Patient Perceptions of Myeloma Imaging:

A survey study investigating perceptions and acceptance of the whole-body imaging techniques used for the diagnosis of myeloma

By

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Abstract

Purpose

To investigate patient perceptions and acceptance of the three whole-body imaging modalities used for diagnosing myeloma; radiographic skeletal survey (RSS), low-dose whole-body computed tomography (LD-WBCT) and whole-body magnetic resonance imaging (WB-MRI). The secondary aim was to explore the factors affecting the acceptance of whole-body imaging for myeloma.

Methods and Materials

60 participants (median age = 58.5 years) were recruited from three NHS trusts and myeloma support groups via social media. They completed a survey that included scoring different aspects of their experiences of whole-body imaging on a 5-point rating scale. The Kruskal-Wallis test was used to analyse differences in the distribution of scores. Participants were invited to provide open text responses for thematic analysis.

Results

All modalities demonstrated high levels of acceptability (median score = 4). WB-MRI was perceived as more stressful (p = 0.008) and claustrophobic (p = <0.001) than RSS and LD-WBCT. Thematic analysis of open text responses showed patients understood the importance of imaging for diagnosis but were concerned about existing bone damage, pain experienced during imaging and the diagnostic outcome. The duration of WB-MRI had a negative effect on acceptance. Respondents were averse to the physical manipulation required for RSS, whilst remaining stationery was perceived as a benefit of LD-WBCT and WB-MRI. Staff interactions had both positive and negative effects on acceptance.

Conclusions

While myeloma patients perceived psychological and physical burdens associated with whole-body imaging, they accepted its role in facilitating diagnosis. Staff support has a significant influence on imaging acceptance, and imaging choice should be tailored to individual needs. No evidence was obtained that supports the continued use of RSS.

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This thesis is dedicated to the memory of my colleague and friend, Barry Davies.

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List of Abbreviations

ADC	Attenuation diffusion coefficient
ANOVA	Analysis of variance
BJH	British Journal of Haematology
CASP	Critical Appraisal Skills Programme
CT	Computed tomography
DWI	Diffusion weighted images
GDPR	General Data Protection Regulations
HRA	Health Research Authority
IMWG	International Myeloma Working Group
IPEM	Institute of Physics and Engineering in Medicine
IRAS	Integrated research application system
IR(ME)R	Ionising radiation (medical exposure) regulations
LD-WBCT	Low-dose whole-body computed tomography
MGUS	Monoclonal gammopathy of undetermined significance
MRI	Magnetic resonance imaging
mSv	millisievert
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NRS	Numeric rating scale
PET-CT	Positron emission tomography/computed tomography
PPI	Patient and public involvement
PIS	Participant information sheet
QUADAS	Quality assessment of diagnostic studies criteria
REC	Research Ethics Committee
RSS	Radiographic skeletal survey
SDM	Shared decision making
STAI-S	Standardised state-trait anxiety inventory
UHCW	University Hospitals of Coventry and Warwickshire
UK	United Kingdom
VAS	Visual analogue scale
WB-CT	Whole-body computed tomography
WB-MRI	Whole-body magnetic resonance imaging

1. Introduction

1.1 Context and Rationale

The purpose of this study is to investigate patient acceptance and experiences of the different whole-body imaging modalities used within the National Health Service (NHS) for the diagnosis of myeloma in the United Kingdom (UK). Myeloma is an adult haematological cancer of the plasma cells found in the bone marrow which causes multiple bone lesions throughout the skeleton; therefore, the condition is often referred to as 'multiple myeloma' (Hansford and Silbermann 2018: 1). Radiological imaging is required to identify myeloma-related bone lesions for diagnosing and staging the disease and to guide effective treatment.

The three whole-body imaging techniques used for identifying myeloma related bone lesions are radiographic skeletal survey (RSS), low-dose whole-body computed tomography (LD-WBCT) and whole-body magnetic resonance imaging (WB-MRI). The author of this thesis is a Diagnostic Radiographer with experience in all three of these imaging modalities. Since 2002, the author has performed innumerable RSS examinations for the diagnosis of multiple myeloma, and in 2009 began to specialise in CT and MRI. It was not until 2016 that the author first performed WB-MRI examinations for the diagnosis of myeloma as part of a new service being developed within his department at that time. In early 2018 the author assisted with the development of a local LD-WBCT imaging protocol so that this imaging method for myeloma could also be offered. This detailed knowledge of each imaging modality and their fundamental differences, alongside an awareness that all three are still performed in the NHS, led the author to question if there was a clear consensus as to which imaging modality should be the first choice and whether RSS should be superseded by the latest whole-body imaging techniques.

Research investigating the primary imaging choice for diagnosing myeloma considers the question from the perspective of diagnostic value and a definitive consensus has not been made (Minarik et al. 2016; Regelink et al. 2013; Wolf et al. 2014). These studies have not considered the imaging choice from the perspective of the service users. The authors broad range of anecdotal evidence regarding individuals' experiences of all three whole-body imaging modalities led to an interest in attempting to understand the patients' acceptability of these examinations, and whether this could inform the primary imaging choice.

Diagnostic radiographers are in a unique position to address the question of 'which is the best form of diagnostic imaging' from a patient perspective. Radiographers interact with the patient throughout their examination and form part of the patients' imaging experience. The issue of diagnostic value will always be of most importance to the referring clinicians, whilst the technical parameters around each imaging modality are the domain of equipment manufacturers and medical physicists. Diagnostic radiographers have a key interest and involvement in both diagnostic value and technical parameters, whilst being responsible for guiding the patient through their imaging experience. When several different imaging choices are presented, the acceptability of each imaging modality from the patients' perspective became an intuitive line of enquiry for the author, whom has constantly observed the effects that the experience of imaging has on people. Patient choice and involvement is integral to modern healthcare (Harding and Park 2020: 67) and with new access to sources of information, such as the internet and social media, patients and the public are in an excellent position to be well informed of the options that may be available to them. This provides an opportunity for patients and the public to collaborate with healthcare practitioners and share their individual experiences so that their preferences are understood when choices are being made that will ultimately affect them (Phillips 2020: 71-72).

1.2 Background

Until 2014, when the International Myeloma Working Group (IMWG) updated their guidance, the gold standard for myeloma imaging was RSS (Minarik et al. 2016: 305), a series of conventional x-rays of the major bones in the body. This was the only imaging method available for myeloma until the development of whole-body computerised tomography (WB-CT), first reported by Horger et al. (2005). The major drawback of early WB-CT was the significant increase in ionising radiation that the patients were exposed to compared with RSS. As manufacturers have improved the technology of CT scanners, researchers and clinicians have developed methods to reduce the dose of ionising radiation for a whole-body CT for the diagnosis of myeloma. This improved form of whole-body CT is referred to as low-dose whole-body computed tomography (LD-WBCT). Whilst it has been developed and refined over a number of years it has only recently started to be widely adopted (Chantry et al. 2017).

As well as RSS and LD-WBCT, WB-MRI has started to be used for imaging multiple myeloma (Messiou and Kaiser 2018: 511). Conventional magnetic resonance imaging (MRI) is usually performed on a specific organ or area of the body. Technological advances, alongside the development of new MRI scanning parameters that dictate the anatomy and pathology that will be demonstrated, led to the initial development of WB-MRI. Steinborn et al. (1999) was amongst the first to report its effectiveness at identifying metastases in the skeleton, and Lecouvet et al. (1999) explored the possibility of replacing RSS with MRI for staging myeloma. Since this early research WB-MRI has been further refined and developed.

Guidance has been published to assist the clinician with selecting an imaging modality; any of them may be used with LD-WBCT or WB-MRI being recommended if available due to their greater diagnostic value (Chantry et al. 2017). As with many healthcare services, availability and the referring clinicians’ choice still remain key influencing factors.

1.3 Thesis Structure and Overview

Chapter 1 provides an introduction to the topic, the rationale for conducting this study and the aims and objectives.

Chapter 2 is a review of published literature. This begins with a more detailed depiction of myeloma and an explanation of the three whole-body imaging techniques that have been investigated. Research investigating the diagnostic value of different whole-body imaging techniques used in the diagnosis of myeloma, and patient acceptance of imaging is appraised to develop an understanding of the research area.

The first part of Chapter 3 discusses the research methodology and the study design selected. Detail regarding the development and review process of the survey instrument is presented here. The second part of this chapter reports the methods used.

Chapter 4 presents the results of the quantitative and qualitative components of the study and concludes with a summary of triangulation of the findings.

Chapter 5 provides a discussion of the implications of the results and findings of the study. Additionally, reflections and limitations of the research design are explored. This chapter details recommendations based upon the results, and the possible impact of the study.

Chapter 6 is the conclusion of this study and provides a concise summary of the findings.

1.4 Research Question, Aims and Objectives

What is the perceived acceptability of different whole-body imaging techniques experienced by patients being investigated for myeloma?

Aim: To determine the perceived acceptability of different whole-body imaging techniques experienced by potential myeloma patients.

Objective 1: To identify if myeloma patients score a particular whole-body imaging modality (RSS, LD-WBCT, WB-MRI) as either being more or less acceptable than its counterparts.

Objective 2: To demonstrate what factors, relating to both the radiology examination and the individual, influence the acceptability of whole-body imaging.

2. Literature Review

2.1 Method and Rationale for the Literature Review

This chapter will explore and critique the current published literature regarding the use of whole-body imaging for myeloma, and the patient acceptability and experience of imaging through a narrative literature review (Saks & Allsop 2013: 43). Whilst a narrative literature review method is limited by its subjectivity, it provides a valuable depiction of the current research and knowledge within the subject area and demonstrates the concepts, theories and research methods that have guided this study (Bowling 2014: 14; Saks & Allsop 2013: 43). To improve the objective quality of the literature review, the included literature has been reviewed with the Critical Appraisal Skills Programme (CASP 2019) checklists to ensure it is of sufficient quality for inclusion in terms of scientific rigour, the validity of the results and addressing potential bias.

The first part of this literature review is intended to provide a more detailed depiction of multiple myeloma, including the experiences of those living with the condition, to further contextualise the study.

The second part of this literature review includes a detailed description of the whole-body imaging methods being investigated and reports upon the published guidance regarding the different choices of whole-body imaging available.

The third part of this literature review is a critical appraisal of research that investigates the diagnostic value of the three whole-body imaging techniques. The complexities that prevent a consensus on which technique should be primarily utilised are explored.

The fourth part of the review is concerned with critiquing research that examines patient experiences, perceptions or acceptance of whole-body imaging. The purpose of this literature review was to provide an understanding of the current issues that affect patient perceptions and acceptance of radiological imaging.

Two separate literature searches were conducted; the first was to identify literature regarding the diagnostic value of whole-body imaging used for myeloma, whilst the second concerned the patient experience of imaging and living with myeloma. It was not possible to combine these searches as attempts to do this did not identify any relevant literature. The inclusion and exclusion terms for the literature searches are available in table 2.1. The results of the literature searches are available in appendix 2.

Table 2.1: Terms used for the literature searches

Included Terms	**Excluded Terms**
Radiogr* or Radiolog* or x-ray	Radiologist
CT OR Computed Tomography	Teach*
MRI OR Magnetic Resonance Imaging	Education OR Educat*
Technology AND Imaging	Literature prior to 2009
Multiple Myeloma OR cancer OR oncology	PET OR PET-CT OR Positron OR Emission
Patient AND Acceptance OR Experience* OR Perception*	
Survey OR Questionnaire	

The literature searches were conducted using MEDLINE and CINAHL as these databases contain journals that are relevant to medicine, radiology and radiography. Google Scholar was used to identify supplementary papers that were not on these databases. Literature from 2009 onwards was included to account for improvements in imaging technology and to prevent attempts at comparing out of date studies with current research (DePoy & Gitlin 2011: 92-93). These literature searches yielded a total of 162 papers. Titles and abstracts were reviewed, and relevant papers selected for detailed review. To be considered for detailed review selected papers were required to compare the effectiveness of two or more whole-body imaging methods for the diagnosis of multiple myeloma, or to compare patient perception, acceptance or experience of CT, MRI or both types of imaging. These additional criteria ensured selected papers were relevant to the topic investigated in this study. The selection process for included papers was carried out solely by the author, and is shown in figure 2.1. The PRISMA flow diagram was used to guide the selection process (Page et al. 2020).

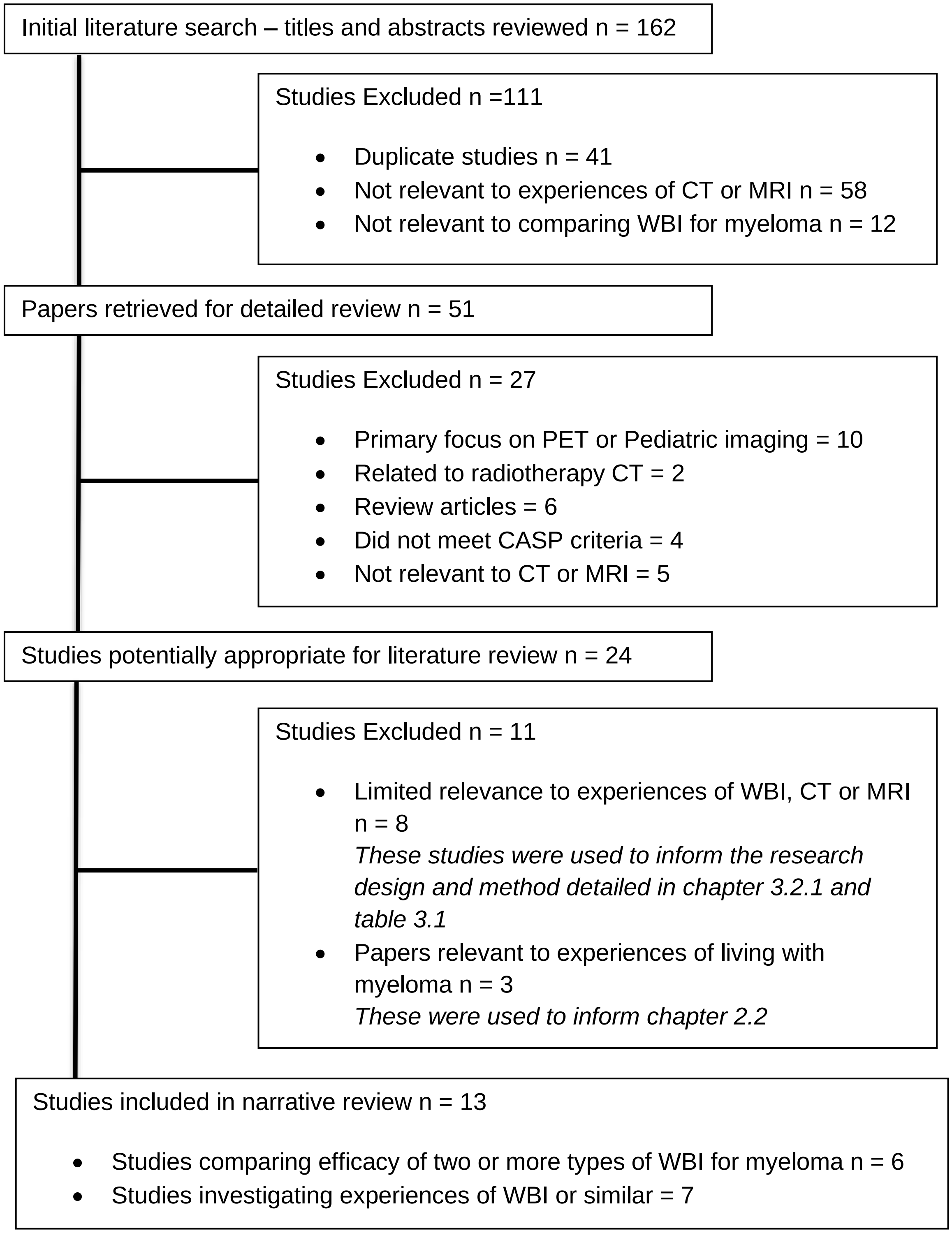


Figure 2.1: Flow diagram demonstrating the selection process of papers for the narrative literature review

2.2 Multiple Myeloma

Myeloma is a cancer of the plasma cells found in the bone marrow and is the most common primary malignancy of the skeleton. It is estimated that there were approximately 17,600 people living with myeloma in the UK in 2010 (Cancer Research UK: 2017) with 5,500 new cases diagnosed in the UK each year (Ashcroft et al. 2018: 3).

The disease starts with the growth of malignant plasma cells in the bone marrow causing an increase in osteoclast activity, bone cells that absorb bone tissue, whilst also suppressing osteoblasts, the cells responsible for producing new bone tissue (Messiou and Kaiser 2018: 509). This excessive osteoclastic activity causes the production of abnormal antibodies and various cytokines, proteins secreted by the immune system that signal an effect on other cells. In myeloma, some of these cytokines encourage the prolific growth of new malignant myeloma cells, beginning a cycle of tumour growth, bone destruction and the further production of abnormal antibodies (Messiou and Kaiser 2018: 509). The excessive osteoclastic activity also leads to areas of bone destruction that can be demonstrated with x-ray, CT and MRI imaging, any of which may identify numerous areas of lower bone density, defined as osteolytic lesions.

No specific cause for myeloma has been identified although age is considered the primary risk factor. Myeloma affects the older population with the median age at diagnosis being 70 years in the UK (King, Gooding and Ramasamy 2015: 149). Other risk factors are gender, ethnicity, a family history of myeloma, autoimmune conditions and obesity (Ashcroft et al. 2016: 5). The patient may initially present with any of the following symptoms: fatigue, weight loss, recurrent infections, pain, and pathological fractures whilst further investigation may also demonstrate anaemia and renal failure (Vlossak and Fitch 2005: 141). Making a differential diagnosis of myeloma requires clinical evaluation through a blood test to demonstrate anaemia, hypercalcaemia or renal impairment through raised creatinine, alongside a urine test to demonstrate the presence of abnormal protein (Field and Clark 2013: 177). The National Institute for Health and Care Excellence (NICE 2016: 47) states that further laboratory tests are then required to detect and quantify the presence of abnormal plasma cells, or abnormal antibodies called paraproteins. The final part of the diagnosis is the identification and evaluation of bony lesions through radiological imaging. The confirmation of a diagnosis of myeloma is not based upon a single factor but a combination of these clinical features, laboratory tests and imaging (NICE 2016: 47).

Myeloma is normally preceded by a much more common condition called monoclonal gammopathy of undetermined significance (MGUS) whereby paraproteins are present with no further symptoms (King, Gooding and Ramasamy 2015: 149). Although not all people with MGUS develop myeloma, those who do will require periodic monitoring of their condition. A second precursor condition to multiple myeloma, ‘asymptomatic myeloma’, has been described by the International Myeloma Working Group (IMWG) as ‘…an intermediate clinical stage between MGUS and multiple myeloma in which the risk of progression to malignant disease in the first 5 years after diagnosis is much higher…’ (Rajkumar et al. 2014: 538).

By investigating the specific whole-body imaging techniques used for diagnosing myeloma, the unique perspective of those with this condition must also be considered. People living with myeloma travel along a continuum of diagnosis and treatment followed by ongoing care with periods of remission and recurrence (Hauksdóttir et al. 2016: 75; Nicoletti 2012: 3-4). Throughout this journey, there will be frequent hospital visits for diagnostic tests, treatment, and follow-up. The impact of myeloma has been recognised by several authors, with Nicoletti (2012: 3) stressing that the quality of life is as important as extending the patient’s life. Vlossak and Fitch (2008: 141) state that although healthcare practitioners cannot presume to know what it is like to have a condition as complex as myeloma, they should still attempt to understand its impact from the patients’ perspective. A meta-analysis of qualitative research conducted by Hauksdóttir et al. (2016: 69) explored the negative effects that a diagnosis of myeloma can have on the patients’ psychological and emotional well-being, with concerns regarding changes in the bones being cited as a specific source of distress. In interviews with a group of myeloma patients, Vlossak and Fitch (2008: 145) found that knowing there will be a definite recurrence of their condition, but not knowing when, was one of the most difficult aspects of living with myeloma. Although Vlossak and Fitch (2008) found that myeloma patients are usually accepting of their required medical interventions, the monthly diagnostic blood tests were a frequent source of stress. Participants stated that each new ache and pain reminded them of the potential of a relapse. None of the authors investigated the impact that imaging can have on those with myeloma, but it may be reasonable to assume that concern over other investigations and bone changes could indicate that there is also a burden associated with whole-body imaging for bone lesions. All of these authors investigating patients' experiences of myeloma identified the need for healthcare staff to provide support in an effort to improve the patient experience throughout their care (Hauksdóttir et al. 2016: 77; Nicoletti 2012: 3; Vlossak and Fitch 2008: 145).

2.3 Whole-Body Imaging Techniques

As myeloma lesions can be present in any number of the major bones of the skeleton, identifying them with radiology requires the use of imaging techniques that do not focus on a specific body part but are instead able to obtain images of the majority of the skeleton. These techniques are frequently referred to as whole-body imaging. There are four primary imaging techniques that can be utilised for whole-body imaging of the skeleton for myeloma; RSS, LD-WBCT, WB-MRI and positron emission tomography (PET-CT). Guidelines published by NICE (2016), IMWG (Rajkumar et al. 2014) and the British Journal of Haematology (BJH) (Chantry et al. 2017) recognise that all of these whole-body imaging methods can potentially be used, although they each provide recommendations that will be discussed in chapter 2.3.5. It is outside the scope of this text to provide an in-depth description of the process of image acquisition, but a summary of each technique is provided in chapters 2.3.1, 2.3.2, 2.3.3 and 2.3.4.

2.3.1 Radiographic Skeletal Survey (RSS)

RSS, occasionally referred to as a whole-body x-ray, is an examination that involves performing conventional radiographs of the bones of the skeleton that are most likely to be affected by myeloma-related osteolytic lesions. The areas that are x-rayed are outlined in table 2.2 with different authors describing various RSS protocols that have different numbers of radiographs, usually dictated by national guidance and local protocol (Dimopoulos et al. 2009: 2; D’Sa et al 2007: 53; Lambert et al. 2017: 2491). A skeletal survey uses relatively low doses of ionising radiation and takes approximately thirty minutes. It does require some manipulation of the patient in order to position them correctly for each radiographic projection which has been acknowledged as being potentially painful for some individuals (Dimopoulos et al. 2009: 2; D’Sa et al. 2007: 51) although research investigating this has not been found. This imaging technique has long been the ‘gold standard’ of whole-body myeloma imaging but has been superseded by new techniques that perform better as a diagnostic tool (Minarik et al. 2016: 305).

An example of the equipment used for RSS and the appearance of osteolytic lesions on the resultant images are demonstrated in figures 2.2 and 2.3.

Table 2.2: Parts of the skeleton and number of radiographs required for RSS

	Number of Radiographers recommended by different authors.		
Body Part	Dimopoulos et al. (2009: 2) International Review	D'Sa et al. (2007: 53) UK	Lambert et al. (2017: 2491) Czech Republic
Skull	1-3 (not specified)*	2	2
Cervical spine	2-3 (not specified)*	3	2
Chest and ribs	1	2	2
Thoracic Spine	2	2	2
Bilateral humeri	2-4 (not specified)*	4	2
Forearm	Not usually required	Not usually required	2
Lumbar spine	2	2	2
Pelvis	1	1	1
Bilateral femora	2-4 (not specified)*	4	2
Tibia/Lower leg	Not usually required	Not usually required	2
Total number of radiographs	≤19	19	19

*Where the author has not specified the number of radiographs for a specific body part the absolute minimum and maximum possible values have been included.

Figure 2.2: An example of standard digital radiography x-ray equipment used in the UK for RSS.

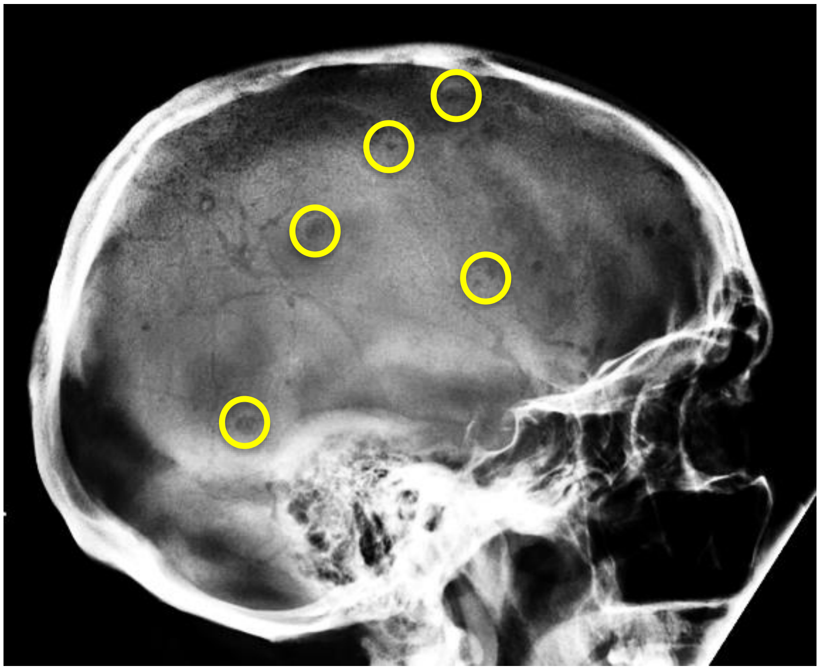


Figure 2.3: A lateral radiograph of the skull demonstrating numerous osteolytic myeloma lesions.

2.3.2 Low-Dose Whole-Body Computerised Tomography (LD-WBCT)

Computerised tomography (CT) is a method of cross-sectional imaging whereby an x-ray tube and an x-ray detector rotate rapidly around the patient creating an x-ray profile. The x-ray profile is then reconstructed into images that represent multiple thin cross-sections of the patient by a mathematical iterative image reconstruction algorithm. There are numerous methods of conducting CT with the specific clinical question usually dictating the method chosen. Amongst the most common method employed is a scan of the thorax, abdomen and pelvis for diagnosing a broad range of disorders of the soft tissue organs. Such a scan uses ionising radiation and an intravenous injection of contrast agent (Adams et al. 2014: 163).

Horger et al. (2005) first developed and tested a method of performing a whole-body CT scan using a reduced dose of ionising radiation in comparison to a conventional CT scan and without the requirement of an intravenous injection of contrast agent for the specific purpose of diagnosing myeloma, in lieu of a RSS. This scan is referred to as LD-WBCT and has only recently been widely adopted and recommended in place of RSS (Chantry et al. 2017: 381). LD-WBCT can be performed in less than ten minutes and with minimal physical manipulation of the patient in comparison to RSS (Ippolito et al. 2014: 2326). The radiation doses of LD-WBCT have been reported as being two to four times greater than RSS (Hillengass et al. 2017: 5) but with advances in technology and refinements in the use of LD-WBCT, Lambert et al. (2017: 2493) have reported equivalent doses of radiation across the two imaging techniques. The primary technological advancements have been an increase in the sensitivity of the x-ray detector allowing for equivalent quality images with a reduced dose of ionising radiation, combined with significantly improved image reconstruction algorithms and modulated exposures; a system whereby the CT scanner is able to account for different densities in the body and either decrease or increase the required amount of radiation accordingly (Samei & Peck 2019: 253-265).

An example of the equipment used for LD-WBCT and the appearance of osteolytic lesions on the resultant images are demonstrated in figures 2.4 and 2.5.

Figure 2.4: An example of a multi-slice helical CT scanner commonly used in the UK for LD-WBCT.

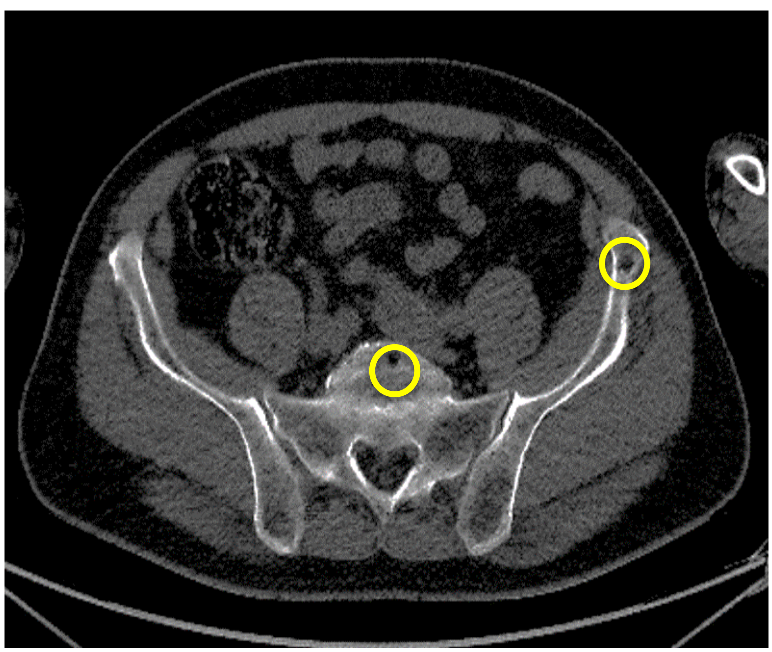


Figure 2.5: A single CT cross-sectional image through the pelvis at the level of the sacroiliac joints. This image demonstrates two osteolytic myeloma lesions.

