
- In GH the body absorbs excess iron which can lead to systematic iron overload within the liver and other internal organs such as the pancreas, heart and joints; eventually causing inflammation and tissue damage. Early symptoms are non specific such as fatigue, abdominal and joint pain and as such, may be considered inconsequential by GP's, resulting in a delay in diagnosis and treatment.
- To date there has been little research examining patient's thoughts and experiences of being diagnosed with GH, a disorder which requires life long treatment with venesection, and which may lead to cirrhosis of the liver and increased risk of hepatocellular carcinoma (Ulvik 2015).

AIM

Explore patient experiences of living with Genetic Haemochromatosis and the diagnosis process and treatment

Design

- Data was collected using semi-structured interviews with a sample of 22 patients with haemochromatosis who responded to a poster advertising the study
- The interview covered their experience of diagnosis and treatment and the effect it was having on their lives
- Patients had been diagnosed between a year and more than 30 years The interviews were recorded and transcribed verbatim. Analysis of the data was conducted using thematic analysis.



....I went to see a female doctor and she said to me your iron levels are up and we think you may have haemochromatosis....actually I don't know much about haemochromatosis but I do know you need to have blood taken

Picture 1: Patient undergoing venesection

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Results

Emerging Narratives around Diagnosis

There were number of common themes that came out of the interviews around the diagnosis process. Firstly, participants talked about the time taken before a diagnosis was made and a perceived lack of knowledge and information from GP about the disease

my joints were aching mainly and my right hand side of my chest....I thought there was something not right here so I kept going back to the doctors to get a load of blood tests ...and this particular doctor I was seeing said, I can't seem to find anything wrong with you.... And I thought there was something wrong with me. I can feel it inside of me

Time taken for diagnosis

Although a handful of patients were diagnosed relatively quickly, most patients interviewed talked about experiencing a delay, in some cases of many years, from first presentation of symptoms to their GP to final diagnosis.

No. Well he wouldn't know anyway because his knowledge about the subject, because I know I went back about something else and I said to him oh by the way I've got this haemochromatosis. "Oh what's that then?"

I didn't ask the doctors no, it was kind of, I suppose you lose a bit of confidence when you are watching them read Google in front of you as to what it is. And I know they have probably got the background and maybe they have got more that they can access but I didn't go back, it was pretty much she just handed me over

Knowledge and Information from GP

Many of the patients felt that GPs lacked knowledge of genetic haemochromatosis and talked about how GPs were unable to give them any detailed information about the disease .

Discussion

- Early detection and treatment for GH depends on increased knowledge of GPs. This qualitative study identified that patients perceive there to be gaps in understanding GH diagnosis and treatment. Ensuring GPs are aware of GH and the strategies for diagnosis could result in improved patient care.

Relevance

- These findings indicate that improved education for GPs regarding GH may be beneficial in order to improve patient care for this condition and potentially reduce delays in diagnosis

Figure 3: Genetic haemochromatosis: a qualitative exploration of patients' experience of

diagnosis. Presented at RCGP annual conference in October 2019. Authored by Gerri Mortimore and Amelia Woodward.

By doing so, highlighted the findings to several thousand attending GP delegates. This led to academic discussion with GP's, establishing that there was a consensus of agreement with the conclusions, thereby improving the study's validity and reliability of the findings.

Presenting quotations as exemplified below (figure 4) and those in the poster presented to RCGPs (**Mortimore** and Woodward, 2019) provided further evidence which supported and validated the findings (Miles and Huberman 1994; Gibbs 2008; Patton, 2014).

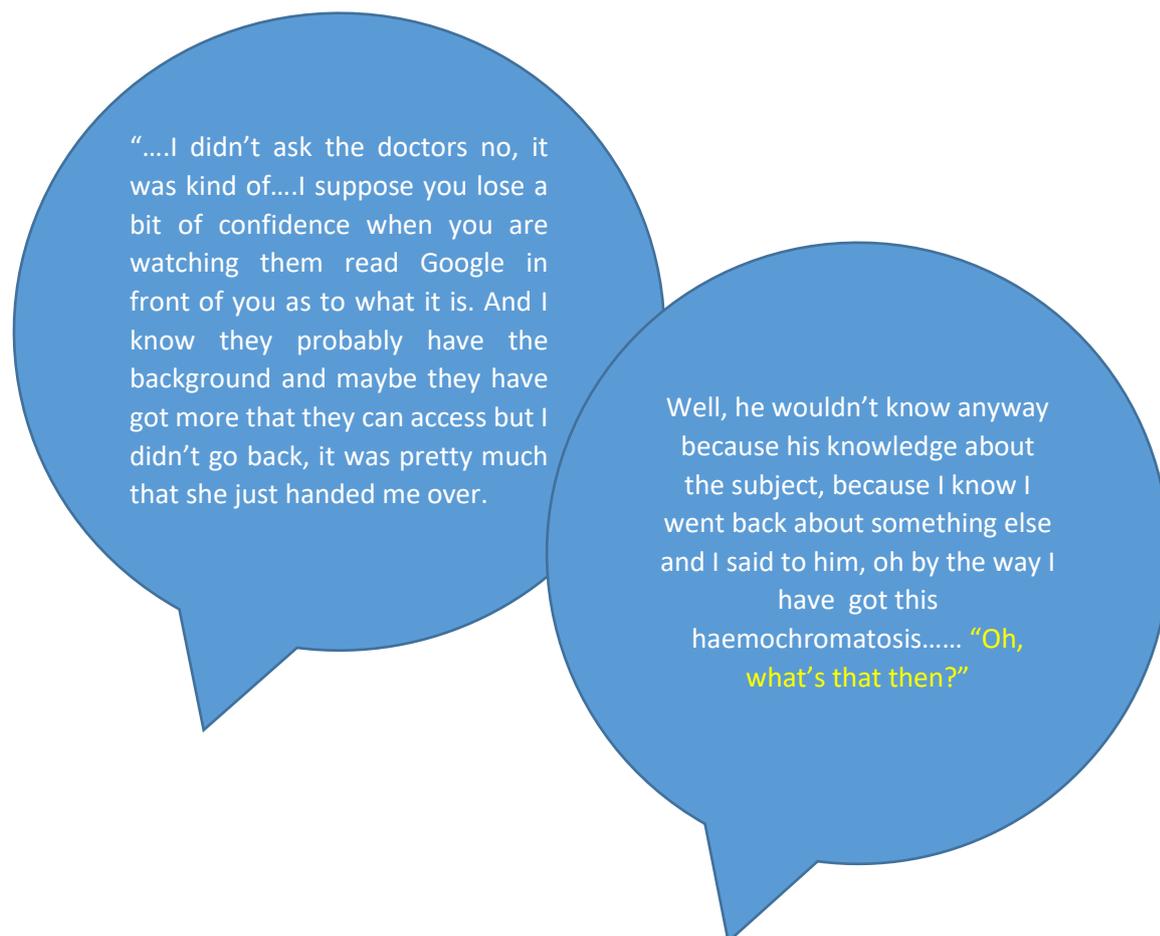


Figure 4: Direct quotes from patient transcripts

2.9.3 Limitations

According to Tobin and Begley (2004) the application of scientific accuracy in qualitative research supports reliability and competence. However, in contrast to this Sandelowski (1997) argues that rigour in qualitative research could suppress creativity. Thomas and Magilvy (2011) concur with this point, adding that rigour implies inflexibility and qualitative research is not rigid in design. It is recognised that qualitative research can be challenging to undertake as there are no accepted consensus regarding guidelines by which the research can be judged.

Bias can occur at any time throughout the research process. As the researcher plays such an active role in the research, there is always the risk that their individual beliefs and values may over influence the data collection and analysis and the research findings could be argued as a collection of the researcher's opinions (Papp, *et al.*, 2014), also known as insider or researcher bias (Greene, 2014). To avoid this, and certainly, pertinent to my qualitative research study "*living with genetic haemochromatosis*" (Mortimore and Woodward, 2019) the interview questions were open ended, to allow the interviewee to freely communicate without coercion (Mannix and Jones 2020; Braun and Clarke, 2013; Guest, McQueen and Namey, 2012). As I was the principal investigator, I was the interviewer in all the interviews. However, because of my interest in the subject of haemochromatosis, I could argue that although concerns could be raised regarding insider bias, my knowledgebase enhanced the study by allowing a greater insight into the phenomenon being studied. However, to minimise bias, all interviewees were invited to listen to the recorded interview, or read the typed transcriptions, with a different experienced researcher from the University research department. The interviewees could delete anything they did not agree with from the recording/transcript.

2.9.4 Professional impact

It is an achievement to undertake research from its conception; where I recognised the importance of listening to patients' concerns and felt empowered to change this for them.

As with all medical research studies the "living with genetic haemochromatosis" study required the completion of the Integrated Research Application System (IRAS) and after its successful completion, which required national ethical approval (appendix 3) local NHS trust ethical approval was sought and granted for this study. As the initial findings (**Mortimore** and Woodward, 2019) demonstrated a lack of perceived GP knowledge, this led HUK to organise UK wide GP webinars, which I personally present, adding to the dissemination of my research to health care professionals.

2.9.5 Research impact

The **Mortimore** and Woodward (2019) study identified that patients perceived gaps in GP's knowledge about haemochromatosis, its diagnosis and treatment. Ensuring that GPs are aware of genetic haemochromatosis and the strategies to diagnose the condition earlier can lead to improved patient care and lessen the long-term burden of chronic liver disease on NHS Trusts. The findings from this research study pathed the way for formal teaching sessions for GPs to be undertaken. Due to Covid-19 restrictions these teaching sessions were undertaken as live webinars, the content of which was to highlight early and late symptoms of haemochromatosis, the importance of the correct diagnostic tests and treatment as well as highlighting the preliminary findings from **Mortimore** and Woodward (2019) study. The highlighted fact that GPs knowledge of the haemochromatosis was poor has been used as evidence by HUK, and continuous professional development (CPD) teaching sessions, via the RCGPs' portal have been organised to highlight the condition, genetic haemochromatosis and

the strategies for diagnosis. Moreover, the findings from this study were presented to Parliament in February 2020.