2.3.3 Whole-Body Magnetic Resonance Imaging (WB-MRI)

Magnetic resonance imaging (MRI) utilises a powerful magnetic field that interacts with the combined magnetic fields of the patient's hydrogen atoms. A radio wave at a specific frequency is applied to the patient. This causes a phenomenon known as resonance, whereby the magnetic fields of the patient's hydrogen atoms synchronise, creating a sum magnetic field that can be detected by a device called a radiofrequency receiver coil. The radiofrequency receiver coil converts the sum magnetic field emitted by the patient into an electric signal through the principle of Faraday's Law. This signal is processed by the MRI scanner through an image reconstruction algorithm that leads to the creation of diagnostic images. The variance in the distribution and molecular configuration of hydrogen throughout the body causes the range of greyscales on the images that represent different tissue types and pathologies. MRI, like CT, is another type of cross-sectional imaging. Multiple sets of images, known as sequences, can be obtained that will demonstrate anatomy and pathology differently to build up a complete clinical picture. Although there can be variation in WB-MRI protocols, the key sequences required for WB-MRI in the diagnosis of myeloma are demonstrated in table 2.3 (Messiou and Kaiser 2018: 514-516). It should be noted that there is no exposure to ionising radiation associated with WB-MRI although there are certain contraindications, such as the presence of intracranial clips or a pacemaker (Graham, Cloke and Vosper 2011: 294). WB-MRI can take up to one hour (Messiou and Kaiser 2018: 515) during which time the patient needs to remain as still as possible. The patient will have receiver coils strapped across the head and body and will require some form of ear protection as the scan can create sound pressures of up to 120 decibels (Graham, Cloke and Vosper 2011: 294).

An example of the equipment used for WB-MRI and the appearance of myeloma lesions on the resultant images are demonstrated in figures 2.6 and 2.7.

Table 2.3: WB-MRI sequences required for myeloma imaging

Type of MRI Sequence and Anatomical Plane	**Body part and anatomical plane**
T1 and T2 weighted sagittal images	To demonstrate the cervical, thoracic and lumbar spines for cord compression or other complications caused by destructive myeloma lesions
Dixon sequence in the axial plane	Provides both fat and water suppressed images from the vertex of the skull to below the knee. This sequence demonstrates anatomy with good resolution
Diffusions weighted images (DWI) and attenuation diffusion coefficient map (ADC map)	Provides images that are highly sensitive to abnormalities of the skeleton, including osteolytic lesions.

Figure 2.6: An example of an MRI scanner used for WB-MRI in the UK.

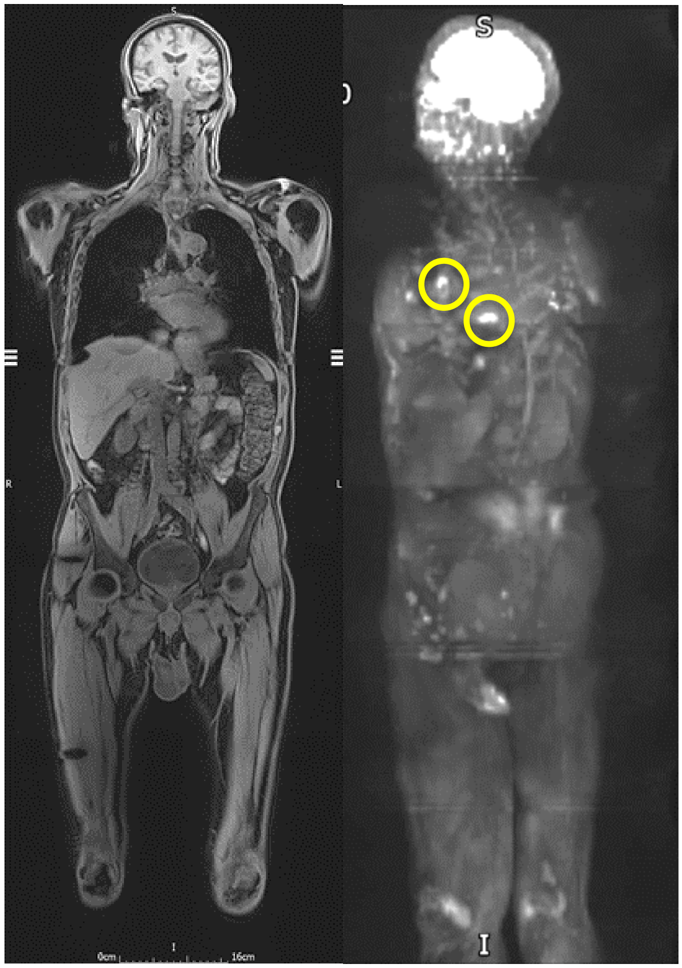


Figure 2.7: Examples of WB-MRI images. The image on the left has been reconstructed in the coronal plane and demonstrates anatomy. The diffusion-weighted image (DWI) on the right has been reconstructed in the coronal oblique plane and demonstrates myeloma lesions in the rib cage.

2.3.4 Positron Emission Computed Tomography

Positron emission computed tomography (PET-CT) combines a whole-body CT scan for the demonstration of anatomy, with positron emission tomography (PET). A radiopharmaceutical labelled with a positron emitter, usually 18-fluorine-fluoro-deoxyglucose (FDG), is given intravenously up to 60 minutes prior to imaging. Areas of increased abnormal metabolic activity, such as myeloma bone lesions, absorb a greater amount of the radio-pharmaceutical making the scan highly sensitive to pathology (Hansford and Silbermann 2018: 3). This combined method of imaging improves both the spatial resolution and the sensitivity of the images (Dimopoulos et al. 2009: 6). Although PET-CT can be used for whole-body myeloma imaging, the guidelines published by the BJH state that there is insufficient evidence to recommend its routine use in cases of newly diagnosed myeloma (Chantry et al. 2017: 385). Furthermore, NICE (2016: 79) do not recommend PET-CT for diagnosing suspected myeloma due to financial costs, although it may be useful for imaging specific myeloma cases of ‘non-secretory’ myeloma or for treatment follow-up. As it is not recommended for routine use in the investigation of myeloma it has been excluded from this study.

2.3.5 Published Clinical Guidance

In 2014 the International Myeloma Working Group (IMWG) updated the criteria for diagnosing myeloma in light of technological advances in the diagnostic tools available (Rajkumar et al. 2014: 542). Previously RSS had been considered the gold standard of whole-body imaging for myeloma (Minarik et al. 2016: 305). The IMWG now recognises the diagnostic value and routine use of LD-WBCT and WB-MRI in identifying myeloma-related bone lesions, if these modalities are locally available. Although the imaging guidelines published by NICE (2016) and the BJH (Chantry et al. 2017) all concur that LD-WBCT or WB-MRI should be used when available, they still recognise the use of RSS as an alternative. In the author's experience, there are very few NHS trust in the UK that do not have a CT scanner locally available. The Institute of Physics and Engineering in Medicine (IPEM) surveyed 117 of the 183 NHS radiology departments and reported a total number of 298 CT scanners (IPEM 2015: 5). A second survey of 73 responding NHS radiology departments reported a total number of 171 MRI scanners (IPEM 2017: 7). Given that these imaging modalities appear to be largely available and are recommended by three expert bodies (Chantry et al. 2017; Rajkumar et al. 2014; NICE 2016) the continued use of RSS must be brought into question.

The published guidance provides recommendations on when to use the different whole-body imaging modalities, although the results of laboratory tests, radiology tests and the patient's symptoms are all factors that will influence what is primarily the choice of the clinician, alongside local availability (Chantry et al. 2017; NICE 2016). This published guidance demonstrates how the new whole-body imaging methods are only being routinely employed within the last few years. Research that will be discussed in detail in chapter 2.4 has attempted to define the efficacy of each test, but both Chantry et al. (2017: 389) and NICE (2016: 85) recognise that the patient acceptance of each imaging modality is unknown and may be an outcome of interest in future research due to the current focus of patient choice and involvement in healthcare. There are failure rates associated with whole-body imaging examinations discussed in chapter 2.4, indicating a variance in acceptability that needs to be better understood (Munn et al. 2015). The authors own anecdotal experiences of providing whole-body imaging for patients has shown that the acceptability of any imaging technique can be unpredictable. Some individuals can find a particular examination to be a difficult experience, whilst others may perceive imaging much more positively.

2.4 Review of Research Investigating the Diagnostic Value of Whole-Body Imaging for Myeloma

The primary purpose of imaging is to provide the clinician with the information needed for a differential diagnosis to be made. In order to assess the value of any diagnostic test, it needs to be compared against a current standard in order to demonstrate whether it is sensitive to abnormalities and whether it is able to specify what the abnormalities are. The number of true positives and true negatives are also vital when investigating the efficacy of a diagnostic test, and the terms sensitivity and specificity are used to refer to this. Although there are a number of factors that will influence the choice of a diagnostic test to be used, such as cost and availability, sensitivity and specificity remain fundamental to imaging choice. In this chapter, research of the diagnostic value of whole-body imaging has been reviewed, with a summary of the papers provided in table 2.4.

Table 2.4: Summary of literature review: Whole-body imaging investigating myeloma

Author	Imaging Compared	Research Design	Sample Size	Reported Radiation Dose	Conclusions and Recommendations
Regelink et al. (2013)	RSS LD-WBCT WB-MRI	Meta-Analysis	32 studies	Not accurately reported	LD-WBCT and WB-MRI performed equally and were superior to RSS.
Wolf et al. (2014)	RSS against LD-WBCT or WB-MRI	Retrospective cross-section	171 patients with myeloma or MGUS	RSS 2.4mSv LD-WBCT 9.4-11.3 mSv	LD-WBCT for diagnosis myeloma WB-MRI for imaging MGUS These imaging techniques potentially altered staging for 83 patients
Minarik et al. (2016)	RSS LD-WBCT WB-MRI	Prospective cross-section No statistical analysis	112 patients with myeloma or MGUS	LD-WBCT 4mSv	Either WB-MRI with limited x-ray imaging, or LD-WBCT with limited MRI imaging Staging altered for 1 patient
Lambert et al. (2017)	RSS LD-WBCT	Prospective cross-section	74 patients with myeloma divided into 486 anatomical regions	RSS 2.5mSv LD-WBCT 2.7mSv	WB-LDCT is superior and altered staging for 24% of cohort.
Hillengass et al. (2017)	RSS LD-WBCT	Retrospective cross-section	212 patients with myeloma	Not accurately reported LD-WBCT 2-4 times greater than RSS	WB-LDCT is superior but did not alter disease staging

Regelink et al. (2013) undertook a systematic review to examine whether there is evidence for the replacement of RSS in the detection of myeloma lesions with ‘modern imaging techniques’, specifically CT, LD-WBCT, WB-MRI or PET-CT. The authors report their search strategy which used the Quality Assessment of Diagnostic Studies Criteria (QUADAS) (Whiting et al. 2011) to ensure studies of sufficient quality and with full results were included. The thirty-two included papers compared two or more imaging modalities against each other. This was done by comparing the sensitivity and specificity, as well as the overall number of detected bone lesions. This data was subject to a meta-analysis by the authors. Before reviewing the results of this study an important limitation needs to be considered; of the 32 studies included only 7 utilised whole-body imaging techniques, the results of which have not been reported separately. Therefore, these results are mostly demonstrating conventional CT and MRI. Both were shown to perform at least equally to RSS in terms of sensitivity and specificity, although the results show that there may be lesions detected by RSS that are not shown on the other imaging modalities. However, when reviewing the overall detection rate of bone lesions, the authors reported that CT and MRI detected up to 80% more lesions than RSS (Regelink et al. 2013: 55). While RSS was shown to be the inferior imaging method, if the lower detection rate of RSS doesn’t affect the accuracy of an individual's diagnosis or the staging of disease then it may be possible to justify using RSS when it is the only imaging modality available. As outlined in chapter 2.3.5, the surveys conducted by IPEM (2015: 5; 2017: 7) indicated good availability of both MRI and CT scanners in the UK.

Regelink et al. (2013: 55) report that most of the CT scans included in the meta-analysis were low dose with two studies using a higher radiation dose. The details provided are insufficient to allow the reader to interpret the radiation doses used for each study. This introduces a significant bias as it is a known scientific principle that radiation dose has a strong impact on image quality which will in turn influence diagnostic value (Samei & Peck 2019: 212-213). As radiation dose is a key variable that effects image quality, this introduces further heterogeneity to the included studies, hampering direct comparison. Another variable that should be considered when interpreting the results is maturation; the effect that time can have on the validity of the research (DePoy & Gitlin 2011: 92-93). In this meta-analysis research from 1985 to 2012 was included. Over this period changes in practice and improvements in technology will further affect the heterogeneity of included studies, a limitation recognised by Regelink et al. (2013: 57-58).

Whilst the meta-analysis by Regelink et al. (2013) highlights the value of WB-CT and WB-MRI it also demonstrates to the reader the barriers in attempting to compare multiple studies. This issue has also been recognised by NICE (2016: 66, 84) who stated that the studies included to provide evidence for their myeloma guidelines suffered from considerable heterogeneity in estimating sensitivity and specificity, and the quality of the evidence was moderate to low when assessed with QUADAS criteria (Whiting et al. 2011). There have been a number of studies published since 2013 that continue to investigate the diagnostic value of different whole-body imaging techniques for myeloma.

Wolf et al. (2014) researched the sensitivity of RSS in identifying myeloma lesions, against either LD-WBCT or WB-MRI. The study was conducted retrospectively, with data collected from 52 patients who had RSS and LD-WBCT, and 119 patients who had RSS and WB-MRI. The images collected were evaluated by two radiologists to identify the size, location and number of bone lesions demonstrated. To eliminate bias through prior knowledge, the radiologists were blinded to the participants' findings on different scans. In addition, having two radiologists review the images eliminated objectivity with Wolf et al. (2014: 1224) reporting that the radiologists were in consensus across all of the images. Wolf et al. (2014: 1224) also provided detailed information regarding the parameters used for LD-WBCT and WB-MRI, in addition to the mean radiation dose. As demonstrated in the meta-analysis by Regelink et al. (2013), different scanning parameters potentially add a number of variables to the imaging technique and effect heterogeneity. By providing these parameters the reader can consider their effect on the study, and sufficient detail has been provided to allow the reader to replicate this imaging. The mean radiation dose for LD-WBCT was reported to be in the range of 9.4 and 11.3 mSv compared to a mean radiation dose of 2.4 mSv for RSS.

Wolf et al. (2014: 1225-1226) report that RSS identified bone lesions in 30 of the 52 patients whilst LD-WBCT identified bone lesions in 42 patients. Through statistical analysis a significant difference in detection was demonstrated between these imaging modalities. Additionally, there were no lesions visible on RSS that could not also be identified on LD-WBCT. In the second group of 119 patients, WB-MRI detected lesions in 43 patients, whilst RSS only detected lesions in 19 patients. Again, this difference in detection rate was shown to be statistically significant (Wolf et al. 2014: 1226). The effect of this improvement in lesion detection is that some patients being investigated for myeloma would have had have their disease up-staged, potentially leading to treatment that they would not have received had they only been investigated using RSS. 8 of the 52 patients who had WB-CT could have received treatment that they would not have had if they had only received RSS, as this would have staged them as having MGUS (Wolf et al. 2014: 1227). For the group of 119 patients that received WB-MRI and RSS, the WB-MRI would upstage 38 patients, but even more significantly, down-stage 45 patients potentially preventing unnecessary treatment in 8 of these (Wolf et al. 2014: 1228). These changes in staging have been retrospectively applied to illustrate the impact of improved diagnostic value and do not reflect the clinical decisions made for any of the patients. They illustrate the importance utilising the most accurate imaging technique to ensure patients are staged accurately and then provided with the appropriate treatment.

The WB-CT performed in this study is reported as being low dose, although the authors recognise that the mean dose of 9.4-11.3 mSv is higher than other reported LD-WBCT doses of 4.1-7.5 mSv of radiation (Wolf et al. 2014: 1229). Although there is a recognised relationship between radiation dose and image quality (Samei & Peck 2019: 212-213) Wolf et al. (2014: 1229) argue that a low-dose CT protocol should not affect the diagnostic accuracy in the detection of osteolytic lesions. This is a valid argument as a reduction in radiation will have the most impact on the image quality of soft-tissue structures, which are outside the scope of a WB-CT examination for diagnosing myeloma, and the image quality of boney structure will be much less effected.

This study demonstrates how whole-body imaging with greater sensitivity can affect the staging and treatment for myeloma patients. Wolf et al. (2014: 1230) also consider patient comfort of RSS and LD-WBCT, stating that the latter may be a more comfortable examination for the participant due to the quick examination time and the minimal positioning requirement, although they do not discuss the comfort of WB-MRI. The conclusion of this study is that LD-WBCT should be utilised over RSS for all cases of myeloma. For patients with MGUS, LD-WBCT should not be used if WB-MRI results are normal. This is because those with MGUS will not necessarily develop into myeloma and the risks of exposure to radiation must be considered.

The results presented by Wolf et al. (2014) do little to support the ongoing use of RSS. The evidence provided indicates that incorrectly staging disease could lead to either unnecessary treatment, or treatment not being given when it could be of benefit. Despite the evidence presented, RSS is still widely utilised and the reasons for this remain unclear.

A limitation recognised by the Wolf et al. (2014) is that it was not possible to compare WB-MRI and LD-WBCT against each other as only two participants in the cohort had undergone both imaging modalities. Due to the ethical considerations of exposing patients that are also research participants to additional ionising radiation, comparing different scan types is normally only possible when imaging is part of the patient's clinical care, or if the study uses a prospective design.

Minarik et al. (2016: 305) conducted a prospective comparison of RSS, LD-WBCT and WB-MRI across 112 participants, the rationale being that RSS may underestimate myeloma-related bone disease. All three whole-body imaging techniques were performed on 43 participants allowing for direct comparison of the number of detected bone lesions. 83 participants were known to have multiple myeloma, and 28 had a diagnosis of MGUS. Minarik et al. (2016: 306) provide demographic data that demonstrates the characteristics of the cohort are representative of the Caucasian population living with monoclonal gammopathies.

The technical parameters of RSS and LD-WBCT are described in moderate detail with the mean dose of radiation for LD-WBCT reported as being 4 mSv. Specific information regarding the WB-MRI parameters is lacking, therefore the reader is unable to make any judgement on the scanning parameters selected, and if those recommended by Messiou and Kaiser (2018: 515) for detecting myeloma have been included. A single radiologist was designated to review all of the LD-WBCT scans, with a second radiologist reviewing the WB-MRI in order to prevent bias due to knowledge of the patient's results on the other imaging technique. Whilst this is an excellent method to eliminate variables, it is unclear how the RSS was reviewed, and if the reviewers were blinded to these results or not.

The presented results are descriptive with percentages provided for the number of detected lesions on each modality; no statistical analysis was performed. The authors have separated the results to show the sensitivity of the different whole-body imaging techniques for different parts of the body, primarily the skull, spine and long bones. Regarding the skull, LD-WBCT identified myeloma lesions in 16% of patients that had a negative result using RSS. WB-MRI was unable to identify any of the skull lesions. In identifying lesions of the spine, WB-MRI demonstrated lesions in 4 of the patients (23%) that had no lesions demonstrated on LD-WBCT, although the authors state that this would not have affected the staging for these patients. Minarik et al. (2016: 306-307) state that as a result of WB-MRI and LD-WBCT, one patient who had a diagnosis of MGUS through RSS was upstaged to multiple myeloma. Throughout the rest of the skeleton, all three imaging techniques were largely in concordance regarding the number of bone lesions although LD-WBCT and WB-MRI identified additional lesions in 15% of the patients (Minarik et al. 2016: 307).

Whilst this research utilised a small sample, myeloma is uncommon, and it was able to collect data prospectively. It has been included in this literature review as the study was able to do comparisons across all three whole-body imaging techniques, although the patients that had received all three imaging techniques are not reported separately. The results, although descriptive, highlight to the reader a further variable in identifying bone lesions; the location within the skeleton. Minarik et al. (2016: 307) state that as a result of this study, 4 MGUS patients had bone lesions identified using LD-WBCT. Although the lesions were not significant enough to up-stage the patients to multiple myeloma, they will be carefully monitored. Minarik et al. (2016: 308) conclude that RSS may give false-negative results and underestimate bone lesions. While WB-MRI performed better in identifying spinal lesions, the additional costs should be considered. The authors recommend either WB-MRI supported by X-ray of the skull or LD-WBCT supported by MRI of the spine.

The evidence presented by Minarik et al. (2016) does provide some support for the use of RSS for imaging of the skull and long bones of the skeleton, but caution must be taken as under-staging disease through the use of RSS is possible. The issue of cost is addressed, and while the effective use of resources is important for maintaining a sustainable health service, the guidelines on the diagnosis and management of myeloma produced by NICE (2016: 74-78) for the NHS argue that a more expensive imaging modality has the potential for long term savings. The estimated cost of RSS is £108.82, LD-WBCT is £147.17 and WB-MRI is £203.06. The NICE (2016) guidelines conclude that there is a strong case that using LD-WBCT or WB-MRI is cost-effective due to the benefits of early detection and negating the need for additional more detailed imaging if RSS demonstrates bone lesions. Therefore, if the cost of imaging is not the reason that RSS is sometimes selected over other whole-body imaging modalities, availability must be considered as an influencing factor.

Two further studies have provided a detailed analysis of the diagnostic value of RSS and LD-WBCT, whilst also considering the associated dose of ionising radiation and the location of lesions in the skeleton. Lambert et al. (2017) performed RSS and LD-WBCT on a group of 74 patients, giving a total of 486 separate anatomical regions. Images were reviewed by two observers to ensure consensus, and statistical analysis was performed using the Wilcoxon signed-rank test or pairwise t-test. RSS identified bone disease in 127 of 486 anatomical regions, and these findings were compared to LD-WBCT. RSS gave false-negative results in 16% of patients and gave false-positive results in a further 8%. Lambert et al. (2017: 2492-2493) were also able to demonstrate that RSS was significantly less sensitive at identifying bone lesions in the spine, ribcage and scapulae, supporting the descriptive study conducted by Minarik et al. (2016). Lambert et al. (2017: 2493) argue that the overall lack of sensitivity of RSS is mitigated by good sensitivity in the long bones. However, this study reported that LD-WBCT adjusted the staging for 24% of the study participants when compared to staging made using only RSS (Lambert et al. 2017: 2493). As stated previously, adjusting the staging of myeloma has the potential to influence treatment decisions and therefore the use of LD-WBCT over RSS has to be recommended.

Lambert et al. (2017: 2492) provide accurate data regarding the comparative dose of ionising radiation with RSS being reported as having a mean dose of 2.5 mSv and LD-WBCT of 2.7mSv, showing the reader how effective LD-WBCT can be at an equivalent dose. This dose is comparable to the ionising radiation doses reported in an audit at the author's workplace of 2.45 mSv (Wayte 2020), although the mean dose of RSS at the author's workplace has not been audited. Both of these mean doses are significantly lower than the mean dose of 9.4-11.3 mSv reported by Wolf et al. (2014: 1227). A number of possibilities exist that could account for the difference, most notably improvements in technique and equipment over time are likely to push doses down. These figures serve to demonstrate that it is possible to get the dose of ionising radiation for LD-WBCT to be comparable to that of RSS, which would further support the argument for using LD-WBCT. However, if an imaging modality exists the requires no exposure to ionising radiation then it becomes possible to completely mitigate the associated risks. Therefore, the reason for the continued use of all three modalities is likely to return to the issue of resources and the availability of whole-body imaging equipment and expertise.

Research by Hillengass et al. (2017) collected retrospective data from 212 participants who had received RSS and LD-WBCT across eight sites worldwide. Detailed information is provided regarding the imaging techniques used and associated radiation doses. Images were reviewed for consensus by three blinded observers. Of the 212 participants, LD-WBCT identified bone disease not demonstrated on RSS for 54 patients. Conversely, RSS was able to identify bone disease in 12 patients that was not seen using LD-WBCT, providing further evidence that there may not be a single whole-body imaging technique that will always reliably identify myeloma lesions. The findings of this study further support the research conducted by Minarik et al.

(2016) and Lambert et al. (2017) with LD-WBCT demonstrating significantly higher detection rates of myeloma lesions in the spine and ribcage (Hillengass et al. 2017: 3).

In a valuable sub-group analysis, Hillengass et al. (2017: 3-4) compared the prognostic value of RSS and LD-WBCT for both multiple myeloma patients and asymptomatic myeloma patients. They concluded that there was no significant prognostic difference in identifying additional lesions using LD-WBCT but agreed with Minarik et al. (2016) that identifying additional lesions can demonstrate if an asymptomatic myeloma patient has a greater risk of progressing to multiple myeloma (Hillengass et al. 2017: 5). They state a concern of identifying myeloma lesions earlier is that the potential exists for beginning treatment at a time when it is not yet necessary but leading to potential side effects and complications for patients (Hillengass et al. 2017: 4). Although this concern may exist, in the NHS each patient would be treated on an individual basis; the results of imaging would be reviewed alongside other laboratory testing by a Haematology Consultant with further input from a multidisciplinary team meeting before treatment decisions are made.

Hillengass et al (2017: 5) recommend LD-WBCT over RSS. Although they have not reported a mean dose of radiation, they believe the radiation dose of LD-WBCT to be between 2 - 4 times greater than that of RSS but argue that LD-WBCT is faster and more convenient for the patients.

A summary of the research that has been reviewed is presented in table 2.4. These studies share a common theme; identifying an imaging modality that always outperforms its counterparts is not possible due to the largely unpredictable nature of the sites of bone disease and the additional variables introduced through different scanning techniques and doses of ionising radiation. Whilst some research has demonstrated that more accurate scanning can alter the staging of a patients' disease, other authors have warned of the possibility of starting treatment when it may not yet be necessary through over staging (Wolf et al. 2014: 1227-1228; Hillengass et al. 2017: 4). However, if cost effective technology exists to obtain the most accurate diagnostic information, not utilising it to its fullest extent seems irresponsible, especially when the diagnosis and treatment decisions are supported by a number of other tests and clinical expertise outside of radiological imaging.

All of the research reviewed here shares a second consensus; RSS is not recommended over its counterparts. In spite of this evidence it is still used in the UK when other imaging techniques are unavailable, and no researchers or professional bodies have recommended that the use of RSS be completely discontinued, but instead recommend the use of other imaging modalities whenever possible. Availability of LD-WBCT and WB-MRI has been explored as a possible barrier to its more frequent use, as well as the dose of ionising radiation associated with LD-WBCT. However, this literature review has shown how the radiation dose of LD-WBCT can be comparable to RSS and does not need to exceed a factor greater than 2. Reviewing these imaging techniques from a technical and medical perspective has not provided a definitive consensus regarding the best imaging choice. For the author, the logical step is to consider the imaging techniques from the perspective of the service users. Some of the research detailed above briefly mention the differences of whole-body imaging from a patient perspective, in terms of the comfort and length of examination and whether manipulation of the patient is required (Wolf et al 2014: 1230). However, it is outside the scope of these studies to investigate this in detail. This perspective is explored in chapter 2.5.

2.5 Review of Research Investigating Patient Experiences of Radiological Imaging

The experience of undergoing some form of imaging to investigate myeloma should not be taken for granted and could have a serious and unpredictable impact on the patient. By investigating and understanding the impact that imaging has on the myeloma patient group, healthcare practitioners can be better equipped to improve the experience and acceptability of whole-body imaging. Research specific to patient perceptions and acceptance of the whole-body imaging methods unique to myeloma was difficult to find, especially for LD-WBCT and RSS where no published literature has been uncovered. However, there is research investigating WB-MRI and CT in more general terms that will be reviewed here and considered in the context of the oncology patient. The papers reviewed have been summarised in table 2.5.

Table 2.5: Summary of literature review: Patient experiences of CT and MRI imaging

Author	Imaging Modalities Compared	Research Design	Sample Size	Conclusions and Recommendations
Munn and Jordan (2011)	MRI	Qualitative Systematic Review	15 studies	Significant impact of healthcare professional on patient experience. Service users need information.
Adams et al. (2014)	WB-MRI CT with contrast injection	Prospective Survey	36	WB-MRI preferred over CT. Contrast injection causes a patient burden
Munn et al. (2015)	MRI	Meta-analysis	18 studies	Failure rates of MRI due to claustrophobia between 0.46% to 5.29%
Heyer et al. (2015)	CT without contrast injection CT with contrast injection	Prospective Survey	592 + 260 = 852	Examination associated anxiety is an equal problem in CT as it is in MRI. Radiation exposure may cause additional anxiety. Previous experience of imaging may reduce anxiety.
Evans et al. (2017)	WB-MRI CT and PET-CT (grouped) All with contrast injection	Qualitative one-to-one interviews	51	WB-MRI is perceived as more challenging than other scans but is still sufficiently tolerated.
Evans et al. (2018)	WB-MRI CT and PET-CT (grouped) All with contrast injection	Prospective Survey	115	WB-MRI is marginally less acceptable than CT and PET-CT. Comorbidities, psychological distress and staff support will affect acceptability.
Oliveri et al. (2018)	WB-MRI MRI CT and PET-CT with contrast injection (grouped)	Prospective Survey	135	WB-MRI better tolerated than other imaging techniques. Previous experience and information given prior to imaging improve acceptability. Results and outcome remain a key concern for patients.