2.10 Peer review

Within the academic and scientific community, peer review is an essential element of the writing process and is an effective form of research evaluation to help select the highest quality articles for publication (Kelly, Saneghieh, Adeli, 2014). All the publications within this thesis were submitted for double blind peer review, prior to publication (**Casey et al.**, 2006; Li *et al.*, 2006a; Li *et al.*, 2006b; Rye *et al.*, 2016; Rye *et al.*, 2012; Watson and **Mortimore**, 2019; **Mortimore**, 2018d; 2017b, 2017c, 2017d), NICE website (NICE [QS152] 2017; NICE [CG50] 2016; NICE [CG188] 2015a; NICE [QS104] 2015b; NICE [CG100] 2010).

2.11. Research Philosophy

Embarking on my research journey in the late 1990's, little thought was given to the underpinning research philosophy of the medical studies. However, I now appreciate how my beliefs, assumptions influenced the chosen research strategy and methodology of the research being undertaken. In Casey *et al.*, (2006); Li *et al.*, (2006a); Li *et al.*, (2006b); Rye *et al.*, (2016) a deductive approach was utilised, which falls under the positivist paradigm, associated with scientific research (Crossan, 2003). These studies investigated facts such as portal pressure measurements (Rye *et al.*, 2016), pain scores and morphine consumption (Casey *et al.*, 2006); biopsy needle size, pain scores and analgesic consumption (Li *et al.*, 2006a; Li *et al.*, 2006b) and tested hypotheses that emerged from those theories. As my understanding and insight of research developed, I realised when listening to patients views and anxieties, that from my own epistemological concerns, the medical research we were undertaking was not tackling their issues and another methodology was required.

In the “Living with genetic haemochromatosis” study (**Mortimore** and Woodward 2019), I explored the perceptions of patients living with haemochromatosis. I believed that phenomenology was the most suitable approach to this research as phenomenology seeks to describe the phenomenon by exploring it from the perspective of those who have experienced it (Manen, 1997). According to Lavery (2003), by examining subjective experiences, new meanings can be developed to inform how we understand that experience. From my personal axiological viewpoint, I placed great value on social interaction thus, interviews were my preferred method as they could provide a richness of data regarding patients views than an anonymous questionnaire. This understanding of research philosophy enabled me, as a researcher, in the later research of Francis, **Mortimore** and HUK, (2020) and **Mortimore** and McClements (2020; 2020a), to choose the most appropriate methodology and methods, changing to a Pragmatic approach. This will be discussed further in chapter 3.

2.12 Reflection

This chapter evaluated my research contribution and how this influenced my professional standing. It also evidenced how my published research has added to the body of knowledge in the form of EBM, and as such, is advancing health professionals’ knowledge of liver disease. This knowledge assists to improve the standards of medical and nursing care for patients receiving treatment for liver disease. Reflecting on my research philosophy, I am one of a few researchers who has undertaken quantitative medical research under the positive paradigm and, after listening to patient experiences, undertook qualitative research under the interpretivist paradigm. The knowledge gained from both was utilised to undertake research under the pragmatic paradigm leading to the development of national and international

guidelines and educational resources, which will be discussed further in the next chapter.

Chapter 3: Theme 2 - As an influencer of national policy

The previous chapter provided an overview of how my career and experiential research knowledge shaped and developed me from a novice nurse researcher into nurse expert within the field of hepatology. This chapter demonstrates how my research and expert knowledge has been utilised as a platform to advance health professionals' knowledge of liver disease and influence the public through my contribution to national guidance and direct dialogue with Government. A significant impact of this body of work has been raising the profile of liver disease on a national and international level.

3.1 Researcher Goal

A goal for any researcher is for their expertise and research findings to be used to inform and influence local, national, and international policy (Ellenbecker and Edward, 2016). In relation to the field of health and social care, informing and influencing policy may in turn improve, or even transform lives for the better. Although it is recognised that health policies are regularly developed, Wakefield (2009) acknowledges that these policies are frequently written and implemented without the evidence of research conducted by the nursing profession. The Institute for Government, the leading "think tank" which explores key challenges facing government, goes further to state that although academic evidence and expertise can inform and improve government policy, many academics find engaging with policy making, difficult and as a result, policy influence is often limited (Sasse and Haddon, 2019). Arguably, little has changed over the last twenty years as evidenced by Gough and Walsh (2000) and Hart (2004), who suggested that it was difficult for nurses to be seen as credible in strategic policy making. However, in contrast to these findings, I will evidence how my research has led me to be involved in national guidance, direct dialogue with

Government and authored reports which have been shared with not only the English, Northern Ireland, and Welsh Parliamentarians but also the Scottish Government and UK Blood Transfusion Service (BTS).

3.2 NICE Guidelines

Over the last forty years, the UK has witnessed over a 400% - 500% increase in mortality caused by liver disease, whereas death rates from other diseases have fallen (Williams *et al.*, 2018; PHE 2018; Williams *et al.*, 2015). This factor highlights liver disease and its treatment as an essential area for HCPs, Clinical Commissioning Groups and NICE to utilise evidence-based medicine to inform and advance care in these areas.

Clinical guidelines are born out of the systematic review of relevant and best available research literature which is paramount to avoid biased results (Polit and Beck, 2014; NICE, 2020a). This research evidence is assessed, examining both the harms and benefits of treatment options, clinical effectiveness, and projected economic implications, with recommendations intended to optimise patient care (Kredo *et al.*, 2016). Although Murad (2017), acknowledges that although guidelines are intended to improve patient care, guideline adherence is variable.

An integral component of NICE clinical guidelines is the advice and guidance from the invited health care experts involved in the topic. My expertise within the field of liver disease (as evidenced in Chapter 2) enabled me to be successfully selected as a member of the expert panel in the following guidance.

- Alcohol Misuse Disorders (CG 100, 2010)
- Gallstone disease (CG 188, 2015a)
- Liver Cirrhosis (CG 50, 2016, updated 2020)

In recent years, the increasing importance of systematic literature reviews in health and social care, to inform evidence-based clinical practice and health care has been acknowledged (Aveyard, Payne, and Preston, 2016; Polit and Beck, 2014; Bowling 2014). As evidenced, systematic literature reviews are an essential process in NICE guidance (NICE, 2014) and as such, NICE employ professional researchers to undertake this work. Whilst being involved in devising NICE guidance it became apparent that the reviewers were often not from a health background. Occasionally, the reviewers used incorrect or inadequate search terms. Our remit, as part of the expert panel was to review the search terms to minimise error; suggest published research, or research imminently about to published, or seminal published research which fell outside the “year” search parameters.

3.2.1 Professional Impact

NICE guidelines offer recommendations for the treatment and care of patients in England and Wales, based on the best available evidence thus, improving outcomes for patients, whilst ensuring efficient use of healthcare resources.

My many years of experience within the field of hepatology as well as my involvement in collaborative medical research led to my successful appointment as an expert advisor in NICE Clinical Guidelines. In addition, in October 2020, I received a formal letter of appreciation from NICE regarding my contribution of time and expertise into the development of the cirrhosis surveillance report, stating that my contribution informed NICE’s decision to update the NG50 guideline (NICE, 2016). The recommendations for an update have now been published on NICE’s website and promoted to guideline stakeholders, other relevant organisations as well as interested individuals.

My expert influence in developing NICE Guidelines means I have assisted in standardising the level of service delivery of care across England and Wales, enabling a patient centred approach to health care. I have used this knowledge to educate HCP's, within an HEI, knowing that by doing so, I am contributing to evidence-based medicine.

3.3 Quality Standards

In addition to my involvement in devising three national guidelines I assisted in developing NICE Quality Standards (QS) in:

- Liver disease (QS 152, 2017)
- Gallstone disease (QS 104, 2015b)

QS set out priority areas for quality improvement for health and social care and cover areas across England and Wales where there is a disparity in care. Each standard consists of prioritised measurable statements designed to support the measurement of improvement. QS are intended to improve the quality of care offered, although it is accepted that this may not always be appropriate in practice (NICE, 2020a) and consideration must be taken regarding professional judgement, safety, shared decision-making, and patient choice (NICE, 2020a; The Kings Fund, 2015). For example, regarding the QS on gallstone disease (NICE, QS 104, 2015b); quality statement 1: "*Adults with acute cholecystitis will have a laparoscopic cholecystectomy within 1 week of diagnosis*" (NICE, QS 104, 2015b, page 10). Due to the lack of operating department availability at the local NHS Trust, it was not possible to offer every patient admitted with cholecystitis a cholecystectomy within seven days of admission, which goes against direct advice within the quality standard.

3.3.1 Professional impact

By being directly involved in devising QS and through the implementation of my research, in particular Rye *et al.*, (2016); Rye, *et al.*, (2012); White, *et al.*, (2011) and Li, *et al.*, (2006a; 2006b). I have assisted in providing patients, carers, service providers and health care professionals with relevant definitions of high-quality healthcare directly related to liver and gallbladder disease.

In addition, my involvement on the expert advisory panel, with published NICE clinical guidelines and QS, supports the Government's vision on a health and care system focused on delivering best practice in patient care nationally (DHSC, 2012) and clearly demonstrates my direct impact on the outcomes of services being developed and delivered. It was because of my input into the three published NICE national guidelines and two Quality standards for England and Wales that I was formally awarded the title, "NICE Expert Nurse Advisor", thereby confirming my expert status.

3.3.2 Research Impact

NICE Guidance and QS are freely available to download from NICE websites for HCPs and lay people. They are referred to within all aspects of health care from primary to secondary care and community settings. NICE (2020b); DOH and PHE (2014) acknowledge that NICE publications influence national and international health policy. Consequently, being a member of the expert panels that devised NICE clinical guidelines and QS in liver disease, substantiates the fact that I have informed national and international policy.

3.4 Venesection Best Practice Guidelines

In 2017, as part of my on-going research activity, I contacted the charity, Haemochromatosis UK (HUK), to inform them of my proposed qualitative study examining the patient's experience of living with Genetic Haemochromatosis (GH).

With the patient voice in mind, I requested if HUK were satisfied with the planned themes I was proposing to explore from a patient perspective. According to the NIHR (2020) and Hørder, Konge and Nielsen (2020), patient insight into research design brings many benefits, including providing a unique awareness into living with the condition, highlighting points that may not have previously been considered to the researcher and helping to identify problem areas that potentially may be off-putting or restrictive for patient participation in the trial. HUK were delighted to endorse my study and stated that any research that raised the profile of haemochromatosis was of benefit.