Murphy (2001: 195) conducted interviews with 26 patients who had experienced either conventional CT or MRI scans to better understand how the patient responds to high technology imaging from a human perspective. As demonstrated throughout chapter 2.4, this interaction is often overlooked in favour of assessing imaging technology from the perspective of functionality and technical details (Evans et al. 2018: 1). The research conducted by Murphy (2001: 193-194) demonstrated the potential for modern imaging technology to induce fear or anxiety which can lead to depersonalisation and other emotional burdens. Many reasons for this are explored by Murphy (2001: 194, 197-199) with claustrophobia, poor preparation and knowledge prior to imaging, and the separation of the patient and the healthcare practitioner all being cited. Although manufacturers frequently try to improve the patient experience by advances in hardware, such as increasing the amount of space in a scanner, there is still a real potential for radiological imaging to propagate a psychological and physical burden (Munn and Jordan 2011: 326). It is the experience of the author that in busy NHS radiology departments, the efficient acquisition of images and throughput of patients is sometimes prioritised over the care of individuals, leading to a negative experience (Harding and Park 2020: 62). This is supported by a qualitative systematic review of 15 studies investigating patients' interactions with imaging technology conducted by Munn and Jordan (2011: 324, 330). They identified staff support as being an important part of ensuring that a patients' interaction with imaging technology is a positive one, and also commented on the significant impact healthcare staff have on the patient experience, both positive and negative. Additionally, people undergoing imaging feel a need for information which they may obtain from a number of sources, both credible and non-credible (Munn and Jordan 2011: 326). The information provided and the method of delivery will form part of the patient experience and should be considered throughout.

One of the first studies investigating the patient experience of WB-MRI was carried out by Adams et al. (2014: 163) at a time when the use of WB-MRI was just starting to enter clinical practice. They performed a comparison of the experiences of 36 lymphoma patients having both WB-MRI and CT using questionnaires with four-point Likert scales. Adams et al. (2014) did not report upon how the questionnaire was developed and tested, therefore its validity is unknown. The median scores regarding the concepts 'worry prior to the examination' and 'experience of the examination overall' showed that WB-MRI scored lower than CT, with median scores of 1 and 2 respectively on a four-point Likert scale (where 1 is attributed to 'no worry' or a 'not unpleasant experience). This indicates that patients' experiences of WB-MRI were superior to

CT and confirmed as being statistically significant through analysis using the Wilcoxon signed-rank test, even with a limited sample size. It must be taken into account that this study is investigating a conventional CT scan which utilises an intravenous injection of contrast agent that has some potential associated risks, and the oral consumption of a second contrast agent; WB-MRI usually requires neither of these. Adams et al. (2014: 166) conclude that these contrast agents may cause additional patient burden and must be considered when interpreting these results. The contrast agents consumed for CT are anecdotally considered to be unpleasant and can also increase the amount of time a patient has to spend within a radiology department by one hour. It is for these reasons, in addition to the cost, that oral contrast agents are no longer routinely used in the NHS.

The evidence presented by Adams et al. (2014) contradicts a usually accepted norm that MRI is difficult to tolerate due to the length of the scan and the perception of claustrophobia (Heyer et al. 2015; Munn et al. 2015; Tugwell-Allsup & Pritchard 2018). Munn et al. (2015: 60) carried out a meta-analysis of 18 international studies that investigated claustrophobia in the MRI environment. They reported MRI failure rates due to claustrophobia as being between 0.46% to 5.29%. None of the studies included WB-MRI examinations which tend to be longer than many standard MRI scans (Adams et al. 2014: 163). Although it may seem reasonable to infer that a WB-MRI for myeloma is more difficult to tolerate that other forms of MRI, there are too many intrinsic and extrinsic variables to control for to reliably draw this conclusion. Examples of such variables include the age and design of an MRI system, as more modern systems allow more space, an individual's willingness to complete an examination in spite of negative feelings towards MRI, or the use of sedatives. Munn et al. (2015) recognise the limitations of the meta-analysis due to heterogeneity of included studies. Additionally, those patients who manage to complete an MRI scan, despite experiencing severe claustrophobia or anxiety, are not accounted for. This study still reinforces the idea that MRI can be difficult to tolerate for a small, but significant, percentage of people. As this was a meta-analysis of the prevalence of claustrophobia no data is presented regarding the patient perceptions of MRI.

Recognising that the psychological burden of MRI is well researched, Heyer et al. (2015: 109) conducted a study to measure whether there is a psychological burden related to CT. 852 patients who had undergone a CT scan over a 9 month period completed the state-trait anxiety inventory (STAI) questionnaire, a validated tool for measuring anxiety in a range of settings. In addition to the included 20 questions, the authors added 10 additional questions that were specific to the experiences of radiology. Like the research conducted by Adams et al. (2014), this study investigated conventional CT that may include the administration of intravenous and oral contrast agents. Heyer et al. (2015: 107) reported 260 patients were given intravenous contrast, indicating to the reader that the remaining 592 would have experienced a CT scan without contrast, similar to the experience of WB-CT. The collated anxiety scores demonstrated that patients can experience anxiety prior to CT, and the STAI scores are comparable with the anxiety experienced before MRI reported in other research (Heyer et al. 2015: 111). It should be noted that the MRI systems employed in older research may be quite different to the MRI scanners of recent years, making a direct comparison of experiences difficult. Due to advances in imaging technology newer MRI systems are quieter, more spacious and potentially quicker (Munn et al. 2015: 62). Heyer et al. (2015: 108) note that patients who had never previously experienced a CT scan or required the administration of contrast gave higher anxiety scores. Regarding the use of ionising radiation, only 354 (41.5%) of the cohort stated they felt no anxiety due to radiation and 166 (19.5%) of participants indicated that the exposure to ionising radiation was a moderate or high cause of anxiety (Heyer et al. 2015: 109). People's understanding of radiation and its associated risks and effects varies greatly. Understandably Heyer et al. (2015) have not been able to account for each individual's knowledge in the results, but it still indicates radiation is an additional burden of CT that is not present in MRI. Heyer et al. (2015: 111) conclude that imaging associated anxiety does not only occur prior to MRI but is an equal problem in CT and should be taken seriously.

This research utilised a large sample and a validated questionnaire, demonstrating a rigorous method. The evidence presents a CT experience that would be similar to LD-WBCT allowing for transferability of the findings to those living with myeloma. Although the results were obtained outside of the NHS, the findings serve to highlight the potential burden of all forms of CT, an examination which is commonplace within the NHS, but its burden is frequently overlooked.

Evans et al. (2017) interviewed 51 patients who had received both WB-MRI and conventional CT for the staging of either colorectal or lung cancer. The purpose of this qualitative study was to investigate the patient experience of WB-MRI and compare this with conventional CT and PET-CT to determine if cancer patients are accepting of WB-MRI and whether there are associated burdens, in addition to living with cancer (Evans et al. 2017: 1-2). The authors chose one-to-one interviews to capture a rich description of experience whilst not requiring any prior knowledge of potential responses (Evans et al. 2017: 2). Thematic analysis demonstrated that WB-MRI was perceived to be more challenging than other imaging techniques. The key themes identified were claustrophobia, physical discomfort, noise and the duration of the scan. These themes are to be expected as they are well-documented concerns patients have during MRI. A theme of interest to emerge related to patients considering the scan in the context of their own condition, with individuals contemplating the implications the scan results may have on their own care and treatment. This finding is parallel to the findings by Vlossak and Fitch (2008: 145) discussed in chapter 2.2; knowing that there will eventually be a recurrence of disease is amongst the most difficult aspects of living with myeloma.

A second interesting theme that many participants discussed related to prior experience of MR. Although few participants had experienced MRI in the past, the experience was stated as being of benefit. Some of those that had no prior experience of MRI had discussed the imaging technique with friends and family who had undergone the scan. This vicarious experience was perceived as both positive and negative, depending on the experiences of the third party, but ultimately had little impact on the participants own experiences (Evans et al. 2017: 6). It does illustrate how patients seek out information prior to imaging, a finding also reported by Munn and Jordan (2011: 326). Of the 51 participants, four were unable to complete the WB-MRI but all participants stated that they would be prepared to undergo WB-MRI again if recommended by their clinician, although the authors note that, '...this agreement was offered with varying enthusiasm' (Evans et al. 2017: 7).

The authors conclude by noting the broad range of experiences that they documented, and whilst particular co-morbidities can make WB-MRI more challenging, there were still unexpected situations whereby a participant who felt unable to undergo the scan managed to tolerate the whole scan, whilst another person unexpectedly found the process difficult. This reinforces the importance of understanding individual experiences; whilst healthcare practitioners shouldn't presume to understand what it is like to undergo imaging for cancer, efforts to understand the patient perspective are integral in ensuring staff can better support the service user. Evans et al. (2017: 8) identified communication and support from staff as having the potential to improve the patient experience, as participants reported a variety of differing staff interactions that all had a significant impact on the overall experience.

In a second concurrent study by the same group of authors, 115 oncology patients completed questionnaires concerning their experiences of WB-MRI against other imaging methods in an effort to identify predictors of reduced patient tolerance (Evans et al. 2018: 2). The survey tool used has been adapted from a validated tool created by Salmon et al. (1994) and utilises 26 questions per imaging modality with 7 point Likert scales, in addition to collecting detailed demographic data (Evans et al. 2018: 4). Given the length of this survey the possibility of questionnaire fatigue should be a consideration (Bryman 2016: 225-226; Hulley et al. 2013: 231). Nevertheless, the authors were able to meet their recruitment target dictated by a power calculation for the related t-test, assuming a medium effect size (d=0.5), α error probability (p = 0.05), and 95% power. A participant incentive was offered (Evans et al. 2018: 2).

Statistical analysis of the results using the Wilcoxon sign test demonstrated that WB-MRI was perceived to be less acceptable than conventional CT or PET-CT, with 84 participants (77.8%) stating that CT/PET-CT was very acceptable versus only 73 participants (65.2%) finding WB-MRI to be very acceptable. Despite this result, the scores for each imaging technique 'not being at all acceptable' were the same, with only one participant (0.9%) recording this response for both imaging techniques. This indicates that while acceptability may be lower for WB-MRI, it is tolerated just as well as CT or PET-CT. The results from both studies by Evans et al. (2017; 2018) contradicts the data presented by Adams et al. (2014) in that WB-MRI is less acceptable than other imaging techniques. Evans et al. (2018: 7) argue that a reason for the disparity in the two studies is due to the use of intravenous contrast agent with WB-MRI in their study which has been identified as being a burden to the patient (Adams et al. 2014: 166); contrast was not used in the research by Adams et al. (2014). It may be inappropriate to apply the findings reported by Evans et al. (2018) to the myeloma group as they would not require an injection of contrast agent as part of an imaging examination for myeloma lesions. A second additional burden that is not considered by Evans et al. (2018) is the use of ionising radiation which has been identified as a potential additional burden for patients undergoing any form of CT (Heyer et al. 2015:109-110). The two studies were reported four years apart. Although this is a relatively short period of time in terms of imaging technology development it still remains a variable.

Evans et al. (2018) compared participant scores of acceptability with demographic data and found the statistically significant predictors of reduced patient tolerance were co-morbidities and psychological distress, both of which would potentially impact the myeloma group (Vlossak and Fitch 2008; Nicoletti 2012). The authors conclude that patients undergoing a WB-MRI who have these predicting factors may benefit from additional support.

A limitation of the two studies by Evans et al. (2017: 8; 2018) is that participants who have refused a whole-body MRI are not represented within the sampling frame. Learning why some people refuse WB-MRI may provide useful insight. A second limitation is that both of these studies group PET-CT and conventional CT as a single entity. There are some fundamental differences between these imaging modalities and the appropriateness of reporting the results together must be questioned. Although considering the rigour of the survey tool and large sample size of the research conducted by Evans et al. (2017; 2018) the results cannot be overlooked, especially as they are corroborated by two methodologies.

Oliveri et al. (2018) conducted a survey study of oncology patients undergoing WB-MRI, similar to the research by Evans et al. (2018). Oliveri et al. (2018: 246) argue that as WB-MRI does not use radiation and can be performed without intravenous contrast it should be the preferred imaging option for service users, although the issue of cost and availability has not been considered. The aim of this study was to investigate the perceptions and acceptance of WB-MRI. The survey instrument was based on a survey devised by Schönenberger et al. (2007) containing 18 questions with responses mostly recorded using Likert scales. This was administered to the participants both before and after their WB-MRI. 70% of the cohort of 135 patients had experienced some other form of whole-body imaging in the past and 63% of participants reported some concern prior to the examination, although 67% of this group stated their main concern was the outcome of the scan, a variable that is impossible to control for (Oliveri et al. 2018: 248).

Regarding discomfort of WB-MRI, 51.9% of patients reported no discomfort, 44.2% experienced slight or moderate discomfort with the small remainder experiencing strong discomfort. Overall >81% of patients recorded a high or very high degree of satisfaction with WB-MRI, with <1% reporting low overall satisfaction. These results indicate a good level of acceptability for WB-MRI, which is further supported by 69% of patients stating that WB-MRI was more acceptable than other forms of imaging they had experienced, although no reasons are provided for this.

Pearson correlation tests demonstrated that patients with high anxiety prior to the scan and feelings of discomfort after the scan demonstrated a significant correlation (Oliveri et al. 2019: 248-249). A statistically significant correlation using a χ^2 test was reported between patients being provided with information prior to WB-MRI and high global satisfaction. Patients were briefed by a radiologist before their WB-MRI. This would not be standard practice in the UK and may introduce a bias to the results by influencing the participants' perceived acceptability of WB-MRI that does not reflect standard practice. Prior to the scan 80% of participants felt that they were given good or very good information, which may be evidence of this (Oliveri et al. 2018: 248). DePoy and Gitlin (2011: 93) describe a threat to the external validity of research called reactivity, whereby participants are responding to being part of the study, unwittingly influencing the results. Without knowing whether the researchers took steps to account for reactivity, its bias has to be taken into account when interpreting the results. Reactivity could potentially influence any of the prospective studies discussed in this literature review where patients received imaging as part of a research project. Whilst the transferability of this finding is questionable, it once again highlights the benefits of providing information. It could be inferred that the quality of the information provided by the radiologists was the reason for such high satisfaction for an examination that is widely understood to be challenging.

Oliveri et al. (2018: 249) report a further possible bias; the majority of the cohort had some previous experience of MRI, although unfortunately the exact number is not provided. Similar to the research conducted by Evans et al. (2018), Oliveri et al. (2018) have grouped all of the other whole-body imaging techniques together. Reporting them separately may have been more useful in investigating the differences between these techniques. Due to these limitations, it would be difficult to apply the findings of this study to the NHS setting although the study successfully highlights the importance of being provided with information to improve the acceptability of whole-body imaging and to mitigate pre-scan anxiety. A second theme that Oliveri et al. (2018: 249) were able to illustrate was the positive effect that a previous experience of whole-body imaging can have acceptability, which supports the research by Heyer et al. (2015: 111).

The research examined throughout the second part of this literature review, summarised in table 2.5, has demonstrated the variables that influence patients experiences and acceptability of whole-body imaging. Key themes are patient anxiety, comorbidities, staff support, and the information provided. These are in addition to the varying physical aspects of the different imaging techniques, such as time, radiation and a ‘claustrophobic’ environment. The burden of MRI for those undergoing such an examination is well documented and investigated. Of interest is the additional research that investigates the burden of a CT scan. The experience of the author is that this is frequently overlooked as CT scans are performed with increasing regularity in the UK and are perceived as routine by some healthcare professionals, although this perception may not be true for the patients. Uncovering some of the burdens of MRI and CT leads the author to consider if there may be any associated burdens with a conventional x-ray or RSS that have not been investigated or documented, as no research on acceptance or experience of RSS was uncovered. A second point for consideration is whether some of the burdens of having an MRI scan still apply, as Adams et al. (2014) and Oliveri et al. (2018) report WB-MRI as being not only well tolerated, but universally preferred to other imaging. Whether this is due to advances and improvements in MRI equipment and techniques, or as a result of the study designs is difficult to say with certainty.

It is unsurprising that much of the research investigating the acceptance and perception of imaging techniques has focused on oncology patients, as this group frequently requires radiological imaging for diagnosis and staging. The imaging options for myeloma are unique to that patient group; this may account for the lack of research examining perceptions or acceptance of RSS or LD-WBCT.

As three fundamentally different whole-body imaging modalities exist for myeloma, an opportunity is provided to investigate and compare the acceptability and patient perceptions of these imaging modalities. In doing so it may be possible to demonstrate if there is a whole-body imaging technique that is preferred by those living with myeloma, which can be used to inform future imaging pathways and referral guidelines. Secondly, it will allow those who have experienced myeloma to share their stories in order that radiographers and clinicians can further understand the psychological and physical burden of imaging and explore opportunities for reducing this burden. Research investigating the patient acceptability of imaging is an excellent method of educating healthcare practitioners regarding patient perceptions and implementing changes into clinical practice.

3. Methodology, Design and Method

3.1 Methodology

A pragmatic mixed methodology combining aspects of the positivist and interpretivist paradigms was used to design this study and address both of the study objectives. The epistemological view of positivism is that a single reality exists which can be objectively understood through observation and measurement (DePoy & Gitlin 2011: 25). In the context of this study a positivist approach will allow for the measurement of acceptability of imaging through self-reported scoring, addressing the research aim and the first objective. This approach allows for different individuals' experiences to be collectively measured so that an overall objective picture of imaging acceptance can be obtained. Although quantitative methodologies are usually associated with deductive reasoning and the testing of existing theory (Bryman 2016: 21), logical positivism can support an inductive process whereby observations can support and develop existing and new theory (Bowling 2014: 214; DePoy & Gitlin 2011: 31-33; Igo 2017: 2).

The interpretivist ontological perspective states that reality is subjective to individual experience and is constructed through an individuals' interactions with the world around them (DePoy & Gitlin 2011: 26). Attempting to group a range of individual experiences through a purely quantitative methodology would prevent valuable analysis of individual perspectives that could generate theory through induction, vital in addressing the second research objective. Utilising interpretivism to support positivism in answering the research question allows for knowledge to be created through analysis of individuals interpretations of social, cultural and behavioural factors that influence experience (Bryman 2016: 375-377; Igo 2017: 4).

Having explored how the contrasting paradigms of positivism and interpretivism could be used to answer the research question, the paradigm of pragmatism presented itself as a means of ensuring a more comprehensive study and a deeper understanding of the phenomena being investigated (Doyle, Brady & Byrne 2016: 624, 344). By combining two different methodologies it becomes possible to corroborate the findings of each through triangulation, where the same data set collected through each methodology supports its counterpart, enhancing validity (Bryman 2016: 641; Doyle, Brady and Byrne 2016: 624). A critique of mixed methodologies is the possible incompatibility of quantitative and qualitative methodologies due to differences in the underlying ontological, epistemological and methodological assumptions (Denscombe 2008: 273; Doyle, Brady and Byrne 2016: 625; Taylor and Francis 2013: 171). Nonetheless, many authors argue that mixing methods addresses the limitations and offsets the weaknesses of the traditional methodologies (DePoy & Gitlin 2011: 99). If only a quantitative or qualitative methodology were selected, then an opportunity would be missed to produce a more complete picture presented by the data and avoid bias intrinsic to the traditional methodologies (Denscombe 2008: 272).

Pragmatism rejects the traditional dualisms; instead, it accepts the importance of both the physical world and the social and psychological world (Johnson and Onwuegbuzie 2004: 18). Whilst pragmatism is recommended for use in nursing and healthcare research (Doyle, Brady and Byrne 2016: 632), all data produced through such an approach must be considered, not just the data that is convenient to the agenda of the researcher (Johnson and Onwuegbuzie 2004: 23-24; Denscombe 2008: 279).

3.2 Design

To answer the research question and aims, a mixed method, non-experimental, retrospective, cross-sectional survey study was used.

An embedded mixed methods design was applied, whereby the qualitative component of the research is embedded within the quantitative component (Bryman 2016: 639; Bowling 2014: 421; Doyle, Brady and Byrne 2016: 628-629). This design was selected as it is appropriate for research that attempts to collect data for both components simultaneously, and when either the quantitative or qualitative component will form a greater part of the study. For this study, quantitative data forms the larger component. The qualitative data will allow for 'explanation' of the quantitative results, with the qualitative component providing a deeper insight into the findings of this research (Bowling 2014: 419; Bryman 2016: 64).

This study used a non-experimental survey design to answer the research question, as no intervention was tested and no variables manipulated. Survey designs are effective in health research for describing population parameters and predicting relationships between different characteristics across a sample (Bowling 2014: 215; DePoy & Gitlin 2011: 114-115). In the context of this study, these characteristics include the physical parameters of the imaging experience, and individuals' intrinsic factors such as pain and anxiety. The research explored in chapter 2.5 has influenced the design of this study and by adopting a similar approach, comparison with this work is possible (Adams et al. 2014; Evans et al. 2018; Oliveri et al. 2018).

A cross-sectional design enabled the collection of data over a relatively short period of time, and without follow-up (Hulley et al. 2013: 85). This allowed for a realistic approach to data collection within the time available to conduct this project and given the relative scarcity of the myeloma population.

It was necessary to use a retrospective design in order to sufficiently increase the sampling frame, as myeloma is not a common condition. Stull et al. (2009: 933) conducted a systematic review of recall bias in health research and found that there is frequently an inverse relationship between the length of the recall period and accuracy. However, this recall bias is partly offset by the phenomena participants are being asked to recall and its possible impact. For example, having a whole-body scan is a specific infrequent event as opposed to ongoing frequent events such as a weekly blood test. Stull et al. (2009: 931-932) stated that specific events with greater significance are likely to be recalled more accurately even with a longer recall period. Although a prospective design would have the benefit of eliminating much of the recall bias, it would significantly impact the sampling frame which would have a greater impact on validity (Bowling 2014: 320).

3.2.1 Survey Instrument Design

Questionnaires are frequently used in health and social care research to collect data (Bowling 2014: 275-276) and have been successfully used in the research critiqued in chapter 2.5. They are appropriate for descriptive studies and descriptive research questions, where variations in the characteristics of different groups or elements are to be compared (Saks & Allsop 2012: 192). Surveys can also be used to uncover cause and consequence between the elements being studied although defining the causality between variables is not possible (Bowling 2014: 216; Saks & Allsop 2012: 192). Hulley et al. (2013: 223) asserts the importance of the quality of the survey instrument, in this case, a questionnaire, as the validity of any inferred results will be dependent upon it.

It was outside the scope of this study to design and validate a new questionnaire, although a bespoke questionnaire has been implemented that was based upon two previous questionnaires evaluating the acceptance of radiology examinations (Salmon et al. 1994; Schönenberger et al. 2007). The process of developing this questionnaire will now be detailed.

A literature search of published research relating to surveys of patient perceptions and acceptance of radiology imaging was carried out to identify whether a validated survey exists that allows respondents to compare several imaging modalities or to uncover a survey instrument that is used as an industry standard. CINAHL and MEDLINE databases were searched with papers from the previous 10 years included in an effort to reflect current practice. The search terms were the same as those used for the literature review in table 2.1. The most refined search yielded 139 results. Titles and abstracts were reviewed, and relevant papers identified. The reference lists of relevant papers were used to identify other research relevant to surveying experiences of radiology, some of which were published prior to 2009 but included due to their impact. It is worth noting that the research mostly focused on cardiac, lower gastric or general oncology imaging. No research papers were identified that included surveys relating to whole-body imaging specifically for myeloma.

Each survey instrument used in the thirteen selected papers were reviewed and their use considered against the following criteria; whether the survey instrument had been validated, what sort of scale or open text responses were used, the number of questions and the sample size that the survey instrument has been used upon. The results of this review are summarised in table 3.1.

Table 3.1: Summary of the survey instruments used measuring acceptance of imaging

	Scale used (most frequently)	Open questions or space for additional comments?	Number of questions asked (excluding demographic questions)	Sample size
Adams et al. 2014	Rating scale 1-4.	No	6 per modality Total 12	36
Evans et al. 2018	Rating scale 1-7	No (separate qualitative work undertaken)	28 per modality Total 46	115
Feger et al. 2015	Rating scale 1-5 VAS for pain	Yes, plus a table for pros and cons	Total 31	48
Gleuker et al. 2003	Rating scale 1-5 (1 question 1-3)	No	Total 11	1053
Heyer et al 2015	Likert 1-4 (descriptors the same across all questions)	No	STAI-S (20 questions) Supplementary questions (10 questions). Total 30	825
Oliveri et al. 2018	Rating scale 1-5	One question regarding prior concerns	Total 24	135
Prasad et al. 2019	Numerical rating scale 1-5.	Yes - A single section at the end.	18 per modality Total 38	41
Rief et al. 2015	Rating scale 1-5 VAS for pain	Yes, plus a table for pros and cons	8 per modality Total 16	90
Salmon et al. 1994	Likert scale 1-7	No	25 per modality Total 50	110
Schönenberger et al. 2007	Rating scale 1-5.	Yes, plus a table for pros and cons	7 per modality Total 21	111
Svensson et al. 2002	Rating scale 1-4	Yes, several opportunities	9 per modality with some additional questions. Total 27	111
Taylor et al. 2003	Rating scale 1-7	No	25 per modality Each respondent would have 1 or 2 modalities. Total 25 or 50	140
von Wagner et al. 2011	Likert scale 1-7	No	29 per modality Total 58	921

The research papers that failed to report the basis for a survey instrument used or had utilised a bespoke questionnaire without providing a reasonable rationale for its development and use were discounted. This left three core papers that either used a validated survey instrument, or the instrument had been demonstrated to be effective and used by other researchers. These original survey tools are those developed by Salmon et al. (1994), and Schönenberger et al. (2007). The standardised state-trait anxiety inventory (STAI-S) utilised by Heyer et al. (2015) was also considered at this stage as it is a widely used instrument to measure anxiety and has been effectively used to measure patient anxiety during MRI (MacKenzie et al. 1995).

Considering the research aims was fundamental in deciding which survey instrument should be used as the basis for this study. As the purpose of this study is to uncover the 'acceptability' of different imaging techniques, a measure solely of anxiety, such as the STAI-S, may not fully uncover the range of burdens a patient can experience during imaging or aspects of the experience that can ease the burden. Due to the limited available sampling frame, maximising responses was a key consideration in developing a survey fit for purpose. As the STAI-S consists of 10 demographic questions and a further 20 questions that would have to be repeated for each modality being investigated in this study, it's relative complexity may have led to high questionnaire fatigue and impacted the response rate (Bryman 2016: 225-226; Hulley et al 2013: 231). The STAI-S does not use any open responses, although it may have been possible to add these had it been selected for use in this study.

The survey instrument created by Schönenberger et al. (2007) was chosen as the core survey to be used in this study for several reasons. Firstly, it proved effective in their research, demonstrating results at a significance level of p = 0.002. Secondly, it consists of seven relatively simple questions repeated for each imaging technique being compared. As stated previously, a concise questionnaire may improve response rates (Bryman 2016: 225-226) although Bowling (2014: 285) contradicts this, citing two separate studies that reported response rates being the same among surveys with four pages, twelve pages or sixteen pages.

Schönenberger et al. (2007) made provision for free text responses, specifically in a table inviting the respondent to state what they perceive the advantages and disadvantages of each imaging technique to be. Free text responses have provided the qualitative data required for the mixed-methods design adopted in this study. Finally, the survey instrument developed by Schönenberger et al. (2007) has been effectively used in two other studies evaluating patient acceptance of cardiac imaging conducted by Feger et al. (2015: 2117) and Rief et al. (2015: 3).

It should be noted that Schönenberger is listed as an author on both of these studies, although Oliveri et al. (2018: 247) have also adapted this survey instrument for use in their own study. Both Feger et al. (2015: 2117) and Rief et al. (2015: 3) claim that the survey instrument developed by Schönenberger et al. (2007) has been validated, although specific validation work does not appear to have been published. They may be referring to the effective use of this survey in the original research conducted by Schönenberger et al. (2007).

The validated survey instrument developed by Salmon et al. (1994) was originally for the purpose of evaluating patient acceptance of colonoscopy. This survey instrument has been adapted by several other researchers for use in their own studies (Taylor et al. 2003; von Wagner et al. 2011) to allow for a comparison of colonoscopy with computerised tomography colonography, a newer technique used for imaging the large bowel. It has also been used by Evans et al. (2018) to compare WB-MRI with other imaging techniques. Despite the relative complexity of this survey instrument in terms of the length and depth of the questions, the rigorous process of its development and its potential to enhance the validity of inferred results cannot be overlooked.

Saks & Allsop (2012: 193) explained that a survey instrument contains constructs; summaries of the characteristics being investigated that are translated into indicators, or questions. Identifying constructs is the first phase of developing a survey (Fayers & Machin 2016: 61-62). Key constructs that overlap in both surveys by Salmon et al. (1994) and Schönenberger et al. (2007) are comfort, pain, feeling helpless or in control, and overall satisfaction. A construct additionally addressed by Schönenberger et al. (2007) relates to concern and preparation prior to the imaging examination. The survey instrument developed by Salmon et al. (1994) and adapted by von Wagner et al. (2011) addresses the constructs of staff support, patients' understanding of the imaging examination, claustrophobia, stress and anxiety. In developing the survey instrument used in this study, questions that address each of the constructs listed above were included. Two additional constructs were also identified in research investigating the acceptance of WB-MRI (Evans et al. 2017: 1, 4; Oliveri et al. 2018: 250). The first construct investigates the time spent in the scanner, or the time taken for the examination. The second construct investigates the use of ionising radiation. As the different whole-body imaging methods used for diagnosing myeloma are associated with different examination times and different doses of ionising radiation it was appropriate to include these constructs. The survey instrument adapted for this study contained questions for each of these constructs, summarised in table 3.2, in addition to the type of data gathered and the shortened term used for each construct.

Table 3.2: Summary of the 11 constructs affecting acceptance

Evans et al. (2017); Oliveri et al. (2018); Salmon et al. (1994); Schönenberger et al. (2007)

Construct	**Short Title**	**Type of Data**
Worry prior to whole-body imaging	*Prior Worry*	Ordinal
Patient understanding of their whole-body imaging	*Understanding*	Ordinal
Pain during whole-body imaging	*Pain*	Ordinal
Stress or anxiety during whole-body imaging	*Stress During*	Ordinal
Claustrophobia experienced during the whole-body imaging	*Claustrophobia*	Ordinal
Patient feeling in control during their whole-body imaging	*Control*	Ordinal
Staff support during whole-body imaging	*Support*	Ordinal
The comfort of whole-body imaging	*Comfort*	Ordinal
Overall experience of whole-body imaging	*Overall Experience*	Ordinal
Difficulties with the length of whole-body imaging	*Length*	Nominal
Concerns over the use of x-rays or magnetic fields	*Concern x-rays*	Nominal

3.2.2 Survey Review Process

The second phase of designing a survey instrument was to translate the constructs and issues into questions and decide the response format (Fayers & Machin 2016: 68-70). An initial set of questions was drafted using the survey instrument developed by Schönenberger et al. (2007) as a template, with questions for the remaining constructs included. The responses to the closed questions mostly used categorical rating scales where the respondent is presented with five choices ranging from the greatest negative response to the greatest positive response. Labels such as 'not at all' to 'completely' were used instead of numerical rating scales (NRS) to normalise individual responses and prevent respondents from applying a subjective value to an arbitrary 1-5 scale. The wording of the labels was amended to improve clarity, simplicity and neutrality of the adapted survey to enhance the reproducibility and validity of the responses (Bowling 2014: 312-314; Hulley et al. 2007: 227). Open-ended questions were included to provide the respondent with the opportunity to elaborate on answers given in the closed questions in addition to the comparison table of each imaging modality designed by Schönenberger et al. (2007). Two questions required only nominal responses. In both instances these were a binary yes or no choice.

The adapted survey instrument went through a review process, summarised in appendix 3, which generated much discussion regarding the syntax and semantics of the questions. The first review was by both academic and clinical colleagues active in research, some of whom have experience in radiology and myeloma. This was an important step in confirming the survey instrument's content validity and assuring the questions would be able to measure the constructs identified for investigation (Fayers & Machin 2016: 90-93). The subsequent draft was piloted with five clinical staff members from three different professions who are involved in research. Additionally, the questionnaire was reviewed by the author's academic supervisory team on three separate occasions. The purpose of this review was to confirm the adapted surveys face validity.

To confirm the construct validity of the survey, in that it will effectively measure the constructs that it has been designed to measure (Fayers & Machin 2016: 96-98), convergent validity and discriminant validity of responses has been tested using Spearman's correlation coefficient (Field 2018: 351-352). This method ensures consistency across groups within the entire dataset by testing the consistency of responses for a construct against each other construct. Construct validity is reported on in chapter 4.2.6.

Upon completion of survey version 6, the questionnaire was redrafted using *Online Survey* (Jisc 2019) software providing an attractive and clear layout in order to increase the response rate (Bryman 2016: 225-226) and to make provision for printing paper copies and completion online. During the development of the survey instrument, the participant information sheet and consent statement were drafted using a template provided by Coventry University. The survey instrument developed by Schönenberger et al. (2007) used a visual analogue scale (VAS) to enable the respondent to report their level of pain. As the *Online Survey* (Jisc 2019) has no provision for a VAS, a ten-point NRS was used. A systematic review of the clinical measures for pain by Harrington et al. (2018: 84) highly recommends the use of NRS for measuring pain, scoring its effectiveness as being equal to the VAS.

The third phase of survey design is to pre-test the survey instrument (Fayers & Machin 2016: 74-75). The first pass of this was with clinical and academic colleagues, seven in total. This was to identify issues of ambiguity, wording, semantics and clarity. After revising the survey, it was then given to a local NHS Patient and Public Involvement in Research (PPI) group for further review and criticism, before final revisions were made addressing further feedback from healthcare practitioners. This process has been important in further ensuring the face and content validity of the proposed survey. The amendments made throughout the development of the survey have been summarised in appendix 3, and the final survey is available in appendix 5.

3.2.3 Patient and Public Involvement Group Review

The organisation INVOLVE, on behalf of the Health Research Authority (HRA), have published guidance on the use of patient and public involvement in research (PPI) groups. They state that potential benefits can include the researcher being provided with a different perspective and improving the quality of the research. This could be through reviewing the language and content of participant facing material, ensuring that the outcomes are of value and increasing public participation in research projects (2012: 8). UHCW's PPI group was accessed to review the bespoke questionnaire that was to be implemented. Five members of the public agreed to review the questionnaire, providing a second opportunity to pre-test the survey (Fayers & Machin 2016: 74-75). Obtaining a non-expert opinion demonstrated parts of the survey that were clear and well understood, as well as highlighting ambiguous wording. One of the PPI reviewers also identified a key question that could be added in order to obtain further qualitative data; where the respondent is asked whether they understood the examination that they are having it was suggested to include the question, 'If not, what could be clarified?'. The process of

PPI review proved to be of great benefit as several potential issues were identified that had not been apparent to the clinical or academic reviewers. As a result, these issues were addressed, and amendments made to further improve the face validity of the survey instrument (Fayers & Machin 2016: 90-93). A summary of the amendments and the full feedback letter from the UHCW PPI group are available in appendices 3 and 4.

3.2.4 Helplessness and Control

The survey developed by Schönenberger et al. (2007) incorporated a question asking respondents to rate their feelings of helplessness. In adapting their survey instrument for use in this study, this question was met with criticism by members of the clinical peer group and the supervisory team. Additionally, the wording of the follow-up open-ended question requesting further details about helplessness was queried by one of the PPI reviewers. The first issue raised was whether this was a leading question; by asking a respondent to report their feelings of helplessness it is possible that they will indicate some helplessness even if they had not considered it prior to being asked. The semantic meaning behind the question was examined in depth. Mosby's Dictionary of Medicine, Nursing and Health Professions (2017) defines helplessness as being, 'a feeling of a loss of control or ability, usually after repeated failures, or of being immobilised or frozen by circumstances beyond one's control, with the result that one is unable to make autonomous choices.' Whether the question could be a useful indicator of a negative emotional state was contemplated. In an effort to obtain further information about the development and inclusion of the question, attempts were made to contact the corresponding author stated in the research conducted by Schönenberger et al. (2007) but no response was received. It was decided that this question could be replaced with an equivalent question from the work conducted by Salmon et al. (1994) regarding the construct 'control'. The concept of control is a key component relating to patient influence over a situation and a positive emotional state, although Salmon et al. (1994: 344) argue that it can also be modestly associated with physical discomfort. Understanding whether a patient feels in control during whole-body imaging is useful in further understanding the perception of the imaging techniques, especially when combined with additional qualitative data.

3.3 Method

3.3.1 Ethics

This study was subject to the research governance legislation of the United Kingdom's HRA which is outlined in the UK Policy Framework for Health and Social Care Research (2017). As well as reviewing this policy, advice was sought from the UHCW's Research and Development department as this study involved the survey of NHS patients. The Society and College of Radiographers (2013) code of conduct and the British Psychological Society Ethics Committee's Guidance on the use of social media (2012) were both reviewed to ensure this project complies with this guidance, as per Coventry University's policy on research ethics.

In conducting a survey on patients with a treatable but incurable condition sensitivity towards discussing myeloma must be at the forefront of the study design. Any potential participant that was approached to take part may have no wish to contemplate any aspect of their condition and care, nor provide details unnecessarily (HRA 2017: 12-13).

The risks and burdens in this study came from asking participants to consider their condition and give details about the imaging experiences they have had. It is possible that some participants had negative experiences that they revisited in order to complete the survey or could have found it emotionally distressing to consider aspects of their condition. Participants were informed in the participant information sheet that they will be asked questions relating to their experience and their condition. This allows the participant the opportunity to consider whether they wish to take part. In order to ensure non-maleficence, participants were informed of the content of the survey and how they can withdraw at any time (Bowling 2014: 183). Details on how to obtain further support through the participants healthcare provider or a myeloma charity were provided at the end of the survey to address any concerns raised and to ensure that the ethical principle of beneficence is adhered to.

A second potential burden came from participants having concerns about being asked about a whole-body imaging technique that they have not had or were not offered. This could lead to feelings that individuals were not consulted when being referred for imaging, even when the referring clinician chose the most appropriate imaging technique for that particular patient. To address this the questionnaire aimed only to obtain a 'snapshot' of experience. A statement on the questionnaire informed participants that all of the whole-body imaging methods mentioned in the questionnaire are valid and widely used within the NHS (see appendix 5). It is important not to undermine the expertise of the referring clinician and the patients' trust in their healthcare.

To ensure compliance with research governance and the General Data Protection Regulations (GDPR 2018), no databases were used to identify potential participants. No identifiable or personal data was obtained as it is not required for this study. This is in line with the GDPR principles of data minimisation and integrity and confidentiality.

Applications to the Coventry University ethics committee and the HRA were submitted for this project (page i and appendix 1). Following ethical approval, applications for participation at three NHS trusts were submitted. The charity, Myeloma UK, were also contacted to allow access to their service users. All the project documents were sent to the Coventry University ethics committee, HRA and each site for review. Throughout the duration of the study two non-substantial amendments were submitted to change document wording, and to allow for the inclusion of the MGUS group, as advised by the HRA Research Ethics Committee (REC). Further detail is provided in chapter 3.3.4.

3.3.2 Consent

The UK Policy Framework for Health and Social Care Research (HRA 2017; 6) states that informed consent must be given prior to any research activity. This would include using databases or other records that fall under GDPR to identify and approach participants if it is outside normal clinical care provided by the researcher. To address this, clinical teams were given information about the study to pass on to patients. Additionally, participants for this study were approached passively through an advertising flyer (paper or online) allowing them to decide whether they wish to obtain further details about the study.

In an effort to simplify the process of consent for this study and to comply with GDPR it was decided not to obtain any identifiable information, including when recording consent. The consent section of the Integrated Research Application System (IRAS) confirmed recorded consent is not always necessary for survey studies, as the return of the questionnaire is evidence of implicit consent. Guidance produced by the HRA (2018a: 16; 2018b: 5-9) regarding proportionate approaches to receiving consent, by post and electronically, states including a tick box or simple electronic signature is appropriate for low-risk research at this level. As per this guidance, a participant statement was prepared to ensure potential participants have sufficient information to reach an informed decision regarding their participation. At the end of this statement is a short declaration that the participant must tick stating that they understand the information provided to them and consent to take part (available in appendix 5). This allowed for consent to be obtained and recorded whilst still protecting the confidentiality of all respondents.

3.3.3 Sampling and Recruitment

A purposive self-selection sampling method was used to ensure respondents have the relevant knowledge to provide data that will answer the research question (Bryman 2016: 408; Denscombe 2017: 41) whilst also ensuring a sufficient sampling frame as myeloma is an uncommon condition (Bowling 2014: 199). A problem with purposive sampling is the introduction of sampling error, whereby the sample is not truly representative of the entire population and so introduces bias into the results due to skewed responses (Bowling 2014: 200-201). This bias could be reduced if a probability sampling method was employed (Bryman 2016: 174; Saks & Allsop 2012: 174-175) but due to the requirement for participants to be able to self-select for this study, it was not practical to adopt this approach. Instead, the sampling frame was maximised to invite the largest number of potential respondents as possible and reduce the introduction of bias due to sampling error. In order to increase the sampling frame within the limits of the resources available, participants were recruited from one of three NHS Trusts: UHCW NHS Trust, George Eliot Hospital NHS Trust (GEH) and South Warwick Foundation Trust (SWFT). In addition, the Myeloma UK charity was also approached to advertise the study to their service users, alongside other advertisements to UK based online myeloma support groups and social media. This increased the sampling frame from the local geographic area to the whole of the UK which will enhance the external validity of results (Gray, Grove & Sutherland 2017: 222). Finally, by using a retrospective design, the sampling frame was further increased (Bowling 2014: 320).

Non-response in a survey study is another means by which bias can be introduced (Bowling 2014: 180; Bryman 2016: 184-186). For this study, the concern was that only those who have had specific experiences will complete the survey. For example, if a participant had a particularly good or bad experience of whole-body imaging it is quite possible that they would be more inclined to complete the survey, and the non-responders would be those who had no specific experiences of acceptability of myeloma imaging. Although it is impossible to specifically identify where such bias exists it must be recognised and considered when analysing the results. In an effort to address this bias, steps were taken to improve response rates whilst still allowing respondents to participate willingly and without coercion. These included a clear participation information statement and making the survey layout clear and easy to read. Stamped addressed envelopes were provided for postal surveys (Bryman 2016: 225). These were given to clinical teams to handout to potential respondents. Providing an incentive for completion was outside the scope and resources of this study.

3.3.4 Inclusion and Exclusion Criteria

To answer the research question, the sample must include respondents who have experienced whole-body imaging for the diagnosis of myeloma lesions. It was initially decided to exclude the MGUS group as having imaging that excludes disease may naturally be viewed positively and introduce a bias that would render meaningful results indeterminable. The HRA Ethics committee asked for justification for this exclusion as the experience of having whole-body imaging is the phenomena being investigated. Following discussion with the research team and a Consultant Haematologist, it was decided to include all those who have received imaging for myeloma or any of its precursor conditions including MGUS. This would increase the sampling frame and allow a broader range of experiences of imaging to be recorded.

In an attempt to control for recall bias, excluding participants whose most recent experience of whole-body imaging was greater that 6 months ago was initially one of the exclusion criteria. This six-month period was an arbitrary value; as discussed in chapter 3.2, there is no standard recall period for measuring or understanding phenomena (Stull et al. 2009: 940). As a number of respondents who had experienced imaging more than six months ago still completed the survey and provided valuable data it was decided to include all responses.

To meet the governance requirements outlined in the ethics application, respondents were required to be 18 years or over and have the capacity to read and understand the patient information statement and indicate their consent. This may impact the involvement of respondents who are unable to read English, although no requests were made requesting a translation of the survey. A summary of the inclusion and exclusion criteria is provided in table 3.3.

Table 3.3: Inclusion and exclusion criteria for participation in the study

Inclusion Criteria	**Exclusion Criteria**
Has experienced whole-body imaging to investigate myeloma, asymptomatic myeloma or MGUS in the UK	Has not had specific whole-body imaging.
Aged 18 years or over.	Under the age of 18.
The capacity to consent, understand and complete the survey study.	Does not have the capacity to consent, understand and complete the survey study.

3.3.5 Sample Size and Participants

A sample size was estimated assuming analysis with the one-way analysis of variance (ANOVA) parametric statistical model (Cohen: 1992). One-way ANOVA was used to guide the sample size estimate as McDonald (2014: 164) and Fan, Zhang and Zhang (2011) all highlight the difficulties in estimating a required sample size for non-parametric statistical models.

The conventional values of 0.05 for α error probability (p = 0.05), a statistical power of 0.8 (1-β error probability, 1-0.2) and a medium effect size of f = 0.25 were selected to calculate the estimated required sample. These are conventions proposed for general use in health and social care research (Taylor and Spurlock 2018). 52 responses would be required for each imaging modality, leading to a sample of 156 sets of responses. This sample estimate was also confirmed using G*Power software (Faul et al. 2009). The quantitative component of this study dictated the sample size for the qualitative component.

3.3.6 Data Collection

Data was collected over a period of four months from November 2019 to March 2020. The decision was taken to cease data collection at the time of the Covid-19 pandemic due to the significant effect the pandemic had on public access to healthcare services. Combined with a media campaign supporting healthcare workers, variables could be introduced that cannot be controlled for. Across the United Kingdom (UK) many non-urgent imaging appointments were being postponed or cancelled by both patients and healthcare providers. Myeloma patients also fall into one of the high-risk groups for Covid-19 and should avoid the risk of exposure where possible.

62 individuals completed the survey, two of which were excluded. One was based outside of the UK, and another had not experienced any of the imaging techniques being investigated. The 60 included respondents provided a total of 121 sets of responses across the three imaging modalities. As this is 35 responses short of the initial sample size estimate of 156 data sets an effect size calculation for the achieved sample size was performed and reported upon in chapter 3.3.7**.**

3.3.7 Quantitative Analysis Methods

Participant demographics were analysed to illustrate 'who' the participants were and contextualise results. SPSS V25 (IBM 2020) was used to perform descriptive and statistical analysis, and for producing charts and tables. The responses given on the categorical rating scales for each construct within the survey were converted to numerical acceptance scores for analysis.

Test of Normality

As the research data obtained is from a survey it was expected that this data would not follow a normal distribution and would require non-parametric statistical tests to be used for analysis. To confirm this, the Kolmogorov-Smirnov test was applied to each construct in the dataset (see table 3.2 for a list of constructs) (Field 2018: 249-251). This test will compare the scores in the dataset to a normally distributed set of scores with the same mean and standard deviation as the dataset. The Kolmogorov-Smirnov test demonstrated that the data for each survey construct deviated significantly from the norm (p = <0.001). The Kolmogorov-Smirnov statistic for each survey construct measured with ordinal data were as follows; worry prior to imaging, D (df 120) = 0.281; understanding the procedure D (df 120) = 0.278; stress D (df 121) = 0.276; claustrophobia D (df 121) = 0.275; feeling in control D (df 119) = 0.255; feeling supported by staff D (df 120) = 0.372; comfort D (df 120) = 0.210; overall experience D (df 121) = 0.239. This demonstrates that the data does not follow a normal distribution and should be analysed with non-parametric statistical models. A second test of normality that can be applied to the pain scores reported by respondents is through calculation of the kurtosis and skew using SPSS V25 (IBM 2020). These values indicate whether the data is either above, below or either side of the expected normality curve and will be presented alongside the results where relevant.

Statistical Tests and Effect Size

As the estimated required sample was not met, calculating the effect size of the achieved sample will demonstrate the magnitude of differences between groups in any observations made using the survey instrument (Field 2018: 113). Using G*Power software (Faul et al. 2009), an effect size of f = 0.286 was calculated using the achieved sample size of 121 responses, the same α and β error probabilities as the sample estimate calculation in chapter 3.3.5 and the one-way ANOVA statistical model. This effect size lies between the medium (0.25) and large (0.4) effect sizes described by Cohen (1992: 156). This demonstrates that as the sample size of 156 was not achieved the statistical analysis may not be sensitive in observing smaller effects (<0.286) within the data as measured by the size of the standard deviations from the mean (Field 2018: 114-120). These calculations assume a normal distribution of data, although as demonstrated above, the data obtained does not meet this assumption and an effect size appropriate for a non-parametric statistical model must be calculated.

To compare all three whole-body imaging modalities, the Kruskal-Wallis test was used as the data is not normally distributed (McDonald 2014: 157-164; Field 2018: 286-316). Where statistically significant results were demonstrated, additional pairwise analysis was performed to demonstrate the differences between two different groups or pairs of imaging modalities. Part of this pairwise analysis requires the calculation of post-test effect sizes, *r*, using the following equation, where *z* is the test statistic and *N* is the total sample size of each pairwise group (Field 2018: 318-319).

$$r = \frac{z}{\sqrt{N}}$$

The calculated effect sizes have been reported on in chapter 4.2.2 and again serve to demonstrate the magnitude of differences observed using the survey instrument. The non-parametric effect size, *r*, can be approximately compared to the parametric effect size calculated using Cohen's *f* given above. A limitation here is *f* assumes more than two groups and a parametric model whereas the post-test effect size, *r*, is calculated against pairs using a non-parametric model. Using an effect size calculator, Pyschometrica (Lenhard & Lenhard 2016), it is possible to convert Cohen's *f* to *r,* and vice versa. Cohen's f = 0.286 equates to r = 0.275, whilst f = 0.577 equates to r = 0.5. This indicates that for smaller effects sizes of < 0.3, *r* and *f* may be comparable, although at effect sizes of > 0.5 the differences may be more pronounced with the value of *f* being greater than *r*.

The Mann-Whitney U test was used when two independent groups were being compared. The Wilcoxon signed-rank test was used for analysing dependent pairs of variables. Spearman's correlation was used to analyse multiple variables measured with ordinal or ranked data.

Across all statistical testing, where outliers are identified that have the potential to bias results, they have been marked on boxplots to indicate to the reader where the outliers were in the data (Field 2018: 227-229). Outliers are scores that are 1.5 times greater than the IQR.

As multiple statistical tests were performed on the data, the possibility of a type I error increases (Field 2018: 308). Therefore, the *p*-values in the analysis were adjusted using the Bonferroni correction when appropriate, reducing the probability of making a type I error (Field 2018: 83). The convention for this is to divide the conventional significance level, $p = 0.05$, by the number of statistical tests to give the adjusted *p* value. McDonald (2014: 254-26) warns a very low *p* value calculated this way can reduce the statistical power and increase the chance of type II errors.

3.3.8 Qualitative Analysis Method

A qualitative description approach has been described by Bradshaw, Atkinson and Doody (2017: 1) as an appropriate method for healthcare researchers who have limited experience of complex qualitative methodologies. Qualitative description allows the researcher to understand the phenomenon being investigated and the perspective of those involved. It is an inductive process whereby it can add to existing knowledge and recognises the subjectivity of individual responses and the influence of the researcher (Bradshaw, Atkinson and Doody 2017: 2). Bradshaw, Atkinson and Doody (2017: 1, 5) state it as being suitable for mixed methods research and recommend thematic analysis as the named framework for data analysis.

Thematic analysis is a widely used and flexible qualitative analytical method described by Braun and Clark (2006: 78) as being a foundational method suitable for the novice qualitative researcher. Whilst thematic analysis can be suitable for a number of qualitative methods from different epistemological positions and methodologies, within this study it has been used from the perspective of qualitative description (Braun & Clark 2006: 78; Saks & Allsop 2012: 139-140). This enables the examination of personal lived experience without requiring the theoretical and technical knowledge of interpretative phenomenological analysis methodology (Smith & Osborne 2015: 41-42). The data was reviewed at a 'semantic' level where analysis focused on describing what participants have written and patterns within the content (Braun & Clark 2006: 84). This is followed by interpretation of the semantic level analysis so that conclusions can be made regarding its significance and implications. The limitation of thematic analysis at a semantic level is that it is not possible to attempt to investigate the underlying concepts and assumptions at a deeper level using latent level analysis (Braun & Clark 2006: 84). Given the relatively 'light' level of qualitative data collected in this survey, it would not be appropriate to attempt a deep latent level analysis, an approach more appropriate for detailed data, such as focus groups and interviews. As stated in chapter 3.1, by considering an interpretivist ontological perspective whereby reality is subjective to individual experience, then using thematic analysis from a realist epistemology allows for a straightforward analysis of individual responses (DePoy & Gitlin 2011: 26). A unidirectional relationship between a respondent's meaning and their experience is assumed (Braun & Clark 2006: 85), meaning that what a respondent has written directly expresses their experience. Although this is a relatively simplistic qualitative standpoint, it is again appropriate to the level of qualitative data obtained within this project and correlates to analysis at a semantic level.

Process of Thematic Analysis

To demonstrate the dependability and trustworthiness of the data analysis, a fully reported audit trail of the thematic analysis process is provided here, with additional details in appendices 6, 7, and 8 (Murphy and Yielder 2010: 65). Thematic analysis is a both a reflexive and iterative process. The effect of the researcher's involvement in the interpretation of respondents meaning has to be taken into account, while results and analysis develop together as repeated analysis continues to shape and refine the data (Murphy and Yielder 2010: 65-66). QSR International's (2020) NVivo V12 software was used to manage and analyse the open text data. The 6 phases of thematic analysis have been summarised in table 3.4 and detailed below.

Table 3.4: Summary of the six phases of thematic analysis

Reproduced from Braun and Clark (2006: 87)

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

Phase 1: Familiarity

The author reviewed each respondent's survey to confirm its internal consistency. To ensure the trustworthiness of completed surveys, individual responses were assessed for consistency to ensure that there is no discrepancy between negative and positive responses. Reading through each respondents' survey ensured the author was familiar with the qualitative data.

Phase 2: Initial Codes

The author reviewed each written response and assigned one or more codes to them using NVivo V12 (QSR International 2020). Whilst the author had a strong sense of the initial codes that would be used to reflect the constructs being investigated within the survey, additional codes evolved. 104 codes were used in total. Some small amount of overlap was noted between codes, for example 'disadvantages of WB-MRI' partly overlaps with the codes ‘claustrophobia’ and ‘stress or anxiety’. Coding in this way allowed for easier reference to positive and negative recorded experiences. Each code and the number of times a code was assigned to a part of the dataset are listed in appendix 6. Using NVivo V12 (QSR International 2020) a word frequency table was generated which was used to support the development of the codes and themes in subsequent phases. This list is available in appendix 7.

Phase 3: Initial Thematic Map of Potential Themes

The data compiled in phase 2 was used to produce a thematic map containing numerous themes, presented in appendix 8. Each theme is considered in relation to the research question, and whether it captures useful or informative qualitative data (Braun & Clark 2006: 82). Whilst prevalence is not necessarily a driving factor in the value of a theme, prevalence certainly highlights shared experiences and indicates issues that are of importance to the respondents through repeated patterns of meaning (Braun & Clark 2006: 86). At the end of phase three, 80 themes had been identified for further refinement.

Phase 4: Refined Thematic Map of Supported Themes

These candidate themes were reviewed to ensure there was sufficient data to support them. Where themes overlapped, they were combined into a single theme encapsulating a broader concept. For example, several themes referring to bone damage identified in phase 3 were encapsulated into two new candidate themes; ‘imaging identifying bone damage’, and ‘bone damage causing pain during imaging’. Braun and Clarke (2006: 93) state that at the end of phase 4, the data within a theme should consistently relate to that theme, with each theme being distinct. The outcome of phase 4 is a refined thematic map (see appendix 8).

Phase 5: Final Thematic Map

The dataset was then reviewed again to check the proposed themes against the data and to recode any missed data points as part of the iterative process of thematic analysis (Braun & Clarke 2006: 93). Once this process was complete a final thematic map was produced for the fifth phase of thematic analysis. Three primary themes and eleven sub-themes were identified. The themes were compared against one another to ensure minimal overlap and compared to the dataset to ensure each theme captures the importance of the patient experiences. The final thematic map and the final phase of thematic analysis, reporting upon the data, will be explored in chapter 4.3.

4. Results

4.1 Demographic Analysis

4.1.1 Age, Sex and Condition

The mean age of respondents in this study was 59.1 years (median = 58.5 years, IQR = 13, range = 39 – 79). 10 respondents (16.7%) were aged 70 years or more.

Of the 60 respondents, 27 (45%) were male, 23 (38.3%) were female, while the remaining 10 (16.7%) did not report their sex. Considering only the respondents that reported their sex, 54% were male and 46% were female. These demographics are further detailed in table 4.1

Table 4.1: Age and sex of respondents

			Gender			
			Male	Female	Not stated	Total
Age	< 40	Count	0	1	0	1
		% of Total	0.0%	1.7%	0.0%	1.7%
	40-49	Count	4	2	1	7
		% of Total	6.7%	3.3%	1.7%	11.7%
	50-59	Count	12	10	3	25
		% of Total	20.0%	16.7%	5.0%	41.7%
	60-69	Count	6	6	5	17
		% of Total	10.0%	10.0%	8.3%	28.3%
	> 69	Count	5	4	1	10
		% of Total	8.3%	6.7%	1.7%	16.7%
Total		Count	27	23	10	60
		% of Total	45.0%	38.3%	16.7%	100.0%

2 respondents (3.3%) reported a diagnosis of MGUS, 8 respondents (13.3%) reported a diagnosis of asymptomatic myeloma and the remaining 50 respondents (83.3%) stated they had multiple myeloma. Due to the disparate group sizes, sub-group analysis by condition was not attempted.

23 respondents (38.3%) had been diagnosed with their condition over four years ago, 21 respondents (35%) had been diagnosed between 1 to 3 years ago and the remaining 16

respondents (26.7%) had received a diagnosis in the past 12 months. These demographics are further detailed in table 4.2.