It was because of HUK's knowledge of my qualitative research study and my interest and expertise regarding GH, as evidenced by my published articles **Mortimore** (2017b); White, *et al.*, (2011), that I was approached by the charity in 2018, to assist in devising venesection guidelines for the UK, where no such provision existed. These guidelines were several years in the making as it required evidence, obtained from nurses and patient experiences from across the UK and Ireland. Best Practice study dates were arranged in 2018 and again in 2019, to reach a consensus of what was considered good practice, in relation to venesection procedure and care. Comparisons of local venesection guidelines from around the UK, and additional data gathered at these study days highlighted that patient experience differed widely, which has serious implications for patient care and safety. These implications were dependent on the diversity of nursing care delivery, its commissioning, equipment used and environments for venesection, including blood disposal which varied around the country. The NMC Code (2018); Hallam, *et al.*, (2016) and Loveday, *et al.*, (2014) acknowledge that it is the health care professionals' responsibility to ensure that each patient receives best possible safe care and treatment.

3.4.1 Professional Impact

The Venesection Best Practice Guideline (VBPG), (Francis, **Mortimore**, HUK, 2020) address the shortfalls highlighted during the Best Practice Study Days and by listening to the patient voice, aim to improve the quality and safety of patient care and experience. Additionally, it demonstrated collaborative working with a national charity and has assisted in standardising the care of thousands of patients undergoing venesection every year not just haemochromatosis but polycythaemia; primary and secondary, and transfusion related iron overload.

This guidance published in January 2020, was endorsed by RCN, signifying that it conforms to the RCN quality criteria for professional standards and is deemed suitable for national UK nursing practice (RCN, 2020). As the VBPG has this endorsement, this publication is permitted to use the RCN's logo.

This VBPG project won awards from two major organisations, the Patient Safety Learning and The Patient's Association, working for the wellbeing of hospital patients. As cited in the University of Derby's Press release on the 22nd June 2020, and reiterated in the Nursing Notes website, the venesection guideline is *"a testament to the skill and thoroughness of the authors that this guide has now been endorsed by the Royal College of Nursing as a national best practice guidance..... and will benefit tens of thousands of patients every year"* (appendix 4).

In March 2021, my co-author and I were announced winners of the prestigious BJN Nurse of the Year Awards, 2021 (appendix 5). This evidences the importance of the VBPG as it not only standardises practise across the British Isles and Republic of Ireland but is accessible to patients and HCPs worldwide.

3.4.2 Research Impact

The VBPG (Francis, **Mortimore**, HUK, 2020) acknowledges the increasing importance of the use of evidence in informing standards of nursing care for patients undergoing venesection and furthermore, recognises the role of patients and HCPs in contributing to the body of evidence to enable sustainable improvements in quality and safety of patient care.

The guideline is available from all RCN libraries and most academic and public libraries within the UK and Republic of Ireland. It is freely available to all health care workers and patients worldwide, by being distributed through a global organisation in Amazon. This impact clearly evidences how this work is advancing HCPs' knowledge of liver disease within a national and international arena.

3.5 Research Dissemination

According to Bowling (2014), dissemination of research findings is essential for health service development and researchers have a duty to ensure their findings, either negative or positive, should be disseminated. Presentations at key meetings and conferences and publications in appropriate journals are likely to be accessed by target audiences.

In recent years, in recognition of my research reputation, I have been invited to speak at numerous national conferences on liver disease and nurse leadership. My first national conference was in 2012 and since 2018, I have spoken at thirteen national and local conferences; disseminating, informing, and increasing health professionals' knowledge in liver disease (appendix 6).

3.6 All Party Parliamentary Group and Freedom of Information Report

My continued interest in genetic haemochromatosis, through published papers (**Mortimore** 2017; White, et al., (2011), including the addition of a poster presentation at the Royal College of General Practitioners' Conference in 2019 (**Mortimore** and Woodward 2019) and involvement with the VBPG (Francis, **Mortimore**, HUK, 2020), led to an invitation from HUK to become an expert nurse advisor to an All Party, Parliamentary Group (APPG) on haemochromatosis. To this end, I was requested to write a preliminary report on the findings of Freedom of Information (FOI) requests made to all UK Hospital Trusts regarding GH and included numbers of patients treated, if they possessed written guidance/protocols regarding diagnosis and venesection (**Mortimore** and McClements, 2020a). This report was verbally presented to the group of assembled Members of Parliament (MP's) who attended the APPG in February 2020, in Westminster.

In September 2020, the final FOI report, "*The State of the Nation*" (**Mortimore** and McClements 2020), was published. This report gave details of NHS Trusts who did not respond to FOI requests despite it being a statutory requirement (FOI Act, 2000). It highlighted that 54% of Trusts do not use a protocol for venesection and 46% did not use a guideline to diagnose and treat patients with GH, despite guidelines written by Fitzsimons, Cullis, Thomas, Tsochatzis, Griffiths (2018), published in the British Journal of Haematology. More importantly, it emphasised that less than twenty thousand people are being treated for GH in the UK, when it is estimated from research undertaken from the UK Biobank that three hundred and eighty thousand people are at risk (Melzer, Atkins, UK Biobank, 2019).

3.6.1 Research Impact

There were three target audiences for the “*State of the Nation*” report (**Mortimore** and McClements 2020). The first target audience was for people diagnosed with haemochromatosis to allow for transparency so they could view and compare how their Trusts compared to others around the UK. Thus, the report has been made freely available to all HUK members on their website.

The second target audience was UK Parliamentarians, including those who formed part of the APPG. A copy of the report was sent to every MP in England, Northern Ireland, Scotland, and Wales to raise greater awareness about haemochromatosis and gather support to lobby Government and NHS Trusts for greater action regarding earlier diagnosis and treatment for haemochromatosis. This impact has been evidenced by a letter received from the Right Honourable Sir John Hayes (CBE) who submitted two questions to the Secretary of State for Health and Social Care regarding what steps the Department of Health will take to improve the early diagnosis for those suffering with haemochromatosis (appendix 7).

The third audience was the Blood Transfusion Service (BTS). Sadly, the therapeutically venesected blood taken from patients in hospital is not used to make blood products, it is disposed of. HUK are lobbying the BTS to allow haemochromatosis patients more frequent venesections than normal practice, thus allowing their blood to be used towards blood products. This is of immense importance, as it increases blood product availability across the UK, reduces valuable blood wastage and makes it more convenient for people with GH to donate their blood at BTS rather than attend hospital appointments. This is a pertinent point during the Covid pandemic of 2020, where some patients were not allowed into hospitals for their regular venesections.

In view of the diverse audience for the State of the Nation Report (**Mortimore** and McClements 2020, 2020a), the requested remit from HUK was for the report to be easy to read. Over recent years there has been wide debate, regarding the importance of avoiding medical jargon (Rimmer, 2014) and this sentiment has been reflected within academia (Lynch, 2018). Although simply written, the report did contain hard hitting facts in easy-to-understand text, tables, Pie and Bar charts demonstrating the disparities in care across the UK. These results were derived from respondents' answers to the FOI questions and were populated into a excel spreadsheet so the data could be simply and quickly analysed.

3.6.2 Professional impact

This FOI report highlights that genetic haemochromatosis is a relatively common but underdiagnosed condition. By highlighting these important facts to MP's across the UK, presenting the findings to Parliament and the BTS, and with letters from MP's with questions to the Secretary of State for Health and Social Care regarding haemochromatosis, as well as requests to add additional blood tests to the NHS health check (appendix 10), clearly demonstrates that my research is being used to increase liver disease awareness and influence policy. This contradicts the earlier evidence presented by Gough and Walsh, (2000); Hart, (2004); Wakefield, (2004) and Sasse and Haddon, (2019) that nurse academics find engaging with policy problematic and are not seen as credible in strategic policymaking.

3.7 Research Philosophy

According to Dudovskiy (2016), pragmatists will use whatever research method is required or a combination of methods to find the answers to their research questions. Pragmatists solve problems in a practical, achievable, and sensible way rather than by having fixed ideas and theories (Oxford Learners Dictionaries, 2020). Writing the

Venesection Best Practice Guidelines (Francis, Mortimore and HUK, 2020) involved a mixed methodology of qualitative and quantitative techniques; listening to health care professionals and patient views, documenting, and analysing the results as well as examining NHS hospital protocols on venesection, all contributed to the final guidance.

Mixed methods were employed in developing the FOI, “*State of the Nation Report*” (Mortimore and McClements 2020, Mortimore and McClements 2020a) where answers to the FOI questions were entered into an Excel spreadsheet and simple analysis undertaken. Guidelines and protocols sent from various hospitals were collated and examined to ascertain on what research they were based on. In contrast, I chose qualitative techniques for the Living with Genetic Haemochromatosis study (Mortimore and Woodward, 2019) as this was the most appropriate method to explore patients’ perceptions of living with the disease, using in-depth recorded interviews, which offered a richness of data that could not be achieved by a simple questionnaire. The research design in the above studies were chosen as the most pragmatic way to address the research question with the ambition that the research findings would promote change and improve health care practice and care for patients worldwide. The chosen research methods within these studies (Mortimore and McClements, 2020; Mortimore and McClements, 2020a; Mortimore and Woodward, 2019; Francis, Mortimore, HUK, 2020), allowed me to address the practical questions of my research in a flexible manner.

3.8 Reflection

Reflecting on my publications it is apparent that in some instances the research differs from findings from guidelines or other seminal published works. For example, the EASL (2010) haemochromatosis guideline does not advocate the long-term follow-up or treatment of H63D homozygotes. In contrast to this, the White, *et al.*, (2011)

publication which looked at how many H63D homozygotes were diagnosed within a five year period in the local hospital Trust, discovered that 38% of patients homozygous to H63D genotype developed iron overload requiring therapeutic venesection. This was in contrast to papers published in 2016 by Rombout-Sestrienkova *et al.*, and Porto *et al.*, where the authors state there is only a 0.5 – 2.0% risk of patients of this genotype to develop iron overload. EASL (2010) also state that H63D homozygosity does not cause iron overload and of note, France does not offer genotyping for this variant gene.

This findings in the White *et al.*, 2011 study determined that all H63D homozygotes who do not require venesection should have long term follow-up with their GP in the form of two to three yearly blood tests to check ferritin and transferrin saturation levels. Any abnormalities in these readings would necessitate a referral back into secondary care. The conflicting evidence that 38% of H63D patients developed iron overload, which goes against European findings clearly suggests that further research is required in this area.

The report “*State of the Nation*” (**Mortimore** and McClements 2020a) asserted that there are approximately four hundred thousand people with genetic haemochromatosis within the UK: approximately one in one hundred and fifty in England and Wales and one in one hundred and thirteen in Scotland and Ireland. This goes against the evidence provided in the AASLD haemochromatosis guideline (Bacon *et al.*, 2011) which state that it affects one in every two hundred to two hundred and fifty people. Again, further research is required, which I am hoping to be involved with later this year.