Table 4.2: Respondents condition and time since initial diagnosis

			Time since initial diagnosis			Total
			Less than 12 months	1 to 3 years	4 or more years	
Condition	Asymptomatic Myeloma	Count	5	3	0	8
		% of Total	8.3%	5.0%	0.0%	13.3%
	Multiple Myeloma	Count	11	17	22	50
		% of Total	18.3%	28.3%	36.7%	83.3%
	MGUS	Count	0	1	1	2
		% of Total	0.0%	1.7%	1.7%	3.3%
Total		Count	16	21	23	60
		% of Total	26.7%	35.0%	38.3%	100.0%

4.1.2 Types of Whole-Body Imaging Experienced

The 60 respondents provided data for 121 different experiences of whole-body imaging. RSS was experienced by 49 respondents (81.7%), WB-MRI was experienced by 40 respondents (66.7%) and LD-WBCT was experienced by 32 respondents (53.3%). Table 4.3 shows the grouped examinations that respondents experienced, although no data was collected regarding the period of time between an individuals' imaging experiences.

RSS, RSS in combination with WB-MRI or RSS with WB-MRI and LD-WBCT were the most frequently experienced imaging examinations, accounting for 75.1% of the imaging modalities reported. Whilst WB-MRI was also frequently utilised, it appears to be in conjunction with one of the other imaging modalities. Only 3 respondents (5%) stated they had only undergone whole-body imaging with LD-WBCT and 2 respondents (3.3%) just had WB-MRI. Only 11 respondents (18.3%) did not have RSS.

Table 4.3: Cross-tabulation of different imaging examinations experienced by respondent condition

		Condition			Total
Imaging Experienced		Asymptomatic Myeloma	Multiple Myeloma	MGUS	
RSS	Count	2	9	2	13
	% of Total	3.3%	15.0%	3.3%	21.7%
LD-WBCT	Count	0	3	0	3
	% of Total	0.0%	5.0%	0.0%	5.0%
WB-MRI	Count	0	2	0	2
	% of Total	0.0%	3.3%	0.0%	3.3%
RSS and LD-WBCT	Count	0	4	0	4
	% of Total	0.0%	6.7%	0.0%	6.7%
RSS and WB-MRI	Count	4	9	0	13
	% of Total	6.7%	15.0%	0.0%	21.7%
LD-WBCT and WB-MRI	Count	1	5	0	6
	% of Total	1.7%	8.3%	0.0%	10.0%
RSS, LD-WBCT and WB-MRI	Count	1	18	0	19
	% of Total	1.7%	30.0%	0.0%	31.7%
Total	Count	8	50	2	60
	% of Total	13.3%	83.3%	3.3%	100.0%

4.1.3 Time since Imaging Experience

16 of the 60 respondents (26.7%) stated that their most recent experience of imaging was over 6 months ago. The remaining 44 respondents (73.3%) had all experienced at least one whole-body imaging modality within 6 months of their completing the survey. Table 4.4 shows the time between each imaging experience being performed and reported. 59 (49.2%) of the imaging experiences occurred within six months or less of being reported.

Table 4.4: Time elapsed since reported whole-body imaging experience

			When				
			Less than a month ago	1-3 months ago	4-6 months ago	greater than 6 months ago	Total
Imaging Modality	RSS	Count	10	3	11	24	48
		% of Total	8.3%	2.5%	9.2%	20.0%	40.0%
	LD-WBCT	Count	4	4	7	17	32
		% of Total	3.3%	3.3%	5.8%	14.2%	26.7%
	WB-MRI	Count	3	6	11	20	40
		% of Total	2.5%	5.0%	9.2%	16.7%	33.3%
Total		Count	17	13	29	61	120*
		% of Total	14.2%	10.8%	24.2%	50.8%	100.0%

*****Data missing for one respondent

While recall bias is difficult to control for, the following analysis has been performed to demonstrate that the periods of time since a respondent experienced imaging and then reported upon it, is uniform across all three whole-body imaging modalities being investigated. The homogeneity of variance for the length of time since each imaging modality was experienced was tested. Levene's test was performed and demonstrated no significant difference, F (df_1 2, df_2 117) = 0.544, p = 0.582 (Field 2018: 257-262). Therefore, any present recall bias should be similar across all imaging modalities being investigated.

4.1.4 Pain

Each respondent was asked to rate the baseline pain that they experience as a result of their condition on a NRS ranging from 0-10. Table 4.5 shows the frequency that each level of pain was recorded. Whilst the majority of respondents experience a relatively low level of pain, some pain was experienced by all except for 8 respondents. 20 respondents (33.34%) reported pain scores of 6 or more, indicating a level of pain that can have an adverse effect on the quality of life (Harrington et al. 2018: 87). The mean pain score was 3.9 and the median was 3.0 (IQR = 5). The kurtosis for this pain data was -1.040 and the skew was 0.346, indicating that the data does not follow a normal distribution (Field 2018: 23-24).

Table 4.5: Frequency of pain scores

		Frequency	Percent
Pain Score	0	8	13.3
	1	8	13.3
	2	8	13.3
	3	7	11.7
	4	3	5.0
	5	6	10.0
	6	7	11.7
	7	3	5.0
	8	6	10.0
	9	2	3.3
	10	2	3.3
	Total	60	100.0

4.2 Quantitative Data Analysis

4.2.1 Previous Imaging Experience

All respondents were asked whether they had previously experienced a specific type of whole-body imaging before. This was to identify whether a previous imaging experience could be associated with different acceptance scores, in comparison to those who were experiencing an imaging technique for the first time. Using the Mann-Whitney U test, no statistically significant difference was found in acceptance scores between those that had previously experienced whole-body imaging, and those that had not for all survey constructs. The results closest to a critical $p = 0.05$ were 'pain', $p = 0.137$ and 'stress' $p = 0.186$.

4.2.2 Analysis of Ordinal Constructs

Table 4.6 uses descriptive statistics to show the reported median scores for each construct against each imaging modality (the list of constructs is available in table 3.2). These descriptive results show the reported median scores for each imaging modality to be either the same, or similar to one another. Figure 4.1 is a box plot illustrating the range of scores for the construct 'overall experience' and shows the reported scores to be similar for each imaging modality. These descriptive statistics demonstrate high acceptance of whole-body imaging with median scores of 4 for 'overall experience' of each imaging modality. The median score for 'staff support' was 5, indicating respondents experienced excellent staff support for each imaging modality. This result will be explored in context with the qualitative data in chapter 4.4. Median scores for the constructs 'prior worry', 'stress during' and 'claustrophobia' were all either 1 or 2, indicating that negative experiences were infrequently scored.

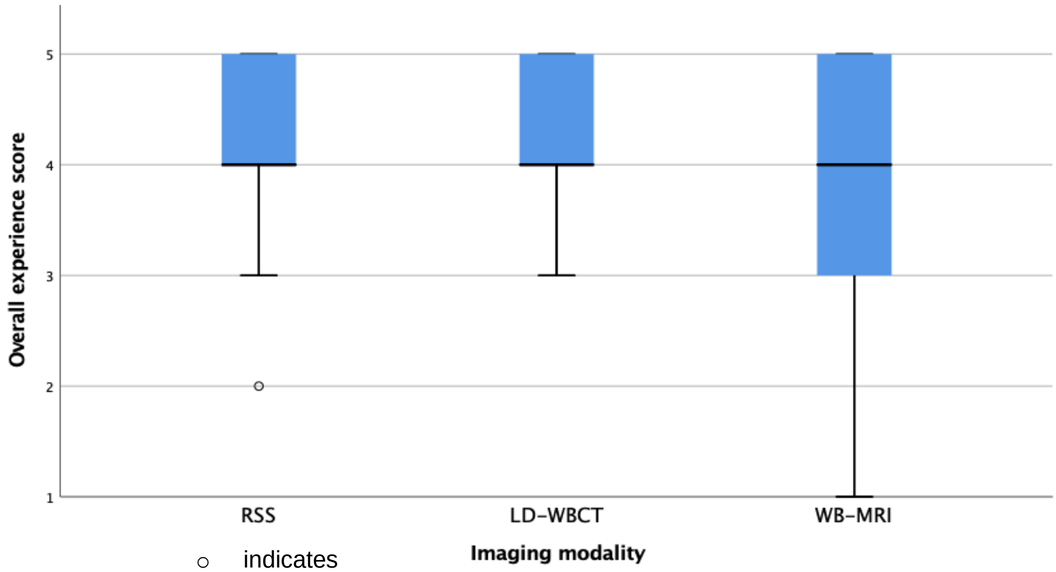
Table 4.6: Median reported scores for each construct and imaging modality

Imaging Modality			Prior Worry†	Understanding‡	Pain During*†	Stress During†	Claustrophobia †	Control‡	Support‡	Comfort‡	Overall experience‡
RSS	N	Valid	48	48	49	49	49	47	48	48	49
		Missing	1	1	0	0	0	2	1	1	0
	Median Score*		2	4	0	1	1	4	5	3.5	4
	Range		4	4	10	4	4	4	4	3	3
	IQR		1	1	2	1	1	2	1	1	1
LD-WBCT	N	Valid	32	32	32	32	32	32	32	32	32
		Missing	0	0	0	0	0	0	0	0	0
	Median Score*		1	4	1	1	1	4	5	3	4
	Range		4	3	10	4	4	4	3	4	2
	IQR		1	1	5	1	1	1	1	1	1
WB-MRI	N	Valid	40	40	40	40	40	40	40	40	40
		Missing	0	0	0	0	0	0	0	0	0
	Median Score*		2	5	1	2	2	4	5	3	4
	Range		4	2	10	4	4	4	2	4	4
	IQR		2	1	6	2	1	2	1	1	2
Overall	N	Valid	120	120	121	121	121	1119	120	120	121
		Missing	1	1	0	0	0	2	1	2	0
	Median Score*		2	4	1	2	2	4	5	3	4
	Range		4	4	10	4	4	4	4	4	4
	IQR		1	1	4	1	1	2	1	1	1

**Possible range of scores for all constructs was 1-5, except 'pain during' where the range of scores was 0-10. Zero indicated no pain, 10 indicates maximum pain.*

† *For these four constructs a low score indicates high acceptance (e.g. little worry or stress experienced), and a high score indicates low acceptance (e.g. a greater amount of worry or stress experienced).*

‡ *For these four constructs a high score indicates high acceptance (e.g. greater support or understanding experienced) and a low score indicates low acceptance (e.g. less support or understanding experienced)*



○ indicates

Figure 4.1: A box plot demonstrating the median scores and IQR for overall experience.

The 9 constructs investigated with ordinal data were analysed using the Kruskal-Wallis test to demonstrate any variance in the scores recorded for each imaging modality. 7 of the survey construct scores did not vary between imaging modality. These were ‘prior worry’ p = 0.200; ‘understanding’ p = 0.700; ‘pain during’ p = 0.464; ‘control’ p = 0.509; ‘support’ p = 0.373 and ‘overall experience’ p = 0.551.

Significant variation in the distribution of the acceptance scores reported by respondents was found for the constructs of stress experienced during imaging, p = 0.008, and claustrophobia experienced during imaging, p = <0.001. These two constructs will undergo post-hoc analysis.

Post-hoc Analysis for Stress Experienced During Imaging

Figure 4.2 shows the distribution of reported scores for the stress experienced during imaging. The median scores reported for RSS and LD-WBCT were 1 (IQR = 2), and for WB-MRI the median score was 2 (IQR = 3). Analysis with the Kruskal-Wallis test showed the stress experienced during WB-MRI was greater than LD-WBCT or RSS, H (df 2) = 9.586, p = 0.008.

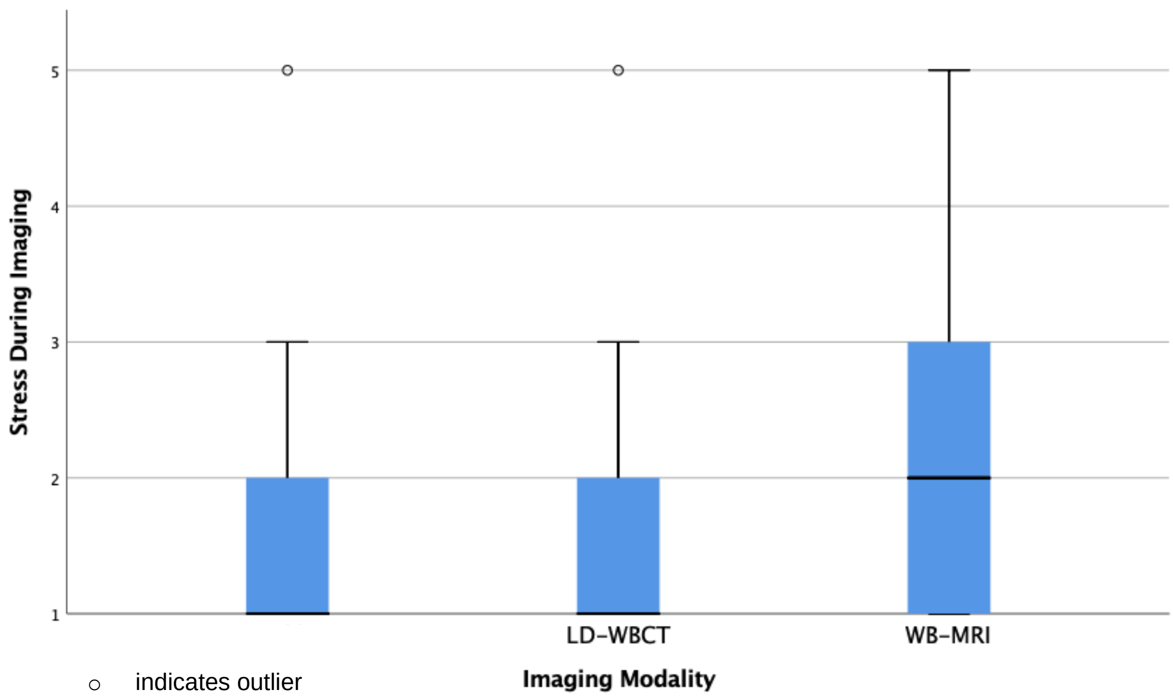
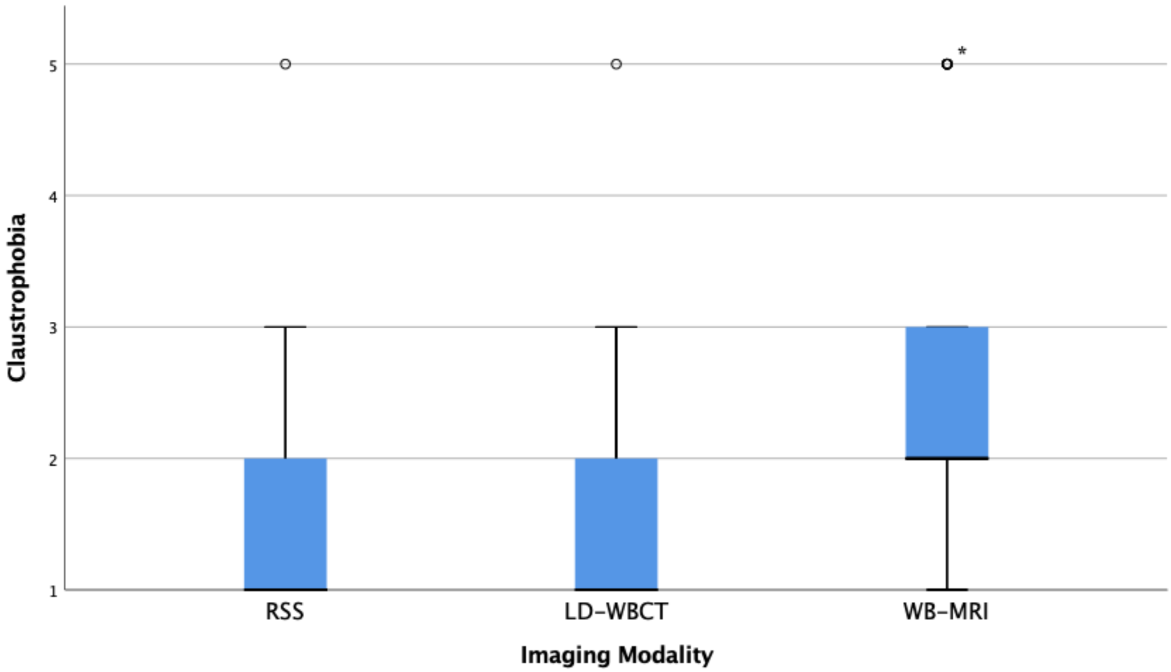


Figure 4.2: A box plot demonstrating the median reported scores and IQR for stress experienced during imaging.

The scores reported for ‘stress’ during imaging were compared against all three imaging techniques, as part of a pairwise analysis using the Kruskal-Wallis test. WB-MRI scores were higher than LD-WBCT scores; *H* = -22.275, *p* = 0.011, *r* = -0.343. There was no statistically significant difference in the reported scores for between LD-WBCT and RSS; *H* = 6.202, *p* = 1.00, *r* = 0.095, or WB-MRI and RSS; *H* = -16.073, *p* = 0.057, *r* = -0.311. For WB-MRI the effect sizes, *r,* were calculated to be greater than 0.3 supporting a strong degree of variation in scores reported by participants that experienced this imaging technique.

Post-hoc Analysis for Claustrophobia

Figure 4.3 shows the distribution of reported scores for the claustrophobia experienced during imaging. The median scores reported for RSS and LD-WBCT were 1, and for WB-MRI the median score was 2. For respondents reporting upon WB-MRI, the stress experienced was greater than the stress reported during LD-WBCT or RSS, *H* (*df* 2) = 24.876, *p* = <0.001.



○ indicates *4 outliers recorded at this point

Figure 4.3: A box plot demonstrating the median scores and IQR for claustrophobia experienced during imaging.

Claustrophobia scores were compared against all three imaging techniques as part of a pairwise analysis using the Kruskal-Wallis test. The scores reported for 'claustrophobia' during imaging for WB-MRI were higher than RSS; H = -29.853 p = <0.001, r = -0.457, and LD-WBCT; H = -33.6 p = <0.001, r = -0.511. These effect size scores were both greater than 0.45, supporting a strong degree of variation. There was no statistical difference in the reported scores for 'claustrophobia' between LD-WBCT and RSS; H = 3.747, p = 1.00, r = 0.057.

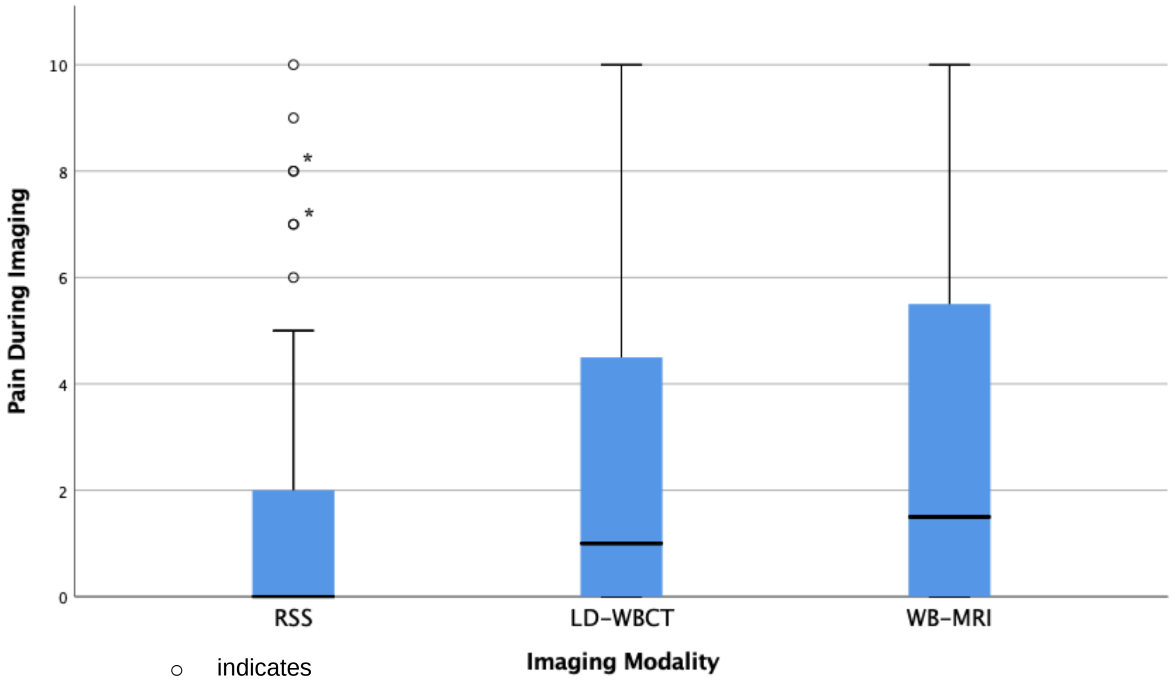
4.2.3 Analysis of Pain Experienced During Imaging

In chapter 4.1.4 the pain experienced by respondents was explored (table 4.5). Similar descriptive statistics for the pain experienced during whole-body imaging have been produced below in table 4.7. The mean pain score across all imaging modalities was 2.31 (IQR 4). For each imaging modality mean pain scores were RSS = 1.9 (IQR 3); LD-WBCT = 2.25 (IQR 5); WB-MRI = 2.85 (IQR 6). Figure 4.4 illustrates the range of pain scores reported for each imaging modality. The kurtosis for this pain data was 0.196 and the skew was 1.212, indicating it should be analysed with non-parametric statistical models (Field 2018: 23-24). No pain was reported for 47.1% of the imaging experiences indicating that the majority of respondents did not experience additional pain. Pain scores of 6 or more were still reported for 18.2% of recorded imaging experiences.

Table 4.7: Frequency of pain scores reported during imaging

		Frequency	Percent
Valid	0	57	47.1
	1	14	11.6
	2	13	10.7
	3	4	3.3
	4	3	2.5
	5	8	6.6
	6	4	3.3
	7	6	5.0
	8	5	4.1
	9	1	.8
	10	6	5.0
	Total	121	100.0

In chapter 4.2.2 it was demonstrated that there was no significant variance in the pain experienced across all three whole-body imaging modalities, H (df 2) = 1.537, p = 0.464. Figure 4.4 shows the median scores and IQR reported for pain with each imaging modality and shows the pain experienced across each imaging modality to be similar. Outliers that are 1.5 times greater that the IQRs have been marked on this boxplot but excluded from analysis (Field 2018: 227-229).



○ indicates

*2 outliers recorded at these points

Figure 4.4: A box plot demonstrating the median scores and IQR for pain experienced during imaging.

Each participant's reported baseline pain score was compared with their reported pain score for each imaging modality they had experienced using the Wilcoxon signed-rank test (Field 2018: 297-300). The results of this analysis showed that the pain scores reported by respondents during imaging were significantly lower than the respondents baseline pain, T = -6.73, p = <0.00, r = -0.61. This result demonstrates that the imaging experience did not cause an increase in respondent pain.

To better understand which respondents experienced higher levels of pain during imaging, the respondents' baseline pain scores and pain during imaging scores were grouped into three categories recommended by Hartington et al. (2018: 87). Pain scores of 0-3 were categorised as low pain, 4-6 as moderate pain and 7-10 as high pain. By categorising the data this way, it was possible to review the descriptive statistics to see which group mostly reported high pain. 57 of the 59 respondents who reported low baseline pain also reported low pain scores during imaging. 35 respondents reported moderate baseline pain, 21 of which reported low pain during imaging and 13 reported moderate pain during imaging. 16 of the 27 respondents who reported severe baseline pain, also reported severe pain during imaging. However, there were 10 instances when those that reported severe baseline pain reported low pain during imaging. These descriptive statistics demonstrate that severe pain during imaging was experienced mostly by the group who already reported severe pain as a result of their condition. Likewise, the group who reported low pain as a result of their condition also reported low pain when undergoing imaging. These descriptive statistics are detailed in table 4.8.

Table 4.8: Cross-tabulation of categorised pain scores reported at baseline and during imaging

			Pain Experienced During Imaging			
			Low pain	Moderate pain	Severe pain	Total
Baseline pain	Low pain	Count	57	1	1	59
		% of Total	47.1%	0.8%	0.8%	48.8%
	Moderate pain	Count	21	13	1	35
		% of Total	17.4%	10.7%	0.8%	28.9%
	Severe pain	Count	10	1	16	27
		% of Total	8.3%	0.8%	13.2%	22.3%
Total		Count	88	15	18	121
		% of Total	72.7%	12.4%	14.9%	100.0%

The results of these descriptive statistics are further supported by correlating reported baseline pain scores with the pain that they have experienced during imaging. Using Spearman's correlation coefficient (Field 2018: 351) a significant positive correlation was found; r_s = 0.644, p = < 0.001. This indicates that respondents who reported a higher level of pain as a result of their condition, also reported higher pain during imaging.

4.2.4 Length of Examination

Cross-tabulation of each imaging modality against the number of respondents who reported difficulty with the length of the examination provides further descriptive statistics, summarised in table 4.9. Difficulty with the length of the examination was recorded 23 times out of 121 overall imaging experiences (19%). 14 of these were associated with WB-MRI (11.6%) and the remaining 9 were associated with either RSS or LD-WBCT (7.4%). 14 respondents out of 40 (35%) who had experienced WB-MRI stated that they had difficulties with the length of this examination, a large proportion of the WB-MRI sample.

Table 4.9: Cross-tabulation of difficulties with the length of imaging against each modality

			Difficulties with Length		Total
			Yes	No	
Imaging Modality	RSS	Count	5	44	49
		% within Imaging Modality	10.2%	89.8%	100.0%
		% of Total	4.1%	36.4%	40.5%
	LD-WBCT	Count	4	28	32
		% within Imaging Modality	12.5%	87.5%	100.0%
		% of Total	3.3%	23.1%	26.4%
	WB-MRI	Count	14	26	40
		% within Imaging Modality	35.0%	65.0%	100.0%
		% of Total	11.6%	21.5%	33.1%
Total		Count	23	98	121
		% within Imaging Modality	19.0%	81.0%	100.0%
		% of Total	19.0%	81.0%	100.0%

To demonstrate a relationship between pain and difficulty with the length of the imaging examination, a second set of descriptive statistics were produced comparing these two variables. Table 4.10 shows that respondents who reported difficulties with the length of an examination reported a range of low, moderate and severe pain scores. For WB-MRI, 8 of the 14 respondents who had difficulty with the length of this examination experienced low pain, and nearly half of the respondents who had difficulty with any imaging examination also experienced low pain. This indicates that pain may not always be the primary factor that effects a respondent’s difficulty with the length of whole-body imaging.

Table 4.10: Cross-tabulation of respondents who stated they had difficulty with the length of imaging against the pain experienced during imaging

			Pain During Imaging			
			Low pain	Moderate pain	Severe pain	Total
Imaging Modality	RSS	Count	2	1	2	5
		% of Total	8.7%	4.3%	8.7%	21.7%
	LD-WBCT	Count	1	1	2	4
		% of Total	4.3%	4.3%	8.7%	17.4%
	WB-MRI	Count	8	2	4	14
		% of Total	34.8%	8.7%	17.4%	60.9%
Total		Count	11	4	8	23
		% of Total	47.8%	17.4%	34.8%	100.0%

To investigate any association between difficulty with the length of each imaging modality and each survey construct, a sub-group analysis was performed using the Mann-Whitney U test. For the WB-MRI sub-group, respondents who stated they had difficulty with the length of the examination reported significantly higher claustrophobia scores than the respondents who did not have any difficulty with the length of the examination, $U = 65.5$, $z = -3.562$, $p = 0.001$, $r = -0.563$. The results of this analysis with the Mann-Whitney U test are illustrated in figure 4.5, which shows two histograms comparing the claustrophobia scores reported for WB-MRI. A limitation of this analysis is the small sample size of each group.

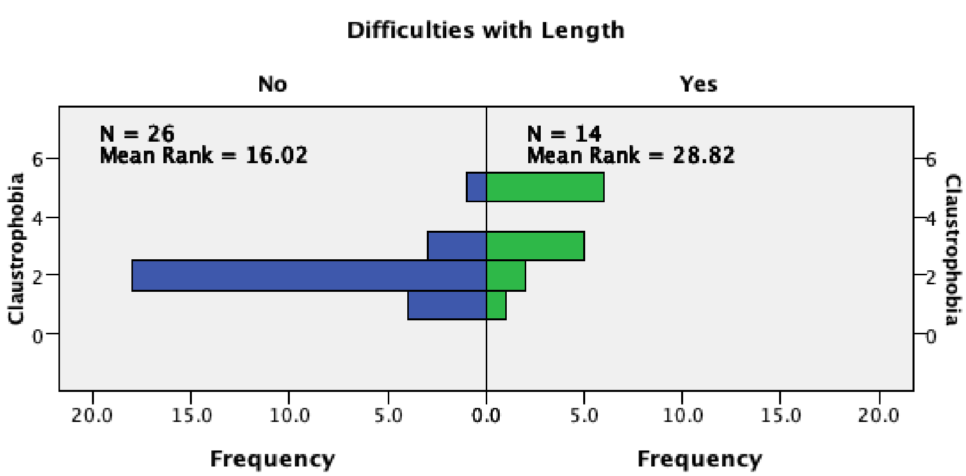


Figure 4.5: Histogram of claustrophobia scores reported for WB-MRI, with respondents grouped into whether they experienced difficulty with the length of the examination or not.

4.2.5 Concerns with the Use of X-rays or Magnetic Fields

9 out 60 respondents (15%) across 12 of 117 recorded imaging experiences (10.3%) indicated concerns regarding the use of either x-rays or magnetic fields. Table 4.11 shows that the greatest proportion of these concerns related to RSS where 7 out of 46 respondents (15.2%) recorded a concern regarding the use of x-rays for this modality. Analysis with the Mann-Whitney U test did not demonstrated any difference in the acceptance scores between those that had a concern with the use of x-rays, and those that did not. The construct 'prior worry' demonstrated the highest unadjusted significance value, *p* = 0.057.

Table 4.11: Cross-tabulation of concerns about the use of x-rays or magnetic fields against each modality

			Concern about the use of X-rays/magnets		
			Yes	No	Total
Imaging Modality	RSS	Count	7	39	46
		% within Imaging Modality	15.2%	84.8%	100.0%
		% of Total	6.0%	33.3%	39.3%
	LD-WBCT	Count	1	31	32
		% within Imaging Modality	3.1%	96.9%	100.0%
		% of Total	0.9%	26.5%	27.4%
	WB-MRI	Count	4	35	39
		% within Imaging Modality	10.3%	89.7%	100.0%
		% of Total	3.4%	29.9%	33.3%
Total		Count	12	105	117*
		% within Imaging Modality	10.3%	89.7%	100.0%
		% of Total	10.3%	89.7%	100.0%

*data incomplete for 4 responses

4.2.6 Survey Tool Validity

In chapter 3.2.2 it was stated that the construct validity of the survey tool would be assessed through convergent and divergent validity (Fayers & Machin 2016: 96-98). Each of the nine constructs that was investigated using ordinal data was correlated against the other constructs using Spearman's correlation coefficient (Field 2018: 351-352). The results of this correlation are demonstrated in table 4.12, with those that are statistically significant highlighted. Correlation coefficients greater than 0.5, or lower than -0.5, have been highlighted orange to indicate stronger correlations. Reviewing the data presented in table 4.12 shows where scores reported for one construct positively or negatively correlates with scores reported for a second construct. This analysis does not demonstrate any causality but supports the validity of the bespoke survey tool used for this study. Overall, there were positive correlations between overall experience and the constructs 'understanding', 'control', 'support' and 'comfort' while there were negative correlations between overall experience and the constructs 'prior worry', 'pain during', 'stress during' and 'claustrophobia'.

Whilst this data was produced to demonstrate the validity of the survey tool, it also shows some significant results. The construct of stress during imaging gave the strongest positive correlation with the constructs 'worry prior to imaging', $r_s = 0.682$, and 'claustrophobia', $r_s = 0.590$. The construct 'control' showed strong positive correlations with overall experience, $r_s = 0.647$; comfort, $r_s = 0.595$ and support, $r_s = 0.565$. 'Stress during imaging' had a strong negative correlation with 'control', $r_s = -0.506$, and overall experience, $r_s = -0.536$. There appear to be no correlations that are impossible to account for or that indicate an error in convergent and divergent validity.

Table 4.12: Spearman's correlation coefficients for each survey construct

Construct Short Title		Prior Worry	Under-standing	Pain During	Stress During	Claustro-phobia	Control	Support	Comfort	Overall experience
Prior Worry	Correlation Coefficient		-0.063	0.135	.682**	.411**	-.444**	-.200*	-.247**	-.298**
	Sig. (2-tailed)		0.496	0.141	0.000	0.000	0.000	0.029	0.006	0.001
Understanding	Correlation Coefficient	-0.063		-0.072	-0.154	-0.097	.402**	.395**	.317**	.392**
	Sig. (2-tailed)	0.496		0.437	0.093	0.294	0.000	0.000	0.000	0.000
Pain During	Correlation Coefficient	0.135	-0.072		.186*	.311**	-.263**	-0.089	-.478**	-.266**
	Sig. (2-tailed)	0.141	0.437		0.041	0.001	0.004	0.331	0.000	0.003
Stress During	Correlation Coefficient	.682**	-0.154	.186*		.590**	-.506**	-.287**	-.419**	-.536**
	Sig. (2-tailed)	0.000	0.093	0.041		0.000	0.000	0.001	0.000	0.000
Claustrophobia	Correlation Coefficient	.411**	-0.097	.311**	.590**		-.411**	-0.088	-.361**	-.363**
	Sig. (2-tailed)	0.000	0.294	0.001	0.000		0.000	0.338	0.000	0.000
Control	Correlation Coefficient	-.444**	.402**	-.263**	-.506**	-.411**		.565**	.595**	.647**
	Sig. (2-tailed)	0.000	0.000	0.004	0.000	0.000		0.000	0.000	0.000
Support	Correlation Coefficient	-.200*	.395**	-0.089	-.287**	-0.088	.565**		.443**	.449**
	Sig. (2-tailed)	0.029	0.000	0.331	0.001	0.338	0.000		0.000	0.000
Comfort	Correlation Coefficient	-.247**	.317**	-.478**	-.419**	-.361**	.595**	.443**		.534**
	Sig. (2-tailed)	0.006	0.000	0.000	0.000	0.000	0.000	0.000		0.000
Overall experience	Correlation Coefficient	-.298**	.392**	-.266**	-.536**	-.363**	.647**	.449**	.534**	
	Sig. (2-tailed)	0.001	0.000	0.003	0.000	0.000	0.000	0.000	0.000	

4.3 Qualitative Data Analysis

Thematic analysis was applied to the 198 text responses according to the method outlined in chapter 3.3.8. Figure 4.6 shows the final thematic map that was produced in phase 5. Three themes were identified, containing a total of 11 sub-themes.

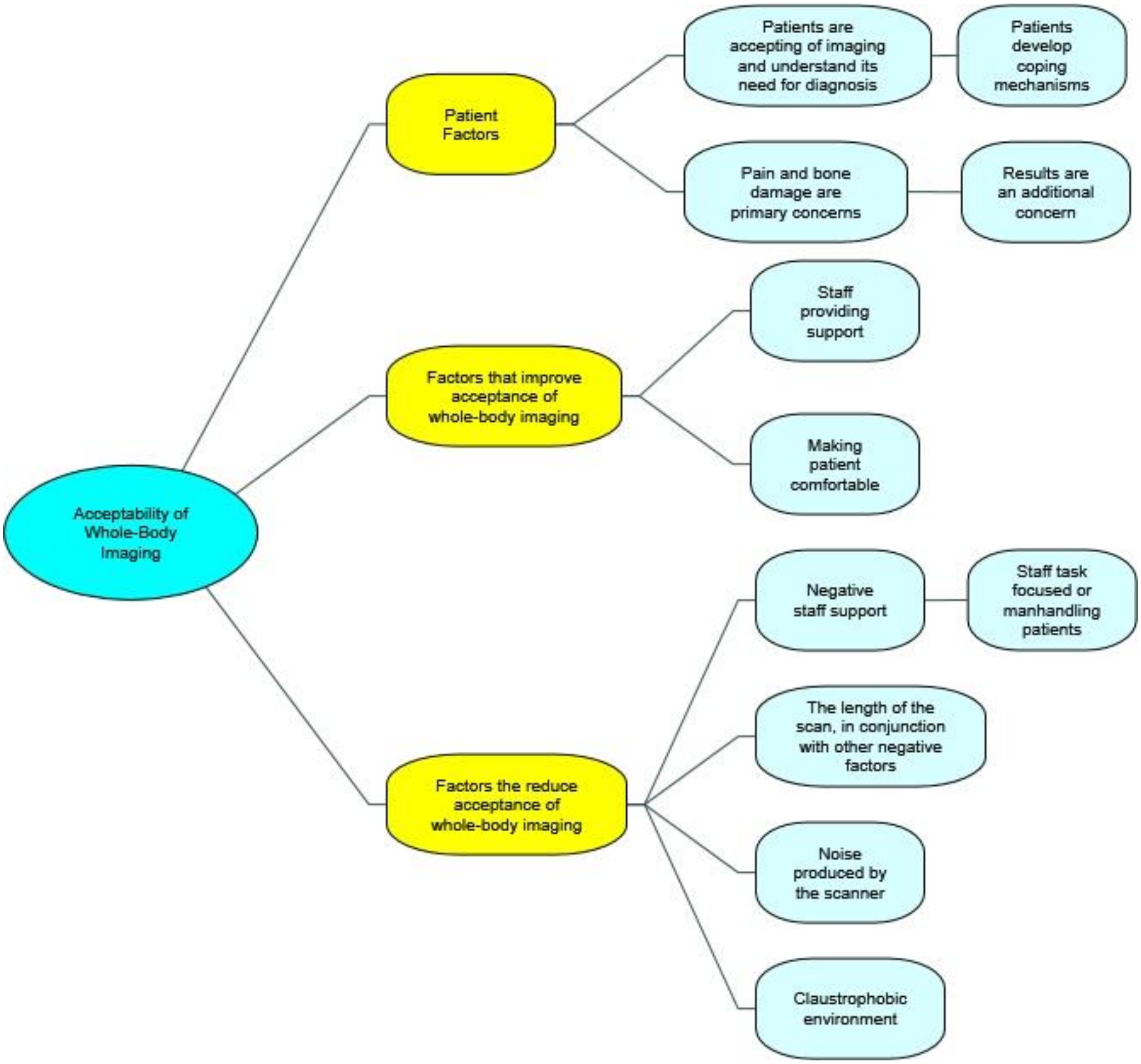


Figure 4.6: Thematic Analysis Map of Themes Developed in Phase 5.

4.3.1 Theme 1: Patient Factors

A number of factors unique to the individual and independent of the imaging technology were identified in the thematic analysis. These subthemes are largely introspective and while they do not relate to a specific imaging modality, they are still linked to the patients' myeloma journey and their associated imaging experiences. Direct quotations from the dataset, as they were written by the participant, will be used to support the proposed themes, alongside a fully anonymised participant identification number.

Sub-Theme 1: Patients are accepting of imaging and understand its need for diagnosis

The coding table in appendix 5.6 shows that 'imaging needed for diagnosis' was the most frequently used code, being used 28 times. Participants indicated a high acceptance of imaging due to understanding its need. Imaging appeared to be perceived as a positive tool, as when asked about the advantages of imaging many respondents stated that they recognised how the imaging and the diagnosis had helped them:

- *"Gives a good picture of the condition of my bones and how much myeloma is in my body"* (s24).
- *"A useful test used to explain why I was experiencing severe back and rib pain which ultimately led to my being diagnosed with multiple myeloma"* (s25).

Other respondents were accepting of imaging from a more pragmatic perspective:

- *"It's important to realise as a patient these examinations are for benefit of the patient. If these scans are required the data that is outputted will aid me, so you need to just get on with it"* (s40).
- *"As multiple myeloma is incurable I was willing to have any procedure deemed necessary to prolong my life and advance treatment"* (s50).

A result that strongly demonstrates the myeloma patients' acceptance is that each of the 60 respondents, for all 121 imaging recorded experiences, stated that they would be prepared to undergo that whole-body imaging technique again if necessary. Although the thematic analysis shows that patients are highly accepting of the need for imaging, this should not overshadow possible associated burdens that will be discussed later in this analysis.

Sub-Theme 2: Patients develop coping mechanisms

Respondents were able to develop coping mechanisms to improve their intrinsic acceptance of whole-body imaging and counteract any associated burdens. The coding around coping mechanisms was recorded seven times and related to WB-MRI most frequently. Participants reported that concentration was an important part of coping with the burden of WB-MRI:

- *"I concentrated throughout to ensure control. It was important that I knew I could call for help if needed"* (s24).

One participant, as well as referencing concentration, described a sense of pride at having been able to complete a WB-MRI:

- *"I am claustrophobic, so found it very difficult. I was in the scanner for an hour and twenty minutes so really had to concentrate to keep calm. The noise was unbelievable too. I am proud of myself for getting through it, and hope I don't need to have one again, but if I do, at least I know what to expect. I wore a sleep mask, which really helped, as I couldn't see how confined the space was"* (s31).

Another participant described some more physical approaches, such as breathing or singing, as a coping mechanism:

- *"Just needed to get myself into a good happy space whilst the process was on going. Practising [sic] breathing exercises and keeping my eyes closed and singing to myself helped"* (s40).

Only two respondents reported that they required the support of an orally ingested sedative prescribed by their doctor to be able to complete their WB-MRI:

- *"I was very anxious before and during the scan. my doctor had to prescribe me a sedative as I really struggle with these scans."* (s09).

Whilst the use of oral sedation could have an effect on an individual's perception and experiences, the need for sedation relates to high levels of scan related anxiety and these experiences should still be considered and included in analysis.

Sub-Theme 3: Pain and bone damage are primary concerns

Bone damage was coded 16 times, and the words ‘bone’ or ‘bones’ were used 17 times across the dataset. Reviewing the text provided by respondents demonstrates a strong theme towards individual concerns about bone damage, whilst understanding the utility of imaging in being able to visualise the bone damage:

- *“I was happy to have an MRI to see if I had any more Myeloma damage to my vertebrae”* (s46).
- *“Reassuring to know damage to bones limited to one area.”* (s50).

Pain has been included in this theme as respondents frequently discussed pain and bone damage in unison. ‘Pain’ was referred to 30 times, the second most frequently occurring word (see appendix 7). The necessity of identifying bone lesions that cause pain appears to be well understood by those living with myeloma:

- *“Needed to get adequate images of my bones, inc any lesions. Last one 1 month ago showed a new one following some recent pain. This indicated a potentially impending spinal cord compression for which I was given a short course of Radiotherapy”* (S51).

Some of the pain reported by respondents was exacerbated by the imaging experienced. One respondent shared their experience of having to change position for RSS:

- *“Standing for some xrays was painful, as was lying flat due to spinal fractures”* (s35).

Another respondent shared a similar experience of increased pain through having to lie still for a WB-MRI:

- *“Due to spinal damage caused by the Myeloma, I am unable to lie flat and it was very difficult to remain in an acceptable position for the length of the scan”* (s26).

Sub-Theme 4: Results are an additional concern

The goal of any diagnostic test is to obtain a result for diagnosis. This is well understood by patients, and many of the respondents in this survey stated the potential results were frequently a source of anxiety. Although the results are a variable that cannot be accounted for it has still been included as a sub-theme due to the number of times it was referenced by the survey respondents, 15 in total. These references were made in relation to all three whole-body imaging modalities. Two examples of the potential results being a source of anxiety are provided below.

- *"Procedure itself wasn't a problem. General anxiety was related to the disease, what the scans would reveal"* (s50)
- *"Just scared about the result and there is nothing anyone could have done about that. Everyone was so kind and professional. There was nothing at all that would have prevented my having a repeat scan, the scariest thing is what it may have shown and equally the same for any repeat scans"* (s02).

4.3.2 Theme 2: Factors that Improve Acceptance of Whole-Body Imaging

The two sub-themes that will be described here are applicable across all three imaging modalities and relate to external factors that have a largely positive effect on acceptance.

Sub-theme 5: Staff providing support

The word staff was referenced 13 times within the dataset, although this is in relation to both positive and negative experiences. However, positive staff experiences were coded four times and appeared to demonstrate how staff support enabled a patient to complete whole-body imaging and improve their overall experience. One respondent documented a burden they experienced during WB-MRI, and how staff supported them through explaining the process:

- *"Noises but staff were supportive and explained whole process"* (s13).

The positive impact of staff explaining the imaging procedure and communicating with the patient was documented by a second respondent, who linked a full discussion about their imaging with a positive impression of staff:

- *"Everything was discussed fully during MRI, CT and x-ray, staff were excellent in all departments. Staff consultants and Dr's at Haematology have been fantastic"* (s34).

The base word 'explain', including stemmed words such as 'explained', was used eight times throughout the dataset. This indicates that patients feel that there is a value or significance to receiving an explanation from the staff guiding them through the imaging process. Within staff support, staff providing an explanation and communicating with staff should also be considered as factors to improve the acceptance of whole-body imaging across all modalities.

Sub-Theme 6: Making patient comfortable

Whilst it seems intuitive that being physically comfortable will increase the acceptance of any whole-body imaging technique, its importance becomes more pronounced when considered against other factors that may hamper acceptance. If a patient is not comfortable, then the factors that reduce the acceptance of whole-body imaging may become prevalent throughout the entire imaging experience. One respondent stated the devices that were strapped across them as part of their WB-MRI improved their comfort and reported it as an advantage:

- *“More comfortable as lying down and 'held' in position”* (s04).

Another respondent also stated not having to keep changing positions was an advantage of WB-MRI:

- *“Do not have to move into different positions”* (s09)

One respondent specifically referenced the comfort of LD-WBCT as being one of several factors that improved acceptance:

- *“With the new volume scanner, the speed was amazing and the mattress was very comfortable. Had I been in pain on one of the old scanners I think it could have been quite tricky.”* (s02).

The theme of comfort also has the potential to reduce patient acceptance, when discomfort becomes pain, which has already been identified as impacting the acceptance of imaging in sub-theme 3. The word ‘uncomfortable’ was referenced 11 times in the dataset. In addition, the base word ‘position’ and related stem words were referenced 12 times, primarily used by respondents to document the experience of being positioned or having to change position for their whole-body imaging. Within the dataset this was frequently associated with some discomfort. The code ‘difficulty with positioning for RSS’ was used 14 times, with 9 of the 48 respondents (18.8%) who had experienced this modality documenting discomfort associated with the physical manipulation necessary for RSS and reporting it as a disadvantage:

- *“Difficulty in standing due to back pain from lying flat (pain started when moving, none during xray)”* (s27).
- *“Having to maintain uncomfortable positions”* (s35).

4.3.3 Theme 3: Factors that Reduce Acceptance of Whole-Body Imaging

The four sub-themes that will be described here are applicable across all three imaging modalities and relate to factors that negatively affect acceptance and are outside the patients' control.

Sub-theme 7: Negative staff support

As sub-theme 5 identified staff support as being a factor that improves acceptance of whole-body imaging, it is therefore intuitive that the opposite would reduce patients' acceptance of whole-body imaging. This polar effect was not evident for every factor that had either a positive or a negative influence on acceptance, but was highly evident in the overall theme of staff support, so has been reported separately.

As stated previously, the word 'staff' was used 13 times in the dataset, and whilst the concept of negative staff support was coded only 7 times by 5 respondents, there was some significant feedback regarding the apparent lack of emotional support or empathy.

- *"Some are more sympathetic than others. To you this is a life changing diagnosis and every procedure can be worrying"* (s50).
- *"Concerns about pending diagnosis. Staff were very practical but not emotionally supportive"* (s13).
- *"Staff being more patient focused than task focused. More explanation throughout the procedure"* (s38).

Sub-theme 5 indicated the value of healthcare staff providing service users with a full explanation. Conversely, three respondents indicated how a lack of explanation or information negatively impacted their imaging experience, as demonstrated in the example below:

- *"Not explained how long I was to be in MRI"* (s14).

Sub-theme 8: Staff task-focused or manhandling patients

An additional sub-theme emerged around the concept of staff support regarding the physical positioning that the radiographer is required to perform upon the patient in order to obtain the full range of radiographic projections for RSS. When asked what could improve the experience of RSS, two respondents reported a negative perception of this staff interaction:

- *“Staff to take it at individual pace and not rush. Explain and allow individual to take positions rather than doing it for the individual”* (s60).
- *“Radiology staff [redacted] were too task focused. They were more interested in getting the images they needed than the discomfort it was causing me. Lots of moving me about, at times quite roughly”* (s38).

Although only two respondents reported this type of experience, the qualitative data they provided demonstrates the significant detrimental impact this had on their acceptance of RSS.

Sub-theme 9: The length of the whole-body imaging

Whilst the length of a whole-body imaging examination in itself appears to have little effect on its acceptance, when combined with other factors such as discomfort or claustrophobia, the length of an examination then has a greater pronounced effect. Time, and similar words, were recorded 26 times in the data set, the third most frequently used set of words. ‘Difficulty with the length of the WB-MRI’ was the second most frequently used code, being used 26 times. 18 respondents documented some difficulty with the length of a WB-MRI examination, in conjunction with other factors:

- *“It’s quite hard to remain still and stay comfortable for such a long time, especially when you a covered from head to toe. It also gets a little claustrophobic when they are scanning your head. It’s manageable but can be tough”* (s53).
- *“Being enclosed and still for a lengthy period was difficult”* (s19).
- *“Very noisy and the length of time it takes can be unsettling. Seems never ending first time and some would definitely find it claustrophobic”* (s29).

Other participants recorded anxiety that being unable to complete the WB-MRI due to the length of the examinations could impact their treatment:

- *“Stress was caused by the concern I would not be able to stay in position for the time required and this may jealousies [sic, jeopardise] my stem cell transplant going ahead”* (s26).
- *“There is a tension that builds up - if you stop for any reason then they have to start from scratch so you do anything to avoid that. That, in turn, can cause its own level of anxiousness”* (s55).

Whilst some respondents documented the perceived diagnostic accuracy of WB-MRI as an advantage, 5 respondents felt that the relative speed of RSS was its main advantage over other imaging modalities:

- *“Can be done in XRay so possibly much quicker wait time than MRI”* (s33).
- *“Quick and relatively easy”* (s39).

Conversely, four respondents found the length of RSS to be difficult, mainly in conjunction with the discomfort experienced due to positioning for the radiographs or a lack of information regarding the length of the examination:

- *“Staff moving me about roughly, seemed to take ages and I got no real indication of how long it was all going to last”* (s38).
- *“Takes a long time, Some postions [sic] are difficult to move into with bone damage and pain”* (s09).
- *“Was difficult standing so long and quite difficult positioning myself”* (s53).

4 respondents perceived the speed of LD-WBCT to be one of its main advantages:

- *“Fast, low dose with new scanners, not claustrophobic”* (s02).

Sub-theme 10: Noise produced by the scanner

The radiographs required for producing a series of x-rays for RSS produce very little noise, whilst the noise produced during an MRI scan is well documented (Graham, Cloke and Vosper 2011: 294). ‘Noise’ was coded 18 times in this dataset, and the word was used 10 times. In both cases it was most frequently in reference to WB-MRI. One respondent documented how being unprepared for the noise of the WB-MRI affected them:

- *“I wasn’t ready for the load banging noises and when it made me jump it was extremely sore”* (s56).

Ear protection combined with music being played through the ear defenders are commonly employed in most modern MRI systems to help reduce the acoustic noise and improve the imaging experience. Some of the respondents provided suggestions regarding improving this system:

- *“I’ve had two full body MRI’s and the headphones/ music is pretty hopeless. Not an easy thing to solve, but it does help as a distraction”* (s55).
- *“Better ear protection due to noise of scanner”* (s44).

Anecdotally, it is understood that CT scanners also produce some acoustic noise, but there appears to be no documented evidence of the associated sound pressures or its effect on patients. Three respondents reported the noise of LD-WBCT to be a disadvantage. One respondent explained how the noise impacted the feeling of control during their LD-WBCT scan due to the effect it had on communication with staff:

- *“I couldn’t hear what was being said and I doubt that anyone would have heard me if I had shouted for them to stop”* (s32).

Sub-theme 11: Claustrophobia

Many of the respondents' quotes illustrating the previous themes have already referenced claustrophobia, a well-documented barrier to MRI acceptance (Munn et al. 2015). Within this dataset the concept of claustrophobia was coded 12 times and the word used 17 times. Respondents frequently reported difficulties with claustrophobia alongside the length of WB-MRI, or as an element to having a lack of control during the examination. One respondent explained that despite having several WB-MRI scans, claustrophobia is a recurrent issue that they have been able to adapt too:

- *“Can be claustrophobic but am learning to cope with this (latest was my 5th in 10 years)”* (s33).

Interestingly, two respondents both reported experiencing claustrophobia with RSS and LD-WBCT. Whilst LD-WBCT can be loosely associated with claustrophobia, it is surprising to hear claustrophobia can be associated with RSS. This may indicate that while the physical parameters of the imaging modality can affect claustrophobia, it is also intrinsic to the individual experiencing the imaging.

4.3.4 Summary of Thematic Analysis

These themes have used the patterns of meaning taken from the participants' written responses to provide a deeper understanding of their experiences, and illustrate what affects the acceptance of whole-body imaging. Disadvantages of whole-body imaging, such as pain, claustrophobia, the duration of imaging and negative staff support were reported with greater frequency than some of the recorded advantages, although the significance attached to these disadvantages varied amongst responses. Overall, the advantages reported by respondents, such as the benefits of imaging in diagnosis or positive staff support, appeared to outweigh reported disadvantages in terms of the importance associated with these benefits. However, there are examples where a greater degree of importance is associated with negative perceptions, specifically sub-theme 8, staff task-focused or manhandling patients, and sub-theme 9, the length of the whole-body imaging.

4.4 Results Summary and Triangulation

The quantitative analysis demonstrates that respondents were highly accepting of all three whole-body imaging techniques, with the scores provided for each construct indicating good levels of acceptability. The first sub-theme of the qualitative results reinforces this; people with myeloma are accepting of whole-body imaging and understand its necessity.

Differences in acceptance scores were analysed using the Kruskal-Wallis statistical model. Although acceptance was high across all three imaging modalities, WB-MRI was associated with a greater degree of stress during imaging and claustrophobia. Evidence from the qualitative component of the results confirms that claustrophobia is a barrier to acceptance. Whilst claustrophobia was predominantly associated with WB-MRI in both the quantitative and qualitative analyses, it was also modestly associated with RSS and LD-WBCT. The qualitative data highlighted some of the stress and anxiety that WB-MRI can induce, although instances where both RSS and LD-WBCT induced stress and anxiety were also documented.

Pain is frequently reported to be a part of living with myeloma. The qualitative results contained several reports where respondents stated the process of whole-body imaging exacerbated pain. Although the quantitative data did not demonstrate any statistically significant increase in the pain experienced during imaging, or in the pain experienced across the three whole-body imaging modalities, the descriptive statistics still indicate pain is a barrier to acceptance for individuals that experience it. Statistical analysis showed a significant positive correlation between the amount of pain experienced during imaging and the level of baseline pain, indicating that individuals who suffer with pain as a result of their condition are more likely to experience pain during imaging. Out of 121 recorded instances, severe pain was experienced 18 times during imaging (14.9%). While this is a low proportion of the sample, the qualitative data highlights the impact pain has on those that experience it.

Difficulty with the length of an imaging examination was documented 23 times out of the 121 recorded imaging experiences (19%) and was mostly associated with WB-MRI. This result is supported by sub-theme 9, although the length RSS was additionally documented as having a negative effect on acceptance. Sub-theme 9 indicates that an examinations duration usually causes a burden in conjunction with other factors such as pain, claustrophobia, stress or noise. Further quantitative analysis supports this, as severe pain during imaging was associated with 14 of the 23 experiences (60.9%) that indicated difficulty with the length of the examination. Of the 40 respondents who experienced WB-MRI, 14 reported difficulties with the length of the examination and were associated with statistically significant higher scores for claustrophobia.

Whilst there were three open text responses where respondents referred to having previously experienced a scan, neither the quantitative or qualitative data provided evidence that a previous imaging experience affects the acceptance either positively or negatively.

Although a small number of respondents indicated concern regarding the use of ionising radiation or magnetic fields, statistical analysis did not demonstrate any significant results. An association nearing significance was indicated between those who had concerns regarding the use of ionising radiation or magnetic fields were also worried prior to imaging, $p = 0.057$. Whilst 9 individuals stated concern regarding the use of ionising radiation or magnetic fields, the qualitative data did not support this. A small number of respondents indicated an awareness of the use of radiation and possible associated risks but were accepting of this in order to facilitate diagnosis.

Both datasets highlight the importance of physical comfort in improving acceptance. The median score for comfort across all three imaging modalities was 3, a moderate level of comfort. Whilst there was no statistically significant difference in the perceived comfort between each imaging modality, comfort negatively correlated to the constructs ‘pain’ and ‘stress’ and positively correlated with ‘control’ and ‘overall experience’. The qualitative data provided further insight into the impact comfort can have on acceptance, and how improved comfort can reduce the pain experienced during imaging.

The quantitative data indicated the highest perceived level of staff support for all three imaging techniques, with a median score of 5. The qualitative results in sub-theme 5 support this by highlighting how staff support improves the acceptance of whole-body imaging. Although poor staff support was infrequently recorded in either the quantitative or qualitative data sets, sub-themes 7 and 8 provide further detail regarding the impact negative staff interactions had on some respondents’ acceptance of imaging. These sub-themes related to the physical and emotional burden that the physical manipulations required for RSS caused for some respondents, in association with a perceived lack of empathy from staff. The respondents who reported these barriers to acceptance appeared to associate a high level of importance to them.