National guidance influences international health policy and improves the standards of medical and nursing care delivered to patients worldwide. Being involved in NICE guidance and quality standards as well as authoring Venesection Best Practice Guideline clearly demonstrates that I have added to the body of research knowledge and contributed to evidence-based medicine.

In recognition of my research and publication outputs I was identified by the University, as a staff member with a Significant Responsibility for Research (SRR) and submitted to the Research Education Framework (REF) 2021 in November 2020. The principle aim of REF *“is to secure the continuation of a world-class, dynamic and responsive research base across the full academic spectrum within UK higher education.”* (REF, 2020). Being part of REF, I was advised to publish in three star journals with international outreach. Although I have published in what is considered 3 star journals, for example the *Journal of Hepatology* with an impact factor of 20.5 and involved in national guidance, the majority of my informative articles have been published in nursing journals and therefore a dichotomy exists between impact and influence.

Nursing journals do not have the impact factor of medical journals. This should not deem them of less importance. For example, the well know British Journal of Nursing (BJN) was noted to have an impact factor of 0.71 (BJN, 2021) but I would argue that by aiming my articles at nurses, and bearing in mind I am a nurse, I am influencing my cohort group to make a positive difference in the care received by patients with liver disease. For every one doctor working in the NHS there are two and a half nurses, with the latest figures in 2020 reporting approximately three hundred thousand nurses in the UK (Department of Health and Social Care, 2020). Despite publishing in what is considered *“lower impact”* nursing journals my ResearchGate score has increased to

26.11, (appendix 8) when three months ago it was 25.92 (appendix 2) demonstrating my increasing research reputation.

In 1982, as a novice nurse, I could not envisage that in the future I would contribute to national policy, write national guidelines, speak with Members of Parliament to attract attention to a medical condition, be involved in research, devise and undertake my own research studies, and be a published author of numerous articles. Likewise, when Benner wrote about “From Novice to Expert” nearly forty years ago, she too would find it difficult to predict the future transformation of nursing and how nurses can not only reach her “Expert” status but can transcend beyond this point. This will be discussed further in the next chapter.

Chapter 4: Theme 3 - As academic/practitioner delivering best practice in the clinical setting.

The previous chapter evidenced how my professional and research impact, advanced HCPs' knowledge of liver disease on a national and international level. This achievement in my personal career did occur suddenly but developed over time, as my experience, confidence and competence grew, following Benner's novice to expert (1984) framework. The Derby Model (**Mortimore et al, 2021**), (figure 2), evidence how my advanced clinical competence, expertise and research in hepatology has now exceeded this level of expert.

Since 2006, my collection of published works, integrating three differing paradigms of positivism, interpretivism and pragmatism shaped and developed me from a novice nurse researcher to an internationally recognised researcher and policy influencer (figure 2) within the field of hepatology. During the late 1990s and 2000s the medical research I undertook was under the auspices of my medical colleagues, as my experience and confidence grew, I worked alongside them as a peer and advised what audit and research they could undertake, to finally undertaking my own qualitative and mixed methods research, without medical input. This latter research has informed policy and led guidelines being produced for the UK.

This chapter explains how my collection of published research and academic articles assisted in advancing health professionals' knowledge of liver disease and strengthened my research reputation, supported by my ResearchGate score. Additionally, I discuss how this increased reputation attracted attention from international pharmaceutical companies seeking advice on research into hepatocellular carcinoma of the liver and educational modules for nurses.

4.1 Publications

Mortality and morbidity from liver disease has witnessed an unprecedented increase over the last four decades. The complex nature of end stage liver disease highlights the importance of advancing HCPs' knowledge of the subject. The dissemination of my research findings and published academic articles regarding the differing types of liver disease adds to the body of EBM and allow HCPs to make informed decisions that will ultimately lead to improved patient outcomes.

My data was pivotal in the audit in the prospective and retrospective published audits undertaken in the 2000's namely: White *et al.*, (2011) and Li *et al.*, (2006a, 2006b). To add clarity to my role in these publications, they could not have been authored without the data I had painstakingly collected, collated, and freely offered to the hepatology research registrars. Disappointingly, when another doctor was asked to assist to write the article, I was never considered to author alongside them, and as such, my name was moved from second to third position as noted in the White *et al.*, (2011) and Rye *et al.*, (2012) papers. It is important to note that this was standard practice at the time and publications for medical journals were written primarily by medical doctors not nurses.

In the original submission of my thesis in chapter two, it was noted that in several places for the Li *et al.*, 2006a and 2006b; White *et al.*, 2011; and Rye *et al.*, 2012 articles I had used the term "my" publications. This was not to deceive the reader but instead to highlight that my name was very much part of that "*et al.*" collective. This has since been corrected.

When discussing the importance of audit and research with medical colleagues, audit appears to take second place to research, and as such, is deemed of less value. In my own professional practice, I feel audit is extremely important but under-rated. This

importance was evidenced by my own audit in paracentesis, where I was able to demonstrate the value of a nurse-led service to improve patient care and save thousands of pounds for the Trust (chapter 2). Moreover, the Li *et al.*, (2006a; 2006b) changed medical practice within the NHS Trust and the White *et al.*, (2011), retrospective audit revealed that in contrast to European haemochromatosis guidelines (EASL, 2010), where they do not test for H63D homozygotes, 38% of H63D homozygotes developed iron over load and therefore, should be offered long term follow up.

In 2016, I became a lecturer within an HEI, teaching advanced practice skills to post graduate professionals allied to medicine. Working within an HEI, the research ethos perceptively changed, and I was actively encouraged to write articles for publication, giving the opportunity from a pedagogical viewpoint, to raise awareness and understanding regarding liver disease and awarded funding to undertake research studies. Because of my research reputation, as evidenced by my involvement with NICE and published papers, I was requested to write an article for hepatology section of Gastrointestinal Nursing Journal (**Mortimore**, 2016a). This is the only UK journal exclusively dedicated to gastrointestinal, stoma care and hepatology nurses and is endorsed by the British Society of Gastroenterology (BSG). Therefore, I felt that this was the most pertinent journal to disseminate information regarding liver disease, diagnosis, treatment, and management.

After searching the literature, I commented that despite the increasing prevalence of liver disease affecting all aspects of medicine and nursing (Williams *et al.*, 2018; Williams, 2015; RCN, 2013) there was dearth of taught liver courses for health professionals (**Mortimore**, 2016a). This article fired my interest in increasing health

professionals' awareness of liver disease and in so doing, established the topic of this critical appraisal.

Because of my research reputation, I was approached by several journal editors to author articles namely the *Nursing Times*, the *British Journal of Nursing*, *Journal of Prescribing Practice and Practice Nursing*.

Since 2016, I authored over forty articles (appendix 9, 10). Although not all the articles are related to liver disease, they do showcase my considerable experience as an ACP and evidence that if provided with vested time, I can deliver. My multiple publications have led to invitations to be a peer reviewer for nursing and prescribing journals, and I currently peer review articles for the *British Journal of Nursing (BJN)*, *Nursing Times*, and the *Gastrointestinal Nursing Journal (GIN)*.

Journal editors, in recognition of the requirement to improve HCPs' knowledge regarding liver disease, treatment, and management, sought my approval to reprint several of my previously published articles. In 2017, I authored an article titled, *Primary Biliary Cholangitis: symptoms, diagnosis, and treatment (Mortimore, 2017d)* and this was reprinted in June 2019 in *GIN*, *Journal of Prescribing Practice (JPP)* and *Practice Nursing Journal (PNJ)*, (Mortimore, 2019a, b, c). Later in 2019, I included a small addition titled, *Primary Biliary Cholangitis an update on treatment (Mortimore, 2019d)*, published in *GIN*. In 2020, this article was republished as a supplement in three journals: *GIN*, *JPP* and *PNJ* (Mortimore, 2020a, b, c). A further article, examining nutrition and malnutrition in liver disease was published (Mortimore, 2019e) and then republished for the same three journals listed above (Mortimore, 2020a, b, c). All of these are examples where the journal editors felt that the information was indeed

important enough to disseminate to a wider audience and my publications were used as a platform to advance health professionals knowledge of liver disease.

4.2 Continuing impact of my research

The impact of my research has led to a number of invitations for radio interviews, charity appeals, increased frequency of venesection by the Blood Transfusion Service for haemochromatosis patients and approaches by pharmaceutical companies (appendix 11). The interest generated by my publications from international pharmaceutical companies reflects favourably on the University of Derby and highlights my impact as an internationally recognised researcher and policy influencer. In addition, I have successfully been awarded research grants which reflects favourably on the strength of my research (appendix 12).

4.3 Widening Research Influence

Since writing the introduction to this critical appraisal, my research reputation, as indicated by the ResearchGate score; a metric that measures scientific reputation based on how your research is received by your peers was 24.59. This increased to 25.92 in March 2021 (appendix 2) and in June 2021, it further increased to 26.11 (appendix 8). This increase in metric evidences my scientific reputation as it is within the top 17.5% of all researchers listed on ResearchGate. Being in the top 17.5%, validates my unique contribution to knowledge in the national and international arena and highlights my research affiliation with the University of Derby.

4.4 Charity Education Manager

In August 2020, I gained employment as HUK charity's education manager for the UK. This position enables me to continue to disseminate my research and continue with HCPs and GP education re haemochromatosis, its diagnosis, treatment, and

management. Part of my remit is to author patient information sheets offering advice on how to deal with issues that can affect patients with haemochromatosis.

4.5 Lecturer in Advanced Practice

Within my role as an ACP and an educator of trainee ACP's, I have published several informative articles not related to liver disease (appendix 9, 10). These publications and associated citations, as well as citations from publications relating to liver disease highlight my contribution at an international level.

4.6 Acknowledged limitations and strengths of my research journey

Undertaking my own research was underpinned by my knowledge and experience honed over many years, where I could see gaps in knowledge and care but most importantly, gained the acumen to make change happen. Making change happen, took time. My nursing and research career is reflected in Benner's (1984) five stages of novice to expert, but I now feel I have reached beyond this level of expert (figure 2) as indicated in the article by **Mortimore et al.**, (2021).

Commencing my nursing student hospital training in the early 1980s was a world away from the university degree student nurses today. Bullying was rife in the 1980's, and accepted behaviour. If you were different, which is now known as the *Tall Poppy Syndrome*, where people who stand out from the 'norm' because of their abilities, qualities, intellect, or because they have achieved great success can be subject to bullying (Gillespie et al., 2017; Dedi, 2015; Meissner, 1986).