The qualitative data was able to capture some additional significant detail that was not demonstrated in the quantitative data due to the nature of the closed questions. The theme regarding respondents concerns of bone damage and the imaging results was prevalent in the qualitative data. Whilst this is a variable that cannot be controlled, it is partly supported by the quantitative data gathered about pain and is worthy of further discussion.

No quantitative data was collected regarding recollection of the noise experienced, although it was identified as a possible barrier to whole-body imaging in the qualitative data, usually in association with WB-MRI. Another theme that emerged from the qualitative data but was not identified in the quantitative data was the coping mechanisms that individuals employ to enable them to complete an imaging examination and increase an individuals' acceptance of whole-body imaging.

5. Discussion

With the advent of new imaging technologies and improvements in existing technologies, ongoing research into the efficacy and use of the whole-body imaging techniques for diagnosing and staging myeloma is crucial. In tandem with this, patient experience and the relative acceptance of different imaging technologies should be a vital element of research as poor acceptance and uptake will have a negative effect on the diagnostic impact of any new technology (Evans et al. 2018: 1). Furthermore, understanding the burden that diagnostic imaging can place upon the individual will equip healthcare practitioners with an insight into the patients' perspective allowing them to better address possible barriers to whole-body imaging (Murphy 2001; 193-194; Munn and Jordan 2011: 326). The work presented in this thesis has added to the body of knowledge regarding imaging acceptance, with a unique line of investigation into the whole-body imaging techniques used for myeloma.

5.1 Acceptance, Staff Support, Imaging Results and Control

The three whole-body imaging techniques investigated all showed high levels of acceptance by the respondents that had experienced them. The median scores for 'overall experience' were 5 for each modality, indicating the best possible experience by the majority of respondents, with no significant variation between imaging techniques.

There has been contradictory research into patient preference for WB-MRI over other imaging techniques, although all the studies report high scores for satisfaction (Adams et al. 2014; Evans et al. 2018; Oliveri et al. 2018). The results presented in this thesis further support high acceptance across different imaging techniques, but support the conclusions made by Evans et al. (2018: 5) in their investigation into experiences of WB-MRI; acceptance of WB-MRI is lower than CT.

Although Oliveri et al. (2018) assert that WB-MRI was preferred to other whole-body imaging techniques, they concurred with Adams et al. (2014) and Evans et al. (2018) in that imaging was well accepted but added the important supposition that the perceived usefulness of the imaging is a contributing factor to acceptance. The thematic analysis within this thesis confirms this; many respondents stated that the ability of imaging to visualise bone disease and damage was a key benefit, and its need for managing their condition was well understood. The qualitative findings also suggest the myeloma group understands the incurable nature of their condition, which may account for the high acceptance of required whole-body imaging observed within this group (Vlossak and Fitch 2008: 145). One of the key indicators of the high level of acceptance was that every respondent indicated that they were prepared to have imaging again, even when they recorded a negative experience.

The quantitative data showed the mean scores reported for staff support were 5 for each imaging modality, indicating the highest level of support. High staff support scores were also associated with greater acceptance scores for all three imaging modalities. Where scores for staff support were lower, they were frequently accompanied with informative qualitative data that was compiled in sub-theme 7 regarding negative staff support. Whilst a diagnostic radiographer is likely to perform upwards of thirty imaging examinations in a single day, the radiographer should not discount the patient experience as a result of their workload (Harding and Park 2020: 62). During the patients visit, they will only experience that single imaging examination and are likely to attach significance to their interaction with healthcare staff. There is also potential that a patients experience during one visit will influence their perception of future imaging examinations, either positively or negatively. The impact radiographers' behaviour will have on patients must be recognised by service managers and radiographers, in spite of increased work pressures. Educating radiographers on the subject of emotional impact and some basic techniques to address this in collaboration with service user groups may help to address this issue.

Although the qualitative data shows the utility of imaging to be perceived as a benefit, this is contrasted by the significant concern respondents had regarding the diagnostic outcome of imaging. While there is nothing that can be done to influence the outcome of imaging, it is important to consider the significant source of anxiety that awaiting results produces and to consider what methods could be employed to support service users throughout this time. Healthcare practitioners should try and consider this burden that patients may experience and provide what support they can.

Whilst the radiographer performing an imaging examination has little influence on the time taken for results to be made available, they are in a position to inform the patient of the results process and reassure patients that this will be done in a timely and efficient manner. It would be ideal for results to be made available immediately but this is impractical, not only because of the workload of radiology departments and the reporting radiologist but also because the patients' haematologist may need time to correlate imaging results with other tests to form a clinical opinion. A more realistic method of attempting to reduce this burden is to consider techniques of managing the patients' anxiety whilst awaiting results. Theme 5 of the thematic analysis highlighted the value of staff providing patients with explanations, supporting the findings of Munn and Jordan (2011). Radiographers interact with patients during every imaging visit and the importance of fully explaining the results process to the patient must not be overlooked. A survey of 202 patients in the US found the median expectation for results to be 3 days after a radiology examination (IQR 5) (Woolen et al. 2018: 276). The research also demonstrated that 20% of participants found that waiting for radiology test results negatively affected their state of mind. Whilst results obtained from the US healthcare system may be inapplicable to the NHS, the study still illustrates the burden waiting for results places on patients. Woolen et al. (2018: 278) established that the majority of the patients in their study would prefer to receive results from their primary clinician over the telephone, instead of in person. It is possible that the patients perceive this as being the quickest method of receiving the results of their imaging and is pertinent in the current healthcare climate with more appointments being conducted over the telephone due to the Covid-19 pandemic.

The NHS (2018) has developed a personalised care operating model that outlines the potential benefits of providing patients with healthcare choices and utilising shared decision making (SDM) between clinicians and patients. These include improved health outcomes and quality of life, as well as increasing the effective use of tailored healthcare resources (Phillips 2020). The NHS Long Term Plan states that all cancer patients should have access to personalised care by 2021. Whether personalised care will be fully realised remains to be seen, but the use of SDM for myeloma WBI referrals has the potential to be of great benefit. SDM, alongside educating service users on the choices available, would allow for the clinician and patient to collaborate on selecting the WBI technique most suited to the patient, whilst also ensuring the clinician obtains sufficient data for diagnosis and informing treatment. The SDM approach may help limit imaging induced anxiety and improving quality of life outcomes.

Part of the personalised care model is ensuring that it is not just practical and physical needs that are met, but also emotional and social needs (Phillips 2020: 74). This could be extended to ensuring service users receive the appropriate emotional support from staff, or receive pertinent explanations of the WBI choices available. Within the context of radiology imaging, personalised care has the potential to mitigate much of the 'worry prior to imaging' or 'stress during imaging' and other barriers to WBI acceptance that were identified in chapters 4.2 and 4.3.3. The benefits of staff providing patients with support were discussed earlier in this chapter, and the personalised care model may provide healthcare staff with the tools required to provide support and improve the acceptance of WBI.

In chapter 3.2.4 the construct of control, and how that can affect the acceptance of whole-body imaging was first considered. The importance of identifying whether service users feel 'in-control' or 'helpless' during their imaging was recognised by both Salmon (1994) and Schönenberger (2009). Within this thesis, the quantitative and qualitative data demonstrated a relationship between positive staff support and feeling in control during imaging. Whilst it is difficult to confirm causality between these two variables, it is intuitive that being supported by healthcare staff will improve a patients' sense of involvement and feeling of maintaining influence over their diagnostic intervention, resulting in an improved psychological state. Further evidence of this is shown in the strong positive correlation between control and overall experience, and the strong negative correlation between control and stress during imaging. Examining what affects perceptions of being in-control would be beneficial in future research, as there is the potential to identify means of improving control for service users, with the associated positive outcomes and reduction in imaging burden. SDM, as part of a personalised care model, may be an effective method of giving patients control of their imaging that could be implemented without much difficulty and would be worthy of further investigation.

5.2 Claustrophobia, Stress Experienced During Imaging and Coping Mechanisms

Claustrophobia is an anxiety-related disorder that is triggered by enclosed spaces (Eshed et al. 2007: 401). It is a well-documented phenomenon during imaging and has been discussed throughout chapter 2.5 (Munn et al. 2015). The results presented in chapter 4.2.4 demonstrated that respondents perceived WB-MRI to be more claustrophobic than RSS or LD-WBCT. In spite of this, the median score for claustrophobia experienced during WB-MRI was 2, indicating a low incidence of claustrophobia across the sample. These results show that while WB-MRI was perceived as being more claustrophobic than other imaging techniques, it was by a small amount and is still an acceptable imaging modality. Only one participant recorded WB-MRI as being less claustrophobic than either RSS or LD-WBCT. Whilst many people refer to having feelings of claustrophobia, it doesn't affect everyone. Nevertheless, the thematic analysis illustrates the impact it has on some individuals which should be recognised so that they can be supported with possible coping mechanisms which will be reviewed within this chapter.

Stress and anxiety during imaging have been explored by other research using validated instruments to measure this phenomenon, such as the STAI-S. Bauml et al. (2016: 110-113) argue that while previous research had indicated that a reassuring scan result would diminish anxiety, they found that for oncology patients the associated stress could last beyond the imaging experience. The prevalence of scan related anxiety varies across different studies but clearly has a significant impact on those affected by it (Al-Dibouni 2019: 23). The results presented in this thesis showed that WB-MRI was perceived as being significantly more stressful than either RSS or LD-WBCT. Again, acceptance scores were still high for WB-MRI with the median reported score for stress being only 2.

As claustrophobia is known to be an anxiety disorder (Eshed et al. 2007: 401) it is perhaps unsurprising that this study found a strong correlation between claustrophobia and stress experienced during imaging. Recognising this link is important so that healthcare practitioners can help service users manage these burdens or refer for an imaging method that is more tolerable to that individual, if appropriate to do so. As stated in the previous section, the results demonstrated that patients who felt 'in-control' during their imaging experience did not record stress or claustrophobia. Exploring this relationship further has the potential to allow for techniques to be developed that could reduce these negative states and associated burdens, potentially improving the acceptance of WB-MRI. Adopting the personalised care model (NHS 2018) has already been discussed as one possibility that has the potential to place patients 'in control' of their imaging examination. In the context of MRI, this would entail allowing the patient to be involved in choosing that specific modality, and having a healthcare practitioner work through any queries or concerns well in advance of the imaging appointment. While the radiographer is likely to be best placed to do this due to their detailed knowledge of the examination, the referring clinician may also be able to fulfill this role. In current practice, the patient will be told they are being referred for a specific imaging examination during consultation. They will then receive an appointment with accompanying information, prior to attending a number of days or weeks later. Between their consultation and the actual appointment patients may have any number of queries or concerns. While they may speak to clerical staff to amend appointments, additional resources could help inform the patient of what to expect from their imaging. Such resources could include digital platforms that portray a realistic imaging experience, or the opportunity to discuss the appointment with a radiographer. A barrier to this approach would be the additional resources required in an already burdened health service that is focused on cutting costs while improving efficiency and capacity (Phillips 2020: 72).

Theme 2 of the qualitative results explored some of the coping mechanisms that respondents had developed that assisted them with completing a challenging imaging experience. Physical aids such as listening to music, eye masks or the ability to summon help are one form of coping mechanisms. All MRI systems employ a call bell system that the patient can use to contact the radiographer and abandon the scan if necessary. Having this mechanism should return some feeling of control to the service user, assuming they are fully briefed regarding its use, and understand that they remain in control of their being inside the scanner. Relaxation exercises, such as breathing, singing or concentrating on maintaining control were reported, and it is interesting to see control being referred to once again. Although knowledge of evidence-based coping techniques might be considered outside the remit of radiographers, pursuing radiographer training in this area, in collaboration with appropriate professions, could lead to a brand new approach to how patients are guided through their imaging experience. Research into coping strategies employed to prevent the need for sedation in pediatric MRI could inform new approaches.

5.3 Pain, Length and Noise of the Imaging Examination

Those living with myeloma often experience increased and significant pain (Vlossak and Fitch 2008: 145). The demographic data collected in this study supports this, with 33% of respondents reporting scores that are shown to have a detrimental effect on an individuals' daily life (Harrington et al. 2018: 87). While imaging did not cause an increase in pain across the group, individuals that reported higher pain as a result of their condition also experienced greater pain during imaging. The pain experienced during imaging was a key component of sub-theme 3 of the thematic analysis. Pain was also identified as a barrier to imaging during lengthy examinations in sub-theme 9, or where physical manipulations were required as identified in sub-theme 8 regarding staff manhandling patients. While pain may not be prevalent, it still has the potential to be a significant barrier to whole-body imaging. It is therefore crucial that pain is mitigated as much as possible prior to imaging. This could be done through pain control medication provided by the primary clinician, or through attempting to improve patient comfort during imaging. Sub-theme 6 of the thematic analysis established that ensuring comfort improves the acceptance of whole-body imaging. This can be attributed to ensuring that the whole-body imaging examination does not cause an increase in pain, therefore negatively impacting acceptance. Although the survey data demonstrated no significant difference in the perceived comfort of each imaging modality, a number of respondents indicated they found LD-WBCT and WB-MRI to be the most comfortable due to being able to lie down in a stationary position.

Although difficulty with the length of imaging was only recorded 23 times across 121 experiences, 14 of these were associated with WB-MRI. The qualitative data was able to explore the reasons why the length of an imaging examination affects its acceptance. Sub-theme 9 highlighted how respondents experienced difficulty with the length of an imaging examination when it was in association with other burdens such as pain, claustrophobia or noise; the length of imaging of itself was not perceived as being a burden. Some respondents documented the stress caused by having to remain still for a lengthy period of time during WB-MRI. Although reported less frequently, some respondents also stated difficulty with the length of RSS.

It is well understood that MRI produces significant noise that is frequently reported to cause some discomfort and has the potential to cause hearing damage (Graham, Cloke and Vosper 2011). A number of different MRI systems produced by a range of manufacturers exist and these all provide some form of ear protection, the specifics of which may be dictated by local practice. It is the experience of the author that headphones are the most common ear protection. Earplugs are sometimes used instead of, or in addition to, headphones. Sometimes music or radio can be played through the headphones, although the effectiveness of this is unclear. Some respondents commented that while music is helpful, it was insignificant over the noise of the scanner. Given the broad range of individual tastes, possibilities for offering a choice of music or radio could be considered to improve the effectiveness of this distraction technique.

5.4 Use of X-rays and Previous Imaging Experience

Although a small number of respondents indicated a concern regarding the use of ionising radiation, they provided little detail on what the concerns were or if they were addressed at the time of the imaging examination. 15% of respondents indicated a concern regarding the use of x-rays or magnetic fields, comparable to the research by Heyer et al. (2015: 109). The qualitative data demonstrated respondents had an awareness of the potential for harm from ionising radiation can cause, but no further detail was given. The Ionising Radiation (Medical Exposure) Regulations (IR(ME)R) (Department of Health 2017) were recently updated and have a specific focus on service users being made aware of the risks versus benefits of the dose of ionising radiation that they have been referred for. How this will be done and by whom is still the subject of some debate in clinical practice (Younger et al. 2019: 88-89). What is clear is the need for service users to be informed of the imaging choices available to them and their potential impact, compared with the risks of not undergoing diagnostic imaging. This applies to all service users requiring radiology imaging, not just those living with myeloma.

Research by authors including Heyer et al. (2015: 111) and Oliveri et al. (2018: 249) indicated that a previous imaging experience may improve acceptability of subsequent imaging examinations. The results of this thesis did not demonstrate any significant variance in acceptance scores between those who had previously experienced a specific whole-body imaging technique, and those that had not. If an individual has experienced a particular imaging modality previously, it should not be assumed that there is a reduced burden with follow-up scans.

5.5 Disadvantages of RSS

Other researchers have commented on the discomfort that the physical manipulation for RSS can cause (Dimopoulos et al. 2009: 2; D'Sa et al. 2007: 51). The author was unable to identify any previous research that attempted to collect data regarding patient acceptance of RSS. However, the data presented in this thesis supports the argument that RSS can cause pain for some individuals. The author found the qualitative data collected in sub-theme 8, regarding the manhandling of patients, to be unsettling. A radiographer is tasked with obtaining diagnostic images, but in doing so should consider the needs of their patients and ensure that they are treated with dignity. RSS does require physical manipulation of the patient by the radiographer, but to have a patient report that they felt 'manhandled' indicates a patient-centered approach was not adopted which is likely to increase the burden and sense of depersonalisation placed upon the patient. Two respondents reported this similar sort of negative experience. Although a low number, this burden is completely avoidable if the radiographer were to adopt a personalised care approach when obtaining the radiographs (Phillips 2020: 72). Whilst the author found these comments disconcerting, it was encouraging to see the data mostly demonstrated excellent support provided by the healthcare professionals.

In chapter 2.3.5 guidelines on myeloma imaging produced by the BJH (Chantry et al. 2017), the IMWG (2014) and NICE (2015) showed that RSS was still considered to be an option for whole-body imaging in the diagnosis of myeloma. RSS was also the most frequently experienced whole-body imaging modality in this study. Whilst this may indicate that RSS is the most frequently utilised form of whole-body imaging, this is impossible to confirm as insufficient data was collected as to when imaging was experienced. It may be that respondents experienced RSS in the past but are now more frequently being referred for LD-WBCT or WB-MRI. Since this study began the IMWG (Hillengass et al. 2019) have published updated guidance on the use of whole-body imaging. LD-WBCT is now recommended over RSS due to its improved sensitivity (Hillengass et al. 2019: 303). The IMWG also recognised that LD-WBCT may be more comfortable for the patient whilst the dose of ionising radiation is less than twice that of RSS. The mean dose of ionising radiation reported locally for LD-WBCT was similar to the doses published by other authors for RSS (Chantry et al. 2017: 381; Wayte 2020). The IMWG recognises that CT may not be available worldwide and RSS may be used out of necessity despite its shortcomings (2019: 303). This does not apply to the NHS however, as IPEM identified 298 CT scanners in 117 surveyed trusts (2015: 5) so availability of CT equipment should not be an issue. Mian and McCurdy (2020: 10) commented on the latest guidance published by the IMWG (Hillengass et al. 2019). They argued that there is insufficient data to support the routine use of either WB-CT or WB-MRI. Furthermore, they discuss the wide variation amongst Canadian physicians' preferences regarding the whole-body imaging methods, and whether it is an efficient use of resources to continue using a more expensive test when a cheaper alternative may still suffice. However, as stated in chapter 2.4, the guidelines on the diagnosis and management of myeloma produced by NICE (2016: 74-78) for the NHS concludes that there is a strong case that using LD-WBCT or WB-MRI is cost-effective due to the benefits of early detection, and negating the need for further detailed imaging if a RSS examination demonstrates bone lesions.

5.6 Limitations and Reflections

With the primary data collection and analysis concluded, the author is able to reflect upon the research methods used and how potential limitations have been addressed. The rationale for selecting a mixed-methodology is detailed in chapter 3.1. Having concluded the study it has become apparent that this pragmatic approached allowed for collecting the broadest range of data possible within the times constraints of the study. The author found that the quantitative and qualitative methods complemented each other, as stated by advocates of pragmatism (Bryman 2016; Doyle, Brady and Byrne 2016) and enabled a deeper interpretation of results that would not have been possible through either a quantitative or qualitative approach.

Where observational survey studies sit within the spectrum of qualitative, quantitative or mixed-methods research is not always clear-cut. This study had two related data sets, one analysed through quantitative methods, the other through qualitative methods. Nevertheless, the primary focus was on the quantitative component and the level of qualitative data, although broad with 198 separate text responses, was relatively light. Ideally, follow-up interviews would have fulfilled the requirements of a mixed-methodology as well allowing for deeper investigation into the issues identified. This was not possible due to time constraints, level of participant consent and ethical approval. Although the qualitative data lacked the depth that could have been obtained through interviews or focus-groups, it has proved worthwhile through triangulation with the quantitative component and the conclusions that were drawn through obtaining this data. The key rationale for obtaining qualitative data was to ensure individual experiences were not lost in quantitative analysis, and the pragmatic method chosen has ensured that.

The median age of the sample was 58.5 years, lower than the median age of 70 reported for myeloma patients in the UK (King, Gooding and Ramasamy 2015: 149). As social media accounted for the majority of recruited participants this may account for this deviation from the reported demographic. Paper surveys were available to participants recruited from local NHS trusts, and to anyone else by request through email. It is possible that this approach limited the response rate of participants who were older than 70. 10 out of the 60 participants were aged 70 years or more. Of these 10 participants, 8 completed the survey online, demonstrating the willingness and ability for the older population to engage with digital platforms. It is impossible to account for the population that was unable or unwilling to complete the survey due to the recruitment methods and the possibility of non-responder bias cannot be discounted (Bowling

2014: 180; Bryman 2016: 184-186). Due to the sampling method, there is a possibility that only patients who actively engage with their healthcare responded.

The prevalence of MGUS has been estimated to be approximately 3% in the overall population (Bird et al. 2009: 147), and the prevalence of asymptomatic myeloma to be between 0.4% and 0.9% (Blum et al. 2018: 22). Although the population of respondents in this study does not reflect these statistics, this is to be expected as those with MGUS or asymptomatic myeloma will require radiological imaging much less frequently than those living with myeloma (Chantry et al 2017: 382-383).

Whilst the number of different whole-body imaging modalities experienced have been reported on, there are a number of variables here that are impossible to control. Participants were recruited from across the UK, and different NHS trusts may only be able to offer certain types of whole-body imaging for myeloma. This could be due to the availability of imaging equipment or the expertise of healthcare practitioners. At the three NHS sites where the study was open to recruitment, each site offered one of the imaging modalities being investigated, with RSS being additionally available at the largest site.

The original sample size estimate of 156 imaging experiences was not met, although post-hoc power calculations demonstrated a sufficient sample size to detect significance. Had a larger sample size been achieved then it is possible that smaller effects (d = <0.286) may have been observed in the data. This means weaker relationships between the imaging modalities and survey constructs may have been shown to be statistically significant.

Whilst the results of this project corroborate with some of the findings from other research, there are two key differences that may hamper direct comparison. This study compared three different whole-body imaging techniques and treated each as a separate entity, and is the only study to investigate the experience of RSS. Other studies only compared two modalities or grouped some of the imaging techniques together. Additionally, this study is unique to the perspective of the myeloma patient group. Whilst some of the other research may be comparable as the experiences of oncology patients were investigated, it should not be assumed that the experiences of all individuals living with cancer will be alike. This should be considered when comparing the results of this thesis to other research.

The original study was designed with respondents having had their most recent experience of imaging within 6 months of completing the survey in an effort to control for recall bias.

Participants were then invited to share their experiences of other whole-body imaging that occurred more than six months ago. 44 participants (73.3%) had their most recent whole-body imaging experience within the last 6 months. It was decided to include this data in the analysis due to its apparent quality and reliability. The first reason for this was to increase the sample size which has the potential to impact the effect size, power or statistical significance of the results. The second reason to include these responses was to allow those who have experienced imaging and wish to be involved in this research project to be able to share their experiences. As discussed in chapter 3.2, there is no standard recall period for measuring or understanding phenomena, but the period should be appropriate to the study (Stull et al. 2009: 940).

The questionnaire provided a written description of each whole-body imaging modality to assist respondents in deciding whether they had experienced that particular examination. The possibility exists that a respondent may have given information for a different imaging modality. For example, a respondent could have experienced a more conventional MRI scan of a specific body part, instead of WB-MRI, and still reported upon it. Although this possibility exists it was not evident in the authors review of each completed questionnaire.

The study was designed to minimise the amount of data collected, including any identifiable data to comply with GDPR (2018) and using the guidance published by the HRA (2018a). By not collecting identifiable data an opportunity was lost to follow-up respondents through telephone interview in this study or future research. Additionally, it is not possible to perform a re-test validity check on the questionnaire, to see if similar responses are provided if the questionnaire were to be completed a second time (Fayers and Machin 2016: 113-114). Two other ways of confirming credibility are triangulation, as discussed earlier in chapter 3.1, and debriefing (Murphy and Yielder 2010: 65). This can be done through publication or presenting findings to knowledgeable third parties. The process of debriefing will occur after the submission of this thesis, but it is the author's intention to publish the results of this project to allow for critical review and to disseminate the findings of this research to the patient group involved. An example of an infographic designed to inform service users about the project has been produced and is available in appendix 9.

Confirming the criterion validity of a survey instrument is a process of assessing it against a known true value (Fayers & Machin 2016: 94). As surveys measure subjective concepts, measuring this survey against the results of an established survey instrument is a reliable method of confirming agreement and therefore criterion validity. The adapted survey employed in this study was based on two validated surveys measuring patient experiences of imaging (Salmon et al 1994; Schönenberger et al. 2007). Although it appears reasonable to assume that criterion validity is therefore established, Zarins (2005: 1672) advises caution when assuming validity of a survey instrument that has been adapted from its original intended use. Given the small scale of this project and the resources available, asking a proportion of respondents to repeat the questions seems to offer little advantage but could increase questionnaire fatigue and participant burden.

Reflexivity is an important part of qualitative research methods, including the qualitative descriptive approach employed in this study (Bradshaw, Atkinson & Doody 2017: 6; DePoy & Gitlin 2011: 229). This process of self-examination allows the author and the reader to interpret the trustworthiness and validity of the research by considering whether the researcher's position, views or attitudes may have influenced the study (Saks & Allsop 2013: 449).

Throughout this thesis the author has been clear in questioning the continued use of RSS, the 'traditional' WBI technique, when newer methods have been developed (see chapters 1.1 and 2.3.5). It was assisting with developing a new LD-WBCT protocol that led the author towards investigating WBI. The author has guided numerous patients through each of these WBI techniques, which has steered the author towards their own preconception regarding the continued use of RSS. Additionally, the author has observed first-hand the negative impact WB-MRI can have on patients, as well as the techniques that can help guide a patient through the examination so that ultimately their experience is a positive one. It is also the experience of the author that the nature of a patients imaging experience can impact their next experience, although no evidence was uncovered to support this.

Recognising their own intrinsic bias, the same questions were asked of all three imaging modalities so that the author's position would not be inferred into the survey tool or the participant's responses. The questionnaire was designed using previously validated survey tools and with independent supervisory input. In terms of sampling, the primary goal was to reach the largest population possible. The study was available at three sites, each provided one of the three WBI techniques being investigated to ensure all three were fairly represented. However, it was not possible to account for the responses from social media.

The process of thematic analysis requires the author to make interpretations of participants responses who made every effort to minimise their own position influencing the results. Throughout the two year duration of this study the author's position has changed somewhat from questioning whether RSS should be used, to vehemently appealing for its use to be discontinued. The author now finds themselves questioning why LD-WBCT is not employed with greater frequency, and has developed further interest in the use of SDM and patient-centered care as a means of giving patients control of their imaging so that they might find a challenging WBI experience a positive one.

5.7 Recommendations

The use of RSS for diagnosing myeloma should be discontinued. The results of this study indicate that service users often find this lengthy examination burdensome, uncomfortable and painful. As demonstrated in the literature review, and as stated by the IMWG (Hillengass et al. 2019) it is less sensitive and specific than other whole-body imaging methods. CT and MRI equipment is available in the NHS to provide the clinician and the patient alternative whole-body imaging methods. Radiology departments that lack the expertise and capability to utilise LD-WBCT or WBI should receive the support and education required to allow these services to be offered. The driver for this change needs to come from radiographers, hematologists and radiologists. Disseminating the findings of this thesis will prime these changes in current practice. Clinicians and service users should be educated on the modern WBI techniques that are available so that the most appropriate can be selected as part of SDM.

Service users should be provided with a full explanation of what their imaging examination entails, including the length of the imaging examination and any associated noise so that they can prepare themselves appropriately. For WB-MRI, effective ear protection should be used, and music offered whenever possible.

There is evidence to suggest that service users who feel 'in-control' of their whole-body imaging examination perceive a reduced emotional burden. Methods of ensuring service users are able to maintain control during imaging should be explored by healthcare researchers, especially the impact of the personalised care model and SDM. Service managers should work with their clinicians and radiographers to ensure they provide a detailed explanation throughout imaging and adopt the personalised care model to meet individual needs during the examination (Phillips

2020: 75). The use of a call-bell during WB-MRI is an obvious means of ensuring service users maintain control, and its use should be fully explained at every imaging appointment.

For some individuals, the perceived burden of WB-MRI is greater than RSS or LD-WBCT due to claustrophobia and feelings of stress. Radiographers and clinical referrers should provide coping mechanisms to allow all patients the opportunity to undergo WB-MRI without a significant burden. Coping mechanisms may include relaxation or breathing exercises, vicarious MRI experience or increased staff support. As radiographers may have limited experience of evidence-based coping mechanisms, collaboration with other professions, such as psychologists, will be vital to implementing this approach.

Healthcare researchers should continue to investigate techniques that improve the patients' experience of WB-MRI. This clearly benefits the patients, but also has the potential to reduce the number of abandoned imaging appointments and make a valuable diagnostic tool available to a greater number of individuals, improving the use of resources for healthcare providers and referring clinicians. The utility of a WBI examination is perceived by many individuals to be a key benefit, and a driver to completing WBI. Therefore, the advantages of having WB-MRI should form part of the patient explanation as it may improve acceptance. Where patients feel unable to tolerate WB-MRI, their clinician should employ SDM to offer an alternative whole-body imaging technique.