I recognise I was a product of the age of "handmaiden to the doctors" but this was an expected role of being a nurse at the time. My early research experience reflects this attitude; my name was not placed on research papers despite being key in producing the scientific work. Even more interesting was that at the time, it did not concern me, whereas now, I see it as an obvious oversight. This, and other events during my career

have made me stronger, persistent and has taught me to treat people with kindness and respect because I appreciate what it is like to be ignored and circumvented. However, my bright-eyed perspective does still irritate people and on a personal note it can be difficult even now to be noticed or taken seriously. Attaining Ph.D. status will help me to feel more confident in my own abilities. However, I will always encourage and support my students and peers to ensure that they are treated with respect and rightfully acknowledged.

4.7 Full circle

In 2006, in recognition of my extensive input into anaesthetic research I was placed as first author on published research findings (**Casey et al.**, 2006). I was grateful of this acknowledgement from previous experience where my input was ignored. This publication heralded a paradigm shift in my thinking and gave me the encouragement, confidence and drive to be involved in research and to write informative articles to increase health professionals' knowledge of liver disease.

My ambition, as a lecturer in a HEI, is to instil this confidence and drive in my students, and since 2019, I have co-authored and published eleven student articles (appendix 9,10). Moreover, I have actively encouraged my colleagues to publish (Reynolds and **Mortimore**, 2021a, 2021b and 2018; **Mortimore** and Mayes, 2019; Watson and **Mortimore**, 2018/2019; Lewis and **Mortimore** 2018 (appendix 10).

4.8 Professional Impact

I am recognised as one of the few academics within the university who endeavours and succeeds in publishing students work. In 2020 alone, I co-authored seven published articles with students from the University of Derby, with two further articles submitted, awaiting double-blind peer review. Furthermore, I have two further articles accepted for publication, co-authored with a colleague.

In an article titled, 'How many articles should a postdoc publish?' it suggests that many postdoctoral academics do not publish (Tetzner, 2020). In contrast to this observation and in consideration that I have not yet attained postdoctoral status, I have a proven track record of publishing which is considered a reliable indicator of future productivity and impact in scientific and academic careers. Moreover, by actively encouraging my students and colleagues to write and submit for publication I hope to inspire them to be the writers, educators, and researchers of tomorrow.

4.9 Aims of the thesis

The aim of this thesis was to demonstrate, through my research and published literature that the impact of my research, nursing practice and published papers is:

- advancing health professionals' knowledge of liver disease within national and international arenas and
- that my research has improved standards of medical and nursing care for patients receiving treatment for liver disease

Both aims have been evidenced by my involvement in writing national NICE guidelines and Quality Standards on liver disease as discussed in chapter three. In addition, my research highlighted the disparity in care for patients undergoing venesection across the British Isles which led to me co-authoring venesection guidance (Francis, **Mortimore** and HUK, 2020). This is available from all British libraries and is freely available as an e-book for international audiences and worldwide dissemination.

- that by listening and responding to patient experiences guides research and assists in the development of educational resources

As well as publishing guidance and writing informative articles for health professionals as discussed throughout this thesis, I have additionally published patient information

booklets for people diagnosed with haemochromatosis such as cardiomyopathy and skin conditions (figure 7).



Figure 5: common skin conditions and cardiomyopathy booklets authored by Gerri Mortimore and Jayne Partridge. Available at: www.huk.org.uk (Accessed 28th June 2021).

In 2021, I developed an educational module on haemochromatosis, freely available to any health care professionals, endorsed by the RCN and worth four continuing professional development (CPD) points (figure 6). Moreover, listening to the patient voice led me to devise my own research titled “*Living with genetic haemochromatosis*” in which posters were presented to the RCGP three day conference in October 2019 and another poster presented at the International Liver Conference (ILC) hosted by EASL in June 2021.

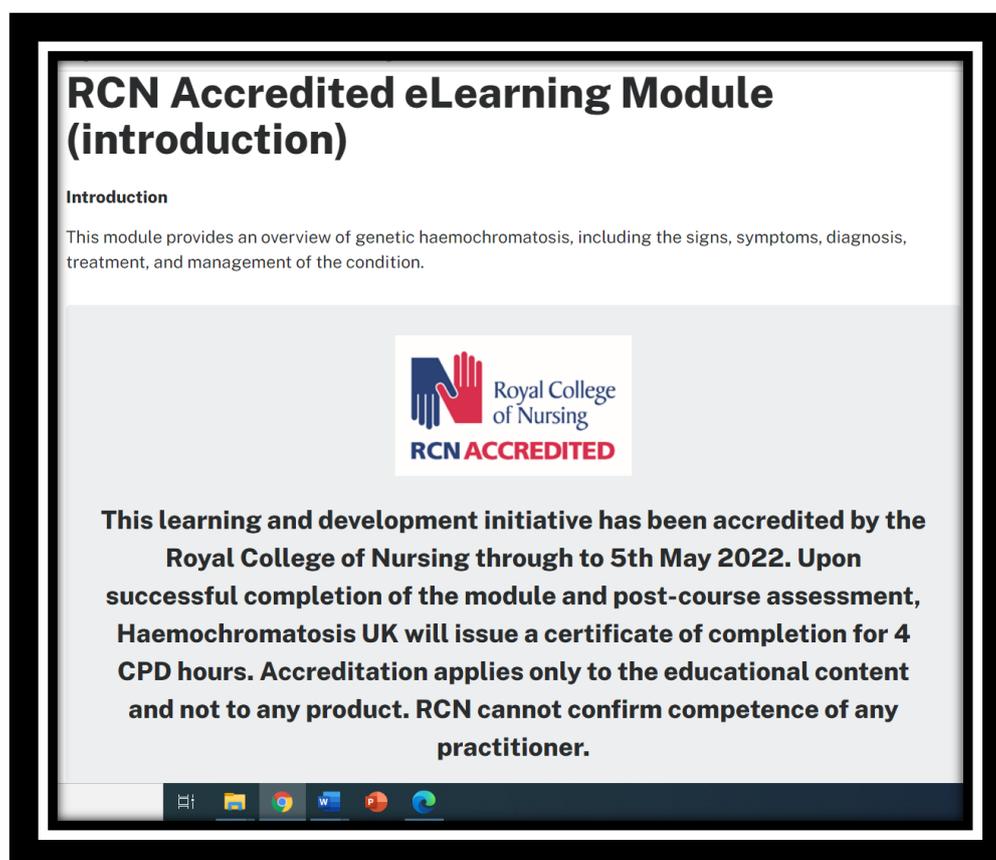


Figure 6: RCN accredited haemochromatosis module authored by Gerri Mortimore. Available at: www.huk.org.uk (accessed 28th June 2021).

My expertise regarding Haemochromatosis led to an invitation from HUK, to deliver live webinars to GPs within CCG's on the diagnosis, treatment, and management of haemochromatosis, as well as informing GPs of patient experiences from the **Mortimore** and Woodward, (2019) study. My first webinar was in August 2020, to a

Liverpool CCG and I have presented monthly webinars since. The GPs who attend are awarded CPD points, which are essential for their General Medical Council revalidation.

The final aim was to demonstrate

- the impact of my research contribution and how this has influenced my professional standing

Due to my expertise in liver disease I was awarded the title of NICE Nurse Expert Advisor in 2015, and in May 2021 was invited to be part of the Specialist Interest Group (SIG) in haemochromatosis as part of the BASL in June 2021, in which I presented to the group the disparity in care for people with haemochromatosis and to highlight the Venesection Best Practice Guidelines (Francis, **Mortimore** and HUK). I was the only nurse in attendance, the rest were medics. In May 2021, I was requested and delivered a podcast for the Gastrointestinal Nursing journal on haemochromatosis. Being a member of the APPG (chapter 3) additionally endorses my expertise.

Due to my publications (appendix 10) I was contacted by a large pharmaceutical company to assist in the authoring of educational modules for HCPs. This again validates my expert status and professional influence and demonstrates how I assisted in developing further educational courses.

This appraisal has evidenced that listening and responding to patient experiences guided my research, which was fundamental in the development of clinical guidelines and educational resources all of which have advanced health professional knowledge. Throughout I have evaluated the research and professional impact.

4.10 Conclusion

This thesis provides a coherent collection of research that evidences how my knowledge, experience has influenced practice standards and processes, which impact on current and future healthcare delivery. This is clearly evidenced by direct dialogue with government and my contributions to national guidance which have reached international audiences.

The evidence presented within this appraisal supports that I have reached expert status (Benner, 1984) but arguably may have surpassed this level to become an advanced expert and an internationally recognised researcher and policy influencer (**Mortimore** *et al.*, 2021), (figure 2). All my published research and informative articles have been used as a platform to advance health professionals' knowledge of liver disease and influence policy. I consider that this body of research has helped shape the care that will be provided today and, in the future, to improve or transform patient lives for the better across the globe.

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Appendix 1



Gerri Mortimore

[FOLLOW](#)

University of Derby

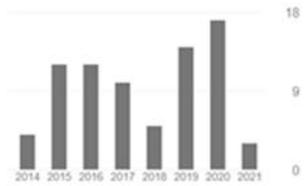
Verified email at derby.ac.uk - [Homepage](#)

Hepatology haemochromatosis teaching nursing advanced clinical practice

TITLE	CITED BY	YEAR
<input type="checkbox"/> Towards noninvasive detection of oesophageal varices K Rye, R Scott, G Mortimore, A Lawson, A Austin, J Freeman International journal of hepatology 2012	40	2012
<input type="checkbox"/> Perioperative Nimodipine and Postoperative Analgesia GM Casey, SA Notcliffe, DJ Sharpe, P Buggy Anesthesia & Analgesia 102 (2), 504-508	16	2006
<input type="checkbox"/> Ludwig's angina: a multidisciplinary concern E Parker, G Mortimore British Journal of Nursing 28 (9), 547-551	7	2019
<input type="checkbox"/> Advanced nurse practitioners: the NHS England framework J Reynolds, G Mortimore Gastrointestinal Nursing 16 (2), 14-17	5	2018
<input type="checkbox"/> The diagnosis and management of pulmonary embolism E Toplis, G Mortimore British Journal of Nursing 29 (1), 22-26	4	2020
<input type="checkbox"/> Alcohol-use disorders: prevention. G Mortimore National Institute for Health and Care Excellence (NICE)	4	2010
<input type="checkbox"/> Non-invasive Diagnosis of Oesophageal Varices Using Systemic Haemodynamic Measurements by Finometry: Comparison with Other Non-invasive Predictive Scores K Rye, G Mortimore, A Austin, J Freeman	2	2016

Cited by VIEWALL

	All	Since 2016
Citations	91	61
h-index	4	4
i10-index	2	1



Co-authors EDIT

No co-authors

Citations for perioperative *Nimodipine and Postoperative analgesia* (Casey et al., 2006) and *Towards Non-invasive detection of oesophageal varices* (Rye et al., 2012). 15th March 2021.

Appendix 2

ResearchGate score (accessed 10th March 2021).



Gerri Mortimore
PhD 25.92 · Pg Cert IPPE; MSc Advanced Practice; BA (Hons) Health Studies - [Edit](#)

[Add new research](#) 

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Stats overview

53.2 Research Interest ⓘ More details	63 Citations View	5 Recommendations Show breakdown	4,684 Reads ⓘ Show breakdown
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Stats history Time: [Weekly](#) ▾

<input checked="" type="checkbox"/> Research Interest	<input checked="" type="checkbox"/> Citations	<input checked="" type="checkbox"/> Recommendations
<input checked="" type="checkbox"/> Reads	<input checked="" type="checkbox"/> Full-text reads	

Appendix 3

IRAS approval for the living with genetic haemochromatosis study



Health Research
Authority

London - Riverside Research Ethics Committee

Level 3 Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 0207104 8204

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

25 September 2018

Mrs Geraldine (Gerri) Mortimore
Lecturer/ Registered General Nurse
University of Derby
KEDLESTON ROAD
DERBY
DE22 1GB

Dear Mrs Mortimore

Study title:	Living with Genetic Haemochromatosis: patient experiences of the disease
REC reference:	18/LO/1518
Protocol number:	N/A
IRAS project ID:	245502

Thank you for your letter of 14th September 2018, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

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 favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Appendix 3 continued

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

We are pleased to welcome researchers and R & D staff at our RES Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

18/LO/1518

Please quote this number on all correspondence

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

Yours sincerely

Pp

REC Manager

Dr

Chair

Email: nrescommittee.london-riverside@nhs.net

Enclosures:
Copy to:

"After ethical review – guidance for researchers"

Appendix 4

University of Derby 2020 press release regarding venesection guideline.



Press release

22 June 2020

Derby lecturer's work helps to create nursing guide to treat common genetic condition

The work of a University of Derby academic has helped a UK health charity to launch a guide which could improve vital treatment for one of the UK's most common hereditary conditions.

Gerri Mortimore, Lecturer in Post-Registration Health Care at the University, has worked with Haemochromatosis UK to help nursing staff treat people with haemochromatosis, which affects an estimated 400,000 people across the UK.

The condition is caused by the storing of too much iron in the body, which can result in liver, heart and pancreatic problems. Its most common symptoms though are chronic fatigue and a discoloration of the skin.

Treating the condition involves taking blood from a patient at regular intervals to bring iron levels down. However, differing guidance for nurses and healthcare professionals to follow has raised concerns about consistency of care for patients.

Gerri and Yvonne Francis, of Guy's and St Thomas' NHS Foundation Trust in London, worked with Haemochromatosis UK and obtained the endorsement of the Royal College of Nursing to produce a single set of nurse-led guidelines for venesection best practice.

Gerri, who addressed fellow academics about her work at the University of Derby's Research and Knowledge Exchange Conference on Thursday (18 June), said: "The need for a single and consistent set of guidelines, written by nursing professionals and based on the best practice available, was clear if the condition was to be treated effectively. There is no known cure for the condition, so regular treatment to lower iron levels in the bloodstream is required.

"Treatment needs to be delivered in the same way in every hospital in the country, so that nursing staff and healthcare professionals are clear about the most effective way of caring for patients. That can then help manage the condition and reduce the prospect of it causing more serious complications with their health in future. It also provides patients with the assurance that wherever they live in the UK, they will receive the same high levels of care."

The project has earned awards from two major organisations working for the wellbeing of hospital patients, Patient Safety Learning and The Patients' Association. The guidelines also have the support of a group of MPs who sit on the All Party Parliamentary Haemochromatosis Group.

Neil McClements, Chief Executive of Haemochromatosis UK, said: "This award-winning initiative is the culmination of over three years' work with more than 200 nurses and other healthcare professionals to identify, document and coalesce best practice for venesection nursing procedures. It's a testament to the skill and thoroughness of the authors that this guide has now been endorsed by the Royal College of Nursing as national best practice guidance. Our charity is delighted to have collaborated in this work, which will benefit tens of thousands of patients every year."

To find out more about the condition, visit www.haemochromatosis.org.uk

For more information about research being conducted at the University of Derby, visit [our website](#).

Appendix 5

BJN nurse of the year award winners



Issue 350 | 10 March 2021



Gerri Mortimore wins Nurse of the Year Award

Gerri Mortimore, Lecturer in Advanced Practice, won the prestigious Nurse of the Year Award at the British Journal of Nursing Awards 2021. Sponsored by The Nursing and Midwifery Council, this award recognises an individual who has made an outstanding achievement in nursing this year.



The awards were announced at a [virtual ceremony](#) hosted by NHS Doctor and TV Presenter Dr Ranj Singh on Monday 8 March.

Gerri shares the accolade with her colleague Yvonne Francis from Guy's and St Thomas' NHS Foundation Trust. In the award entry, Gerri and Yvonne highlighted their work with Haemochromatosis UK and their research into venesection, a common clinical procedure involving the removal of a volume of blood which is undertaken to treat thousands of

patients across the country with genetic haemochromatosis, polycythaemia vera, idiopathic and secondary erythrocytosis.

The project, which involved input from over 200 nurses across the UK and Ireland, culminated in the [Venesection Best Practice Guidelines](#), the only resource specific to this subject.

Speaking about her award win, Gerri said: “I am honoured to have won the Nurse of the Year Award. It is a culmination of three years’ work to support the care of adult patients undergoing therapeutic venesection.

“I would like to thank Haemochromatosis UK and everyone who has been involved in developing this valuable resource, which has been recognised for its significance by the Royal College of Nursing who have endorsed the guidance.”

Commenting on the award, Dr Paula Holt MBE, Pro Vice-Chancellor Dean of the College of Health, Psychology and Social Care, added: “The title of Nurse of the Year is an outstanding achievement and richly deserved.

“To be recognised by the British Journal of Nursing reflects the impact that Gerri’s hard work and research has had on [improving patient safety](#), through the development of best practice guidance for venesection.”

For more information on the British Journal of Nursing Awards, [please visit the website](#).

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The information contained in this newsletter is to be treated as confidential and for employees only.



@DerbyUniPress

Appendix 6

Research dissemination by presenting at conferences

In October 2019, I presented preliminary findings gathered from the “Living with genetic haemochromatosis” study (**Mortimore** and Woodward, 2019), at the Royal College of General Practitioners (RCGP), 3-day conference.

In January 2020, I delivered a 30-minute presentation at the 7th National Nursing Gastrointestinal Conference, regarding haemochromatosis, its diagnosis, treatment, and long-term management, disseminated the primary findings from my qualitative study (**Mortimore** and Woodward, 2019) and announced the publication of the Venesection Best Practice Guidelines (Francis, **Mortimore** and HUK, 2020).

The research findings from **Mortimore** and Woodward (2019) Living with genetic haemochromatosis study and the publication of the venesection Best Practice Guidelines (Francis, **Mortimore** and HUK, 2020) were presented at the 7th National Nursing Gastrointestinal Conference in January 2020. In June 2020, I presented at the University of Derby’s University Research and Knowledge Exchange Conference regarding my ongoing research into genetic haemochromatosis (**Mortimore** and Woodward, 2019) including the findings from the draft Freedom of Information report (**Mortimore** and McClements, 2020a) presented to Parliament in February 2020.

In November 2020, I presented at a celebration event to showcase the advantages of pharmacists working in Integrated Urgent Care, hosted by the University of Derby in partnership with Health Education England (HEE) and NHS England, Scotland, Wales, and Northern Ireland. This gave me the opportunity to discuss with the delegates that the opportunities of advanced practice roles could allow them to achieve expert status (Benner, 1984) and the possibility of exceeding this level attainment.

Appendix 7

Letter to Secretary of State for Health and Social care after reading ‘*State of the Nation report*’ (Mortimore and McClements, 2020).



HOUSE OF COMMONS
LONDON SW1A 0AA

[REDACTED]
Chief Executive, Haemochromatosis UK
Henrith Business Centre
3 Enterprise Way
Pinchbeck
Spalding PE11 3YR

26th September 2020

Dear [REDACTED]

Thank you for the information regarding your ongoing work to improve the treatment of Haemochromatosis.

Having read the State of the Nation report with interest, I have subsequently submitted two written questions to the Minister responsible in the Department of Health and Social Care:

1. To ask the Secretary of State for Health and Social Care, what steps his Department is taking to ensure each NHS Trust is equipped with the (a) expertise and (b) resources needed to treat haemochromatosis.
2. To ask the Secretary of State for Health and Social Care, what steps his Department is taking to improve early diagnosis for those suffering from haemochromatosis.

I will be sure to forward the Minister's response once it has been received by my office.

With best wishes.

Yours sincerely,

[REDACTED]
South Holland & The Deepings

Appendix 7 continued



Rt Hon Matt Hancock MP
Secretary of State for Health & Social Care
Department of Health & Social Care
Ministerial Correspondence and Public Enquiries Unit
39 Victoria Street, London, SW1H 0EU

24th February 2021

Dear Secretary of State,

Improving the nation's health by augmenting the NHS Health Check

Genetic haemochromatosis is the UK's most common genetic condition, there are over 380,000¹ people at risk. Although it is commonplace, the condition is significantly under-diagnosed in the UK. The NHS is caring for fewer than 20,000 people with genetic haemochromatosis². Just 1 in 20 people at risk are aware of their condition and receiving treatment.

Untreated, the condition can lead to iron overload, where the body is unable to process excess iron. Excess iron is extremely toxic. Genetic haemochromatosis can cause liver disease, cancer, heart disease, chronic fatigue, diabetes, severe joint pain, sexual health issues and mental health issues.

Our APPG has received evidence that iron overload can be detected easily and cost-effectively through two simple blood tests – one for serum ferritin (SF), the other for transferrin saturation (TSAT). These tests are not currently included in the NHS Health Check; yet this would be a simple and effective way of identifying people suffering from iron overload.

Although there is no cure for iron overload caused by genetic haemochromatosis, treatment is straightforward – a form of very frequent blood donation, called venesection. Recent policy changes by NHS Blood & Transplant and ScotBlood have made it easier for people with genetic haemochromatosis to become blood donors, to aid not just the national effort around CV19 convalescence plasma therapies but day-to-day provision of whole blood and derivative products, such as platelets for cancer care.

So, our All-Party Parliamentary Group would welcome the opportunity to meet and discuss with you the inclusion of SF and TSAT tests, as a standard part of the NHS Health Check. This would improve the nation's health, improve the quality of life of those families affected whilst also maintaining a sustainable national resource for blood products, through increased blood donation by people with genetic haemochromatosis.

We look forward to discussing the augmentation of the NHS Health Check with you and your team.

Yours sincerely,

Rt Hon. Sir John Hayes CBE MP
Chair, All-Party Parliamentary Group on Genetic Haemochromatosis

Ben Lake MP
Vice-Chair, All-Party Parliamentary Group on Genetic Haemochromatosis

¹ "Hereditary Haemochromatosis - Estimates of Excess Disease In The UK" (July 2019) - Professor David Meizer & the Exeter Haemochromatosis research group, University of Exeter
² "State of Nation" (August 2020) - Haemochromatosis UK & University of Derby (download : <https://www.haemochromatosis.org.uk/state-of-the-nation-2020>)

Appendix 8

ResearchGate score (accessed 29th June 2021)



Gerri Mortimore

26.11 · Pg Cert IPPE; MSc Advanced Practice; BA (Hons) Health Studies · [Edit your information](#)
Add your current activity

Add new research +

Overview Research Experience Stats Scores Following Saved List

RG Score ⓘ
26.11



Breakdown:

- 99.76% Publications
- 0.00% Questions
- 0.00% Answers
- 0.24% Followers

Percentile:
Your score is higher than 82.5% of all ResearchGate members' scores.

h-index ⓘ
4

h-index
4
excluding self-citations

Top *h* cited research:
Towards Noninvasive Detection of Oesophageal Varices
[Article](#) March 2012 · International Journal of Hepatology
[See more](#)

Boost your scores

ResearchGate score accessed 29th June 2021

Appendix 9

Co-authored publications since 2016

Since 2016, I authored the following: Reynolds and **Mortimore** (2021a, b); **Mortimore** (2020a, b, c, d, e, f,); Francis, **Mortimore**, HUK (2020); Boyer and **Mortimore** (2020); Dexter and **Mortimore** (2020); Toplis and **Mortimore** (2020 a, b); Bailey and **Mortimore** (2020); Johnson, Francis and **Mortimore** (2020); Toplis and **Mortimore** (2019); Hudson and **Mortimore** (2019); **Mortimore** (2019a, b, c); **Mortimore** and Mayes (2019); Redfern and **Mortimore** (2019); **Mortimore** (2019d, e); Parker and **Mortimore** (2019); Watson and **Mortimore** (2018/2019); **Mortimore** (2018a, b, c, d, e); Lewis and **Mortimore** (2018); Reynolds and **Mortimore** (2018); **Mortimore** (2017a, b, c, d); **Mortimore** (2016a, b).

Appendix 10

Google Scholar publications since 2016



Gerri Mortimore

FOLLOW

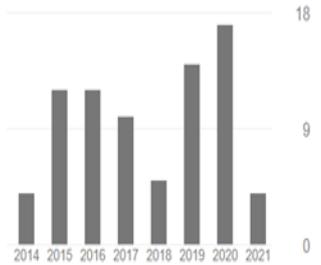
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[Hepatology](#) [haemochromatosis](#) [teaching](#) [nursing](#) [advanced clinical practice](#)

Cited by [VIEW ALL](#)

	All	Since 2016
Citations	92	62
h-index	4	4
i10-index	2	1

<input type="checkbox"/>	TITLE	CITED BY	YEAR
<input type="checkbox"/>	Transitioning to an ACP: a challenging journey with tribulations and rewards J Reynolds, G Mortimore British Journal of Nursing 30 (3), 166-166		2021
<input type="checkbox"/>	The ascent to advanced practice: challenges, support and opportunities J Reynolds, G Mortimore British Journal of Nursing 30 (2), 106-108		2021
<input type="checkbox"/>	Anti-neutrophil cytoplasmic antibodies-associated vasculitis: a guide and case study H Boyer, G Mortimore British Journal of Nursing 29 (22), 1333-1340		2020
<input type="checkbox"/>	The recognition and management of sepsis in urgent care out of hours setting G Mortimore MAG		2020
<input type="checkbox"/>	Recognition and management of sepsis in the urgent care out of hours setting J Dexter, G Mortimore Practice Nursing 31 (7), 282-288		2020
<input type="checkbox"/>	Acute liver failure in paracetamol overdose: management, transplantation and best practice E Toplis, G Mortimore Gastrointestinal Nursing 18 (Sup6), S34-S39		2020
<input type="checkbox"/>	Overcoming the challenges of role transition for trainee advanced clinical practitioners K Murphy, G Mortimore Gastrointestinal Nursing 18 (5), 35-41	1	2020
<input type="checkbox"/>	Bronchiolitis: treatment and management in an urgent out of hours care setting		2020



Co-authors [EDIT](#)

No co-authors

Appendix 10 continued

Gastrointestinal Nursing 10 (3), 33-41		
<input type="checkbox"/>	Bronchiolitis: treatment and management in an urgent out of hours care setting J Dexter, G Mortimore Practice Nursing 31 (6), 246-253	2020
<input type="checkbox"/>	Orthostatic hypotension: clinical review and case study R Bailey, G Mortimore British Journal of Nursing 29 (9), 506-511	2020
<input type="checkbox"/>	Delayed prescribing of antibiotics for self-limiting respiratory tract infections in an urgent care out-of-hours setting J Dexter, G Mortimore Journal of Prescribing Practice 2 (3), 130-135	2020
<input type="checkbox"/>	The diagnosis and management of a patient with acute pyelonephritis C Hudson, G Mortimore British Journal of Nursing 29 (3), 144-150	2020
<input type="checkbox"/>	Venesection best practice guidance G Mortimore, Y Francis, N McClements Haemochromatosis UK	2020
<input type="checkbox"/>	The diagnosis and management of pulmonary embolism E Toplis, G Mortimore British Journal of Nursing 29 (1), 22-26	4 2020
<input type="checkbox"/>	Genetic haemochromatosis: A qualitative exploration of patients' experience of diagnosis in primary care G Mortimore, A Woodward Royal College of General Practitioner's Annual Primary Care Conference	2019
<input type="checkbox"/>	Nutrition and malnutrition in liver disease: an overview G Mortimore Gastrointestinal Nursing 17 (Sup6), S10-S11	2019
<input type="checkbox"/>	Primary biliary cholangitis: an update on treatment G Mortimore Gastrointestinal Nursing 17 (Sup6), S14-S16	2019
<input type="checkbox"/>	Abdominal ultrasound scans for diagnostic imaging of the liver G Mortimore, JP Maves	1 2019

Appendix 10 continued

<input type="checkbox"/>	TITLE	CITED BY	YEAR
<input type="checkbox"/>	Advanced nurse practitioners: the NHS England framework J Reynolds, G Mortimore Gastrointestinal Nursing 16 (2), 14-17	5	2018
<input type="checkbox"/>	Alcohol: is it all that bad? G Mortimore University of Derby		2018
<input type="checkbox"/>	Ascites: drainage and management. G Mortimore		2018
<input type="checkbox"/>	Dry January: the damaging effects of alcohol on your liver. G Mortimore		2018
<input type="checkbox"/>	Share your experience G Mortimore University of Derby		2018
<input type="checkbox"/>	Penny's plan S Watson, C O'Reilly, G Mortimore Dying matters what can we do		2018
<input type="checkbox"/>	Genetic haemochromatosis: diagnosing and treating hereditary iron overload G Mortimore Gastrointestinal Nursing 15 (Sup10), S16-S21		2017
<input type="checkbox"/>	Primary Sclerosing Cholangitis: a premalignant condition G Mortimore Gastrointestinal Nursing 15 (8), 26-33		2017
<input type="checkbox"/>	Primary biliary cholangitis: symptoms, diagnosis and management G Mortimore		2017
<input type="checkbox"/>	Primary biliary cholangitis symptoms, diagnosis and treatment G Mortimore Gastrointestinal Nursing	1	2017
<input type="checkbox"/>	An exploration into the curricular development of a master's programme designed to support advanced nurse practitioner education J Reynolds, G Mortimore		2017

Appendix 10 continued

Continuing impact of my research

BBC radio news interview.

My expertise in liver disease led to three interviews by BBC Radio Derby regarding the topic of alcohol and the liver. One invitation followed on from an evening sessional talk held at the University of Derby in which I discussed alcohol, its effects and demonstrated how we all drink too much. BBC Derby were in attendance and requested an interview to discuss the topic of “Dry January” shortly after.

Blood Transfusion Service

The evidence within the FOI reports (**Mortimore** and McClements 2020; 2020a) was presented to the English and Scottish Blood Transfusion Service (BTS) who have since agreed to allow people diagnosed with GH, once in the maintenance stage of treatment, to donate their blood at their centres, on a more frequent basis than is currently permissible. The blood donated to BTS will be used for blood products, unlike the venesected blood in hospitals which is discarded due to lack of facilities and staff to centrifuge the blood into blood products. With regards to blood shortages, this exceptional outcome is an astonishing fact, and the evidence within this report has contributed to improving patient care.

BBC Radio 4 Charity appeal

The data within the FOI reports (**Mortimore** and McClements 2020, 2020a) and the Venesection Best Practice Guidance (Francis, **Mortimore** and HUK, 2020) was used as evidence for HUK’s charity appeal, launched in February 2021, on BBC Radio 4 by actor Stephen McGann. Radio 4 has far reaching influence and we are hoping that this will increase awareness of genetic haemochromatosis and raise money for the UK charity, HUK.

Pharmaceutical companies

It was because of my published literature on liver disease that Eisai, a Japanese pharmaceutical company with worldwide subsidiaries, became aware of my expertise. These publications were: *Nutrition and Malnutrition in Liver Disease: an overview* (**Mortimore**, 2020d; 2020e; 2020f; 2019e); *Gallbladder Cancer: nursing role in end-of-life care* (**Mortimore**, 2018); *Dying from Liver Disease: the importance of end of life discussions* (Watson and **Mortimore**, 2018); *Primary Sclerosing Cholangitis: a premalignant condition* (**Mortimore**, 2017) and my contribution to the *Cirrhosis Guideline* (NICE [CG50] 2016).

Eisai requested my assistance in developing a UK patient survey on hepatocellular cancer. Although this will be several years in development, it is planned to be published with me as a co-author alongside oncologists, oncology nurses and hepatologists. Eisai additionally requested my expertise to consult on the hepatology aspects of e-learning modules for nurses, regarding hepatocellular cancer aetiology, treatment, and management. These modules will be employed for continuing professional development (CPD) for nurses, across the UK and possibly Europe. Once the modules are authored, Eisai plan to apply to the RCN for e-module CPD endorsement. This necessitated filming of dialogue between myself and an oncologist. It was because of my delivery and knowledge base I was again approached by Eisai to request whether I would be willing to address their UK and Republic of Ireland medical team to discuss issues facing the NHS and patients regarding the Covid-19 pandemic. This was aired as a live meeting in December 2020. Being contacted and requested to assist in projects by an international pharmaceutical company not only validates my expert nursing status in liver disease, but also showcases the University of Derby.

In April 2020, I was contacted by Intercept Pharmaceuticals, an American biopharmaceutical company focusing on the development of novel synthetic bile acid analogues to treat chronic liver diseases. They contacted me as a direct result my published articles on Primary Sclerosing Cholangitis (PSC) (**Mortimore**, 2017c) and Primary Biliary Cholangitis (PBC) (**Mortimore**, 2019a, b, c; 2018e; 2017d). Due to the Covid-19 lockdown, a phone meeting was arranged to discuss potential ideas for non-alcoholic fatty liver disease (NAFLD) publications and projects specifically for nurse audiences in mind.

Appendix 12

Funding

My research experience as an academic researcher within an HEI was in sharp contrast to my experience working as a nurse researcher within the NHS. Within the

NHS it was acknowledged by RCP (2016) and Brown, Hewison, Gale, Snelling and Shneerson, (2015) that the biggest barrier to research was lack of protected time and funding. Working within the HEI I was granted allotted scholarly hours to contribute articles as part of Research Excellence Framework (REF) and actively encouraged to apply for funding to undertake my own research studies. Being awarded REF hours again highlights acknowledgement from the university that I am contributing to the university's research framework.

Successful funding awarded was from:

- **University Research and Knowledge Exchange Office (URKEO)** awarded £3570 in January 2020 from after successful application from the QR Strategic Priorities Fund, to disseminate impact of research at a policy level. This was in relation to freedom of information received from NHS Trusts re the treatment, management of GH and guidelines used, or not. A report was written to be presented to the Houses of Parliament, All Party Parliamentary Group, in February 2020. A final report was authored in September 2020. This has been sent to all UK Parliamentarians and to the BTS.
- **College REF Investment Fund** awarded £12,500 on 02/02/18 This represented £5,000 – maximum award for seed funding and £7,500.00 – maximum award for the mini-sabbatical. To commence my qualitative study "*Living with Genetic Haemochromatosis*".
- **College Scholarship and Research Strategy** awarded £5000 on 11/06/18, to continue with my research into "*Living with Genetic Haemochromatosis*".

Being successful in these funding awards can be, in part, attributed to my consistent track record of undertaking research and continued contribution to authoring

informative articles on liver disease, both of which have advanced healthcare professionals' knowledge of liver disease within a national and international arena. Furthermore, in recognition of my research and publication outputs I have been identified by the University, as a staff member with a Significant Responsibility for Research (SRR) and submitted to REF2021 in November 2020.

Appendix 13

International citations from publications as a lecturer in Advanced practice

An article, published in the *British Journal of Nursing* on pulmonary emboli (Toplis and **Mortimore** 2020), was cited by a Chinese paper published in the Lancet preprints in March 2020. The authors released findings from their experiences with patients diagnosed with the COVID-19 virus who, in 10%, will develop an acute pulmonary embolus secondary to an inflammatory response. In addition to this, an article titled, Ludwig's angina (Parker and **Mortimore**, 2019) has been cited in several international journals, with a further article titled, Advanced Nurse Practitioners: the NHS England framework (Reynolds and **Mortimore**, 2018) has been cited five times (appendix 10), three of which are in international journals.

Appendix 14

Signed CTA forms

Author attribution form

Publication title	Do H63D homozygote patients have clinically significant iron overload? Gut 60 (Suppl 1), A249-A250
Author(s)	K Rye, R scott, G Mortimore , A Lawson, J Freeman, A Austin

Area of activity	LP	AN OTHER
Formulation of objectives (%)	25%	
Contribution to the conception and design of methodology (%)	25%	
Literature review (%)	25%	
Acquisition/collection of data (%)	100%	
Analysis of data (%)	25%	
Interpretation of data (%)	25%	
Drafting the manuscript (%)	N/A	
Revising the manuscript (%)	N/A	
Final approval of the manuscript (%)	20%	
Accountability for all aspects of the work (%)	50%	
Corresponding author (✓)	N/A	-
Responsibility for submissions (%)	N/A	0
Responsibility for revision and re-submissions (%)	N/A	0
Overall attribution	50%	
Signed	[Redacted Signature]	

Criteria for author attribution:

- Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
- Drafting the work or revising it critically for important intellectual content; AND
- Final approval of the version to be published; AND
- Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Appendix 14 continued

Author attribution form

Publication title	'Patient experience of day case liver biopsy: Prospective audit', <i>Hepatology</i> , Vol. 44 Suppl. S1, p. 378A.
Author(s)	Li K., Mortimore G., Jackson M., Clarke D., Freeman J.G., Austin A. (2006a)

Area of activity	LP	AN OTHER
Formulation of objectives (%)		
Contribution to the conception and design of methodology (%)		
Literature review (%)		
Acquisition/collection of data (%)	100 %	
Analysis of data (%)		
Interpretation of data (%)		
Drafting the manuscript (%)		
Revising the manuscript (%)		
Final approval of the manuscript (%)		
Accountability for all aspects of the work (%)		
Corresponding author (✓)	N/A	
Responsibility for submissions (%)		
Responsibility for revision and re-submissions (%)		
Overall attribution	50 %	

- Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
- Drafting the work or revising it critically for important intellectual content; AND
- Final approval of the version to be published; AND

Appendix 14 continued

Publication title	(2016) "Non-invasive Diagnosis of Oesophageal Varices Using Systemic Haemodynamic Measurements by Finometry: Comparison with Other Non-invasive Predictive Scores", <i>Journal of Clinical and Experimental Hepatology</i> , 6(3), pp. 195-202. doi: 10.1016/j.jceh.2016.05.001.
Author(s)	Rye K., Mortimore G., Austin A. and Freeman, J.

Area of activity	LP	AN OTHER
Formulation of objectives (%)		
Contribution to the conception and design of methodology (%)		
Literature review (%)		
Acquisition/collection of data (%)	100%	
Analysis of data (%)		
Interpretation of data (%)		
Drafting the manuscript (%)		
Revising the manuscript (%)		
Final approval of the manuscript (%)		
Accountability for all aspects of the work (%)		
Corresponding author (✓)	N/A	
Responsibility for submissions (%)		
Responsibility for revision and re-submissions (%)		
Overall attribution	50%	
	—	

Substantial contributions to the conception or design of the work; or the acquisition, analysis, or

Appendix 14 continued

Author attribution for

Publication title	(2006b) Prospective audit of liver biopsy practice: Is bigger better? <i>Hepatology</i> , 44, (Suppl. S1), p. 377A.
Author(s)	Li K., Mortimore G., Jackson M., Semeraro D., Clarke D., Freeman J.G., Austin A.

Area of activity	LP	AN OTHER
Formulation of objectives (%)		
Contribution to the conception and design of methodology (%)		
Literature review (%)		
Acquisition/collection of data (%)	100%	
Analysis of data (%)		
Interpretation of data (%)		
Drafting the manuscript (%)		
Revising the manuscript (%)		
Final approval of the manuscript (%)		
Accountability for all aspects of the work (%)		
Corresponding author (✓)	N/A	
Responsibility for submissions (%)		
Responsibility for revision and re-submissions (%)		
Overall attribution	50%	

- Substantial contributions to the conception or design of the work, or the acquisition, analysis, or interpretation of data for the work; AND
- Drafting the work or revising it critically for important intellectual content; AND
- Final approval of the version to be published; AND
- Accountability for all aspects of the work in ensuring that questions related to the

Appendix 14 continued

Publication title	Dying from Liver Disease the importance of end of life discussions
Author(s)	Sharan Watson and Gerri Mortimore

Area of activity	LP	AN OTHER
Formulation of objectives (%)	50%	
Contribution to the conception and design of methodology (%)	50%	
Literature review (%)	50%	
Acquisition/collection of data (%)	-	
Analysis of data (%)	-	
Interpretation of data (%)	-	
Drafting the manuscript (%)	50%	
Revising the manuscript (%)	50%	
Final approval of the manuscript (%)	50%	
Accountability for all aspects of the work (%)	50%	
Corresponding author (✓)	50%	
Responsibility for submissions (%)	50%	
Responsibility for revision and re-submissions (%)	50%	
Overall attribution	50%	
Signed	[REDACTED]	

Criteria for

- Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
- Drafting the work or revising it critically for important intellectual content; AND
- Final approval of the version to be published; AND
- Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Appendix 14 continued

Publication title	Towards Noninvasive Detection of Oesophageal Varices. <i>International Journal of Hepatology</i> , 2012, pp.1-9.
Author(s)	Rye K., Scott, R., Mortimore, G., Lawson, A., Austin, A. and Freeman, J. (2012)

Area of activity	LP	AN OTHER
Formulation of objectives (%)		
Contribution to the conception and design of methodology (%)		
Literature review (%)		
Acquisition/collection of data (%)		
Analysis of data (%)		
Interpretation of data (%)		
Drafting the manuscript (%)		
Revising the manuscript (%)		
Final approval of the manuscript (%)		
Accountability for all aspects of the work (%)		
Corresponding author (✓)	N/A	
Responsibility for submissions (%)	-	
Responsibility for revision and re-submissions (%)	-	
Overall attribution	50%	
Signed		

Criteria

- Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
- Drafting the work or revising it critically for important intellectual content; AND
- Final approval of the version to be published; AND
- Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.