While pain is subjective to an individual, the service user's primary physician should consider pain management alongside any referral for imaging. Pain is a key barrier to imaging acceptance and needs to be managed. The radiographer performing an imaging examination should make every effort to improve the patients' physical comfort to further increase acceptance and the likelihood of the imaging examination being completed.

Patients should be fully informed of the process for obtaining results and given an expectation of how long this may take. This should primarily be by the radiographer who has performed WBI, The results of imaging should be made available to the patient at the earliest practical opportunity, and the onus of responsibility must be taken up by the healthcare providers and service managers. Providing results over the telephone is acceptable and has the potential to improve the speed that results are given to the patient whilst preventing a physical follow-up hospital visit, benefitting both the patient and the healthcare provider (Woolen 2017: 279).

6. Conclusion

The work presented in this thesis has described the current whole-body imaging techniques employed within the NHS for the diagnosis and staging of myeloma. The effectiveness of each technique has been explored in terms of its diagnostic value, and the difficulty in concluding whether a particular technique is better than its counterparts has been discussed. Of greater importance to this study has been developing an understanding of how service users perceive different types of radiology imaging and how they interact with this technology and the healthcare professionals who utilise it. The research presented has measured acceptance of the different imaging modalities and the factors that influence this by investigating patient perceptions of imaging. Through a pragmatic methodology, additional data provided a deeper understanding of the enablers and barriers to whole-body imaging which may not have been captured with a purely quantitative approach.

It is hoped that the data obtained in this research project will serve to inform future practice for both the physicians that refer patients for whole-body imaging and the radiographers that perform the examinations. Through attempting to understand the burdens imaging can place on people living with myeloma and understanding the factors that improve the acceptance of whole-body imaging, healthcare professionals can better equip themselves to meet the needs of service users. This has the obvious benefit of improving the experience of imaging, but also has the added benefit of increasing acceptability of imaging which may reduce the number of abandoned or difficult examinations (Munn and Jordan 2011).

The results of this study do not support the continued use of RSS. Given the research available and the most recent published guidance, its use in the NHS should be discontinued. The ionising radiation exposure associated with LD-WBCT is lower than ever before. Combined with the speed of this examination, and the availability of CT scanners in the NHS (IPEM 2015) then it should be considered as a possible first line whole-body imaging investigation for myeloma. WB-MRI should also be considered as a first line whole-body imaging investigation as despite its higher burden, it is still well tolerated, especially when the patient is provided with the appropriate support.

The use of CT in imaging myeloma may have a greater role in the future. There is emerging research into the use of dual-energy computed tomography (DECT) for diagnosing myeloma (Kosmala et al. 2018). DECT utilises a CT system with two x-ray tubes and detectors, allowing for images to be obtained with different energy levels of ionising radiation. This provides additional data for different tissue types and has been shown to make the sensitivity of CT comparable to that of WB-MRI in measuring myeloma disease in the bone marrow (Kosmala 2018: 5086-5087). Currently, DECT is unavailable in most NHS hospitals.

RSS, once the gold standard for myeloma imaging, has been superseded by advanced whole-body imaging techniques. With the continuous development and innovative implementation of new technologies it is possible that current advanced techniques will also one day be replaced, perhaps by DECT or some other novel implementation of existing imaging technology. Throughout this ongoing development, the patient experience, choice and their acceptance of imaging should continue to be a driving factor in the advancement of whole-body imaging.

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Appendix

Appendix 1: Research Ethics Committee and Health Research Authority Approval

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Appendix 2: Results of Literature Searches

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#	Query	Limiters/Expanders	Last Run Via	Results
S10	S6 AND S9	Limiters - Date of Publication: 20090101-20181231 Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete;MEDLINE Complete	38
S9	AB whole body computed tomography OR AB wbct	Limiters - Date of Publication: 20000101-20181231; English Language Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete;MEDLINE Complete	656
S8	S5 AND S6	Limiters - Date of Publication: 20000101-20181231; English Language Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete;MEDLINE Complete	662
S7	S5 AND S6	Limiters - Date of Publication: 20000101-20181231 Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete;MEDLINE Complete	760
S6	S1 OR S2	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search	47,089

			Database - CINAHL Complete;MEDLINE Complete	
S5	S3 AND S4	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete;MEDLINE Complete	267,950
S4	TI radio* OR AB radio*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete;MEDLINE Complete	1,210,945
S3	TI diagnos* OR AB diagnos*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete;MEDLINE Complete	3,015,762
S2	TI Multiple Myeloma OR AB Multiple Myeloma	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete;MEDLINE Complete	44,931
S1	(MH "Multiple Myeloma/DI/RA")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete;MEDLINE Complete	6,979

MY EBSCOhost

Thursday, July 16, 2020 6:39:37 AM

#	Query	Limiters/Expanders	Last Run Via	Results
S7	S1 AND S2 AND S6	Limiters - Date of Publication: 20090101-20191231; Language: English Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete;MEDLINE Complete	124
S6	S3 OR S4 OR S5	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete;MEDLINE Complete	186,743
S5	TI patien* acceptance OR AB patien* acceptance NOT education	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete;MEDLINE Complete	5,564
S4	TI patien* experienc* OR AB patien* experienc* NOT breathing NOT SPECT* NOT PET* NOT emission NOT photon	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete;MEDLINE Complete	160,261
S3	TI patien* perceptio* OR AB patien* perceptio*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search	23,983

			Database - CINAHL Complete;MEDLINE Complete	
S2	TI (survey or questionnaire) OR AB (survey or questionnaire) NOT TI (education*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete;MEDLINE Complete	1,429,147
S1	TI (radiology or radiography or xray or radiologic technology or radiographic imaging) OR TI (computed tomography or ct) OR TI (mri or magnetic resonance imaging or mri scan) NOT TI (radiologist or teach*) NOT TI (pet or PET or SPECT or spect or positron emission) NOT emission NOT photon	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete;MEDLINE Complete	363,255

Appendix 3: Survey Amendments

Summary of the Major Changes Made to the Questionnaire

Survey Version	Review	Key Changes and Amendments
v1 and v2	Supervisory Team	Developed the rationale for using a particular survey instrument in order to make it relevant to the imaging techniques being investigated. Began drafting constructs into questions.
v3 and v4	Supervisory Team	Produced two questionnaires, one using Salmon et al. (1994) as its basis, the other using the questionnaire by Schönenberger et al. (2007) for direct comparison. The latter was selected. Adjusted the syntax/semantics of some questions to prevent them from leading the respondent
v5	Professional Peers	Included binary responses for some questions. Considered the use of a Visual Analogue Scale for Pain. First review by professional colleagues active in research.
v6	Professional Peers	The survey indicators/questions were submitted to five colleagues for feedback. Several changes to wording. Addition of questions relating to previous experience as this may have a significant impact acceptability.
v7	Professional Peers	The first draft of the questionnaire using Online Survey (Jisc 2019). The order of questions was adjusted to improve the flow of the questionnaire. The patient information and consent sheet were drafted. This version was piloted with three peers responding.
v8	Supervisory Team	Changes made to syntax, semantics and order of questions to further improve the flow and clarity of the survey.
v8	Patient and Public Involvement Group	Please see table on the following page for a list of changes made as a result of the PPI feedback.
v9	Supervisory Team	Final review with the supervisory team, addressing the feedback suggested by the PPI group.
v10	Coventry University Ethics	Provided clarification as to why some questions were being asked. Added information regarding the risks to participants and a GDPR statement.
v11	Professional Peers	Amended terminology of 'smouldering' myeloma to asymptomatic myeloma. Removed staging data as the patients are unlikely to know, and it is irrelevant to the line of inquiry. Instead we have added a question regarding whether participant is currently on treatment or not.
v12	Employers Research Department	Incorporated trust and academic institution logos. Added version document dates and version numbers for research governance compliance.
V13	Supervisory team	Current version.

Summary of the Amendments made to the Questionnaire as a Result of PPI Feedback

Reviewer	Part of the Questionnaire to Revise	Change
1	PIS	Amended paragraph four regarding how long the survey will take
2	PIS	Clarified contact details
2	2	Amended gender choices. Non-binary to other
1, 2	Survey	Blank pages to be removed, other errors removed and tidied.
2	Survey	Ensure it is available by post
3	Survey	Explore alternative background colours to make text easy to read - I found out this is due to black and white printing.
3	Survey	Need to make a stronger request for comments, included in a text box on page 3.
4	PIS	Checked HRA docs to ensure the consent box does not require a signature.
4	19,35,51	Helplessness; for the open response question include ‘if you did (experience helplessness)...’ in order to avoid confusion. (Helplessness question has since been changed to being 'in control')
4	CT	Ensured that there is a clear explanation of whole-body CT and whole body MRI
5	Survey	Considered the overall length of the survey. Length is the same but it now prints to 20 pages.
5	11	Re-visited the issue of inducing concern by answering the survey with the supervisory team.
5, 4	Table	Two comments on what is required of the table and whether people would fill it in.
4	13a	Added question about what could be clarified if a respondent did not understand their test.

Appendix 4: Feedback Letter from Patient and Public Involvement Group

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Appendix 5: Participant Information Sheet and Survey

Myeloma Whole-Body Imaging Experience Survey

Thank you for considering participating in this survey study. The purpose of this survey is to find out how you feel about the different radiology tests you have undergone for diagnosing myeloma.

There are several different imaging tests used in diagnosing and monitoring myeloma. Some of these tests are referred to as 'whole-body imaging' as they take pictures of most of the major bones in the body. The aim of this study is to find out how people with myeloma feel about the whole-body imaging tests used in diagnosing and monitoring their condition and the factors that affect the acceptance of these tests. The study is being conducted by Adam Ryder at Coventry University and University Hospitals of Coventry and Warwickshire (UHCW) NHS Trust.

You have been asked to take part in this survey because you are a myeloma patient that has accessed this questionnaire online or through UHCW, George Eliot Hospital or Warwick Hospital. Your participation in the survey is entirely voluntary, and you can opt-out at any stage by closing and exiting the browser.

If you are happy to take part, please answer the following questions relating to your experiences of whole-body imaging. The questions will ask you about your myeloma, whether having a scan affected you physically and how it made you feel. If you decide to take part the main risk is that you get distressed through recollecting experiences of the scans you have had for myeloma. The questions have been carefully written to try and minimise this risk. Your answers will help us to understand what factors affect the experience of whole-body imaging and will provide the researcher with information that may demonstrate how improvements can be made.

The survey should take less than 15 minutes to complete. Your answers will be treated confidentially and the information you provide will be kept anonymous in any research outputs and publications. The anonymised data will be held on the JISC Online Survey server which is password protected. No identifiable data will be obtained. All data will be deleted by December 2025.

Data Protection Rights
Coventry University is a Data Controller for the information you provide. You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation and the Data Protection Act 2018. You also have other rights including rights of correction, erasure, objection, and data portability. For more details, including the right to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk. Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer - enquiry.ipu@coventry.ac.uk

Please only complete the survey if you have experienced some form of imaging, x-rays or scan for multiple myeloma, asymptomatic myeloma or MGUS in the last six months. Please only complete this survey once.

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About you.

This first section will ask you to provide some general details about yourself and your condition.

		Are you...			
	How old are you?	Male	Female	Other	Prefer not to say
Answer		○	○	○	○

Which condition have you been diagnosed with?

- ○ Asymptomatic myeloma
- ○ Multiple myeloma
- ○ MGUS (Monoclonal Gammopathy of Undetermined Significance)
- ○ None of these
- ○ Don't know

Approximately when were you diagnosed with this condition?

- ○ WIthin the last 12 months
- ○ 1 - 3 years ago
- ○ 4 or more years ago

Have you received any treatment for your condition?

- ○ Yes - currently receiving treatment
- ○ Yes - but not currently receiving treatment
- ○ No
- ○ Don't know

If you have had treatment, please give some details below.

About you.

Does your condition cause you to experience any pain? Please rate your pain using the scale below. (0 = No pain, 10 = maximum intense pain)

Please don't select more than 1 answer(s) per row.

	0	1	2	3	4	5	6	7	8	9	10	
No pain	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Maximum intense pain

Does your condition cause you any mobility problems?

- ◯ Not at all
- ◯ A little
- ◯ Moderate
- ◯ Severe
- ◯ Very severe

Do you have any other conditions that affect your quality of life or cause pain?

- ◯ Yes
- ◯ No

If you answered yes, please specify in the box below.

At which hospitals have you had radiology tests performed? (*This will provide useful information about the types of whole-body imaging used in different hospitals.)*

- ☐ UHCW/Rugby St Cross
- ☐ George Eliot Hospital
- ☐ Warwick Hospital
- ☐ I am unsure/I prefer not to say
- ☐ Other

If you selected Other, please specify:

Skeletal Survey

There are several different imaging tests used in diagnosing and monitoring myeloma. Some of these tests are referred to as 'whole-body imaging' as they take pictures of most of the major bones in the body. Skeletal survey, whole-body CT and whole-body MRI are all types of whole-body imaging. People will have different imaging tests done depending on a number of factors and any of the tests mentioned in this survey may be used. Don't be concerned if you have not had one of the tests mentioned. The aim of this survey is to find out about your experience of the different whole-body imaging tests that you have had.

Please add additional comments in the boxes provided.

Have you ever had a skeletal survey? This is a series of x-rays of most of the major bones in the body and may also be referred to as a 'whole-body x-ray'. * *Required*

- Yes
- No - please go to page 10
- Don't know - please go to page 10

Skeletal Survey

When was your most recent skeletal survey?

- Less than a month ago
- 1-3 months ago
- 4-6 months ago
- more than 6 months ago
- Don't know

Were you worried or concerned prior to the skeletal survey?

- Not at all
- A little
- Moderately
- Intensely
- Very intensely

Have you ever had a skeletal survey before?

- Yes
- No
- Don't know

Did you understand what was happening throughout the skeletal survey?

- Not at all
- A little
- Moderately
- Mostly
- Completely

If not, what could have been clarified or explained?

Skeletal Survey

Did the length of the skeletal survey cause you any difficulties?

- Yes
- No

If yes, please provide further details.

Please rate your pain during the skeletal survey using the scale below. (0 = No pain, 10 = maximum intense pain)

Please don't select more than 1 answer(s) per row.

	0	1	2	3	4	5	6	7	8	9	10	
No pain at all	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Maximum intense pain

Did you experience any stress or anxiety during the skeletal survey?

- Not at all
- A little
- Moderately
- Intensely
- Very intensely

If so, please provide further details.

Did you find the skeletal survey claustrophobic?

- Not at all
- A little
- Moderately
- Intensely
- Very intensely

Skeletal Survey

Did you have any concerns about the use of x-rays (also called ionising radiation) as part of the skeletal survey?

- Yes
- No
- Don't know

If you had any concerns please let us know if and how they were addressed.

Did you feel in control throughout the skeletal survey?

- Not at all
- A little
- Moderately
- Mostly
- Completely

If you did not feel in control, please provide further details.

Did you feel well supported by the staff during the skeletal survey?

- Not at all
- A little
- Moderately
- Well supported
- Very well supported

Please rate your physical comfort during the skeletal survey.

- Very uncomfortable
- Uncomfortable
- Acceptable
- Comfortable
- Very comfortable

Skeletal Survey

How would you rate your overall experience of the skeletal survey?

- ○ Very poor
- ○ Poor
- ○ Acceptable
- ○ Satisfied
- ○ Very satisfied

Is there anything that could have improved your experience?

Would you be prepared to have a skeletal survey again if necessary?

- ○ Yes
- ○ No

If you have answered that you would not be prepared to have this test again, please tell us why.

Please feel free to use the following space to give any other thoughts or details about your experience of having a skeletal survey.

Whole-body CT

Have you ever had a whole-body CT scan? This is a computed tomography (CT) scan from your head to your knees that is done without an injection. It is only used for myeloma bone imaging and may also be referred to as a low-dose CT, or CT skeletal survey. * Required

- ○ Yes
- ○ No - please go to page 15
- ○ Don't know - please go to page 15

Whole-body CT

When was your most recent whole-body CT scan?

- Less than a month ago
- 1-3 months ago
- 4-6 months ago
- more than 6 months ago
- Don't know

Were you worried or concerned prior to the whole-body CT?

- Not at all
- A little
- Moderately
- Intensely
- Very intensely

Have you ever had a whole-body CT before?

- Yes
- No
- Don't know

Did you understand what was happening throughout the whole-body CT?

- Not at all
- A little
- Moderately
- Mostly
- Completely

If not, what could have been clarified or explained?

Whole-body CT

Did the length of the whole-body CT scan cause you any difficulties?

- ◌ Yes
- ◌ No

If yes, please provide further details.

Please rate your pain during the whole-body CT using the scale below. (0 = No pain, 10 = maximum intense pain)

Please don't select more than 1 answer(s) per row.

	0	1	2	3	4	5	6	7	8	9	10	
No pain at all	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Maximum intense pain

Did you experience any stress or anxiety during the whole-body CT?

- ◌ Not at all
- ◌ A little
- ◌ Moderately
- ◌ Intensely
- ◌ Very intensely

If so please provide further details.

Did you find the whole-body CT claustrophobic?

- ◌ Not at all
- ◌ A little
- ◌ Moderately
- ◌ Intensely
- ◌ Very intensely

Whole-body CT

Did you have any concerns about the use of x-rays (also called ionising radiation) as part of the whole-body CT?

- Yes
- No
- Don't know

If you had any concerns please let us know if and how they were addressed.

Did you feel in control throughout the whole-body CT?

- Not at all
- A little
- Moderately
- Mostly
- Completely

If you did not feel in control, please provide further details.

Did you feel well supported by the staff during the whole-body CT?

- Not at all
- A little
- Moderately
- Well supported
- Very well supported

Please rate your physical comfort during the whole-body CT.

- Very uncomfortable
- Uncomfortable
- Acceptable
- Comfortable
- Very comfortable

Whole-body CT

How would you rate your overall experience of the whole-body CT?

- Very poor
- Poor
- Acceptable
- Satisfied
- Very satisfied

Is there anything that could have improved your experience?

Would you be prepared to have a whole-body CT again if necessary?

- Yes
- No

If you have answered that you would not be prepared to have this test again, please tell us why.

Please feel free to use the following space to give any other thoughts or details about your experience of having a whole-body CT.

Whole body MRI

Have you ever had a whole-body MRI scan? This is a scan using MRI (Magnetic Resonance Imaging) that looks at most of the bones of the body and does not require an injection. You may have had some devices called 'coils' positioned over your head and body. * Required

- Yes
- No - please go to page 20
- Don't know - please go to page 20

Whole-body MRI

When was your most recent whole-body MRI scan?

- Less than a month ago
- 1-3 months ago
- 4-6 months ago
- more than 6 months ago
- Don't know

Were you worried or concerned prior to the whole-body MRI?

- Not at all
- A little
- Moderately
- Intensely
- Very intensely

Have you ever had a whole-body MRI before?

- Yes
- No
- Don't know

Did you understand what was happening throughout the whole-body MRI?

- Not at all
- A little
- Moderately
- Mostly
- Completely

If not, what could have been clarified or explained?

Whole-body MRI

Did the length of the whole-body MRI scan cause you any difficulties?

- Yes
- No

If yes please provide further details.

Please rate your pain during the whole-body MRI using the scale below. (0 = No pain, 10 = maximum intense pain)

Please don't select more than 1 answer(s) per row.

	0	1	2	3	4	5	6	7	8	9	10	
No pain at all	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	Maximum intense pain

Did you experience any stress or anxiety during the whole-body MRI?

- Not at all
- A little
- Moderately
- Intensely
- Very intensely

If so please provide further details.

Did you find the whole-body MRI claustrophobic?

- Not at all
- A little
- Moderately
- Intensely
- Very intensely

Whole-body MRI

Did you have any concerns about the use of magnetic fields as part of the whole-body MRI?

- ○ Yes
- ○ No
- ○ Don't know

If you had any concerns please let us know if and how they were addressed.

Did you feel in control throughout the whole-body MRI?

- ○ Not at all
- ○ A little
- ○ Moderately
- ○ Mostly
- ○ Completely

If you did not feel in control, please provide further details.

Did you feel well supported by the staff during the whole-body MRI?

- ○ Not at all
- ○ A little
- ○ Moderately
- ○ Well supported
- ○ Very well supported

Please rate your physical comfort during the whole-body MRI.

- ○ Very uncomfortable
- ○ Uncomfortable
- ○ Acceptable
- ○ Comfortable
- ○ Very comfortable

Whole-body MRI

How would you rate your overall experience of having a whole-body MRI scan?

- ○ Very poor
- ○ Poor
- ○ Acceptable
- ○ Satisfied
- ○ Very satisfied

Is there anything that could have improved your experience?

Would you be prepared to have a whole-body MRI again if necessary?

- ○ Yes
- ○ No

If you have answered no, please tell us why.

Please feel free to use the following space to give any other thoughts or details about your experience of having a whole-body MRI.

Final Comparisons

Please use the following table to score your experience of each whole-body imaging test, whereby 1 indicates a very negative experience and 10 a very positive experience. If you have not had a particular test please select N/A.

Please don't select more than 1 answer(s) per row.

	N/A	1	2	3	4	5	6	7	8	9	10
Skeletal survey	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Whole-body CT	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Whole-body MRI	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

For each test that you have had, please use the table below to compare what you thought were its advantages and disadvantages.

	Advantages	Disadvantages
Skeletal survey		
Whole-body CT		
Whole-body MRI		

Final page

Thank you for taking the time to complete this survey. Your answers will help show what it's like to have a whole-body scan or x-ray.

If you feel you would like some further support or information about myeloma please contact the haematology clinic that you attend. There is also a range of information for people living with myeloma available on the Myeloma UK charity website www.myeloma.org.uk

If you would like information about the results of this survey, please visit www.twitter.com/ResearchRadAd or email the lead researcher at Content removed on data protection grounds

Appendix 6: Frequency of Codes Used for Thematic Analysis

Code Name	**Frequency code was used**
Imaging needed for diagnosis	28
Difficulty with length of WB-MRI	26
Advantages WB-MRI	22
Advantages of RSS	21
Advantages LD-WBCT	18
Noisy	18
Concerned with bone damage	16
Stress and anxiety with WB-MRI	16
Disadvantages WB-MRI	15
Difficulty with positioning for RSS	14
Detail and accuracy of imaging	13
Claustrophobia WB-MRI	12
Pain WB-MRI	12
Stress and anxiety with RSS	12
Disadvantages of LD-WBCT	11
Disadvantages RSS	9

General positive experience	9
Remaining still WB-MRI	9
Fitting of and into equipment	8
Improve experience WB-MRI	8
Not claustrophobic	8
Spread and location of cancer	8
Coping mechanisms	7
Difficulty with length of RSS	7
Pain RSS	7
Stress and anxiety with LD-WBCT	7
X-ray risk RSS	7
Negative staff support RSS	7
Anxiety about results RSS	6
Concerned imaging was insufficient	6
Imaging should be perfomed regularly	6
Lack of control WB-MRI	6
Negative staff support RSS	6
Satisfied with length and speed of RSS	6

Satisfied with length-speed of LD-WBCT	6
Accepting of imaging despite difficulties	5
Improve experience LD-WBCT	5
Able to communicate with staff	4
Anxiety about results LD-WBCT	4
Improve experience RSS	4
Increased risk of cancer with x-ray	4
Pain LD-WBCT	4
Positive staff support	4
Positive view as imaging enabled treatment	4
Terminal illness	4
Understanding of LD-WBCT	4
X-ray risk LD-WBCT	4
X-rays are necessary - accepting - RSS	4
Availability of imaging test	3
Imaging is important	3
Lack of control LD-WBCT	3
Lack of control RSS	3

More timely appointment	3
Music	3
Sedation	3
Staff being 'rough'	3
Staff dependent	3
Uncomfortable LD-WBCT	3
Aids clinicians diagnosis and treatment plan	2
Claustrophobia LD-WBCT	2
Claustrophobia RSS	2
Difficulty with length length of LD-WBCT	2
Feeling weighed down	2
Kept informed RSS	2
Kept informed WB-MRI	2
No previous experience of imaging	2
Non-invasive examination	2
Possible concern about metalwork in body with x-ray	2
Previous experience of imaging	2
Remaining still LD-WBCT	2

Results available quickly - positive	2
Uncomfortable RSS	2
Uncomfortable WB-MRI	2
Understanding	2
Understanding of WB-MRI	2
Useful test	2
All imaging experiences similar	1
Cleanliness	1
Comfortable LD-WBCT	1
Comfortable RSS	1
Comfortable WB-MRI	1
Concern over use of magnets	1
Concern with use of IV contrast agent	1
Delay prior to imaging appointment	1
Did prior research about x-ray RSS	1
Didn't understand what the imaging was for	1
Do not have to go into a scanner	1
Human error	1

Insufficient explanation RSS	1
Kept informed LD-WBCT	1
Manhandling	1
No noise	1
Only one imaging test required	1
Physically supported	1
Proud to have completed imaging	1
Provide feedback	1
Reassurance from results	1
Reduced pain	1
Reduced x-ray exposure	1
Remaining still RSS	1
Restarting the scan	1
Unable to communicate with staff	1
Unable to complete imaging	1
Unable to stop examination	1
Worried that not completing imaging will prevent treatment	1

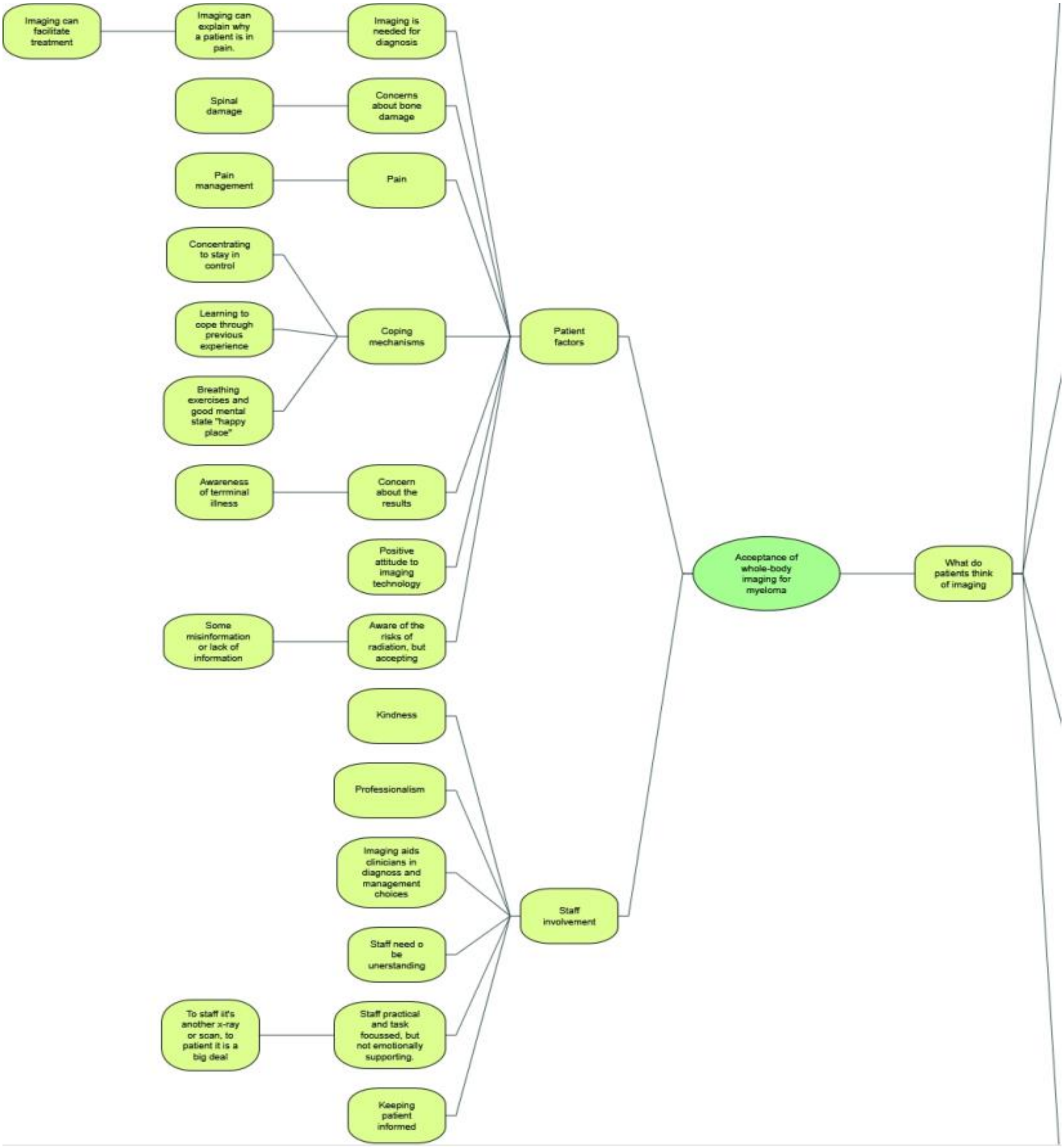
Appendix 7: Frequency of Words Used in Open Text Responses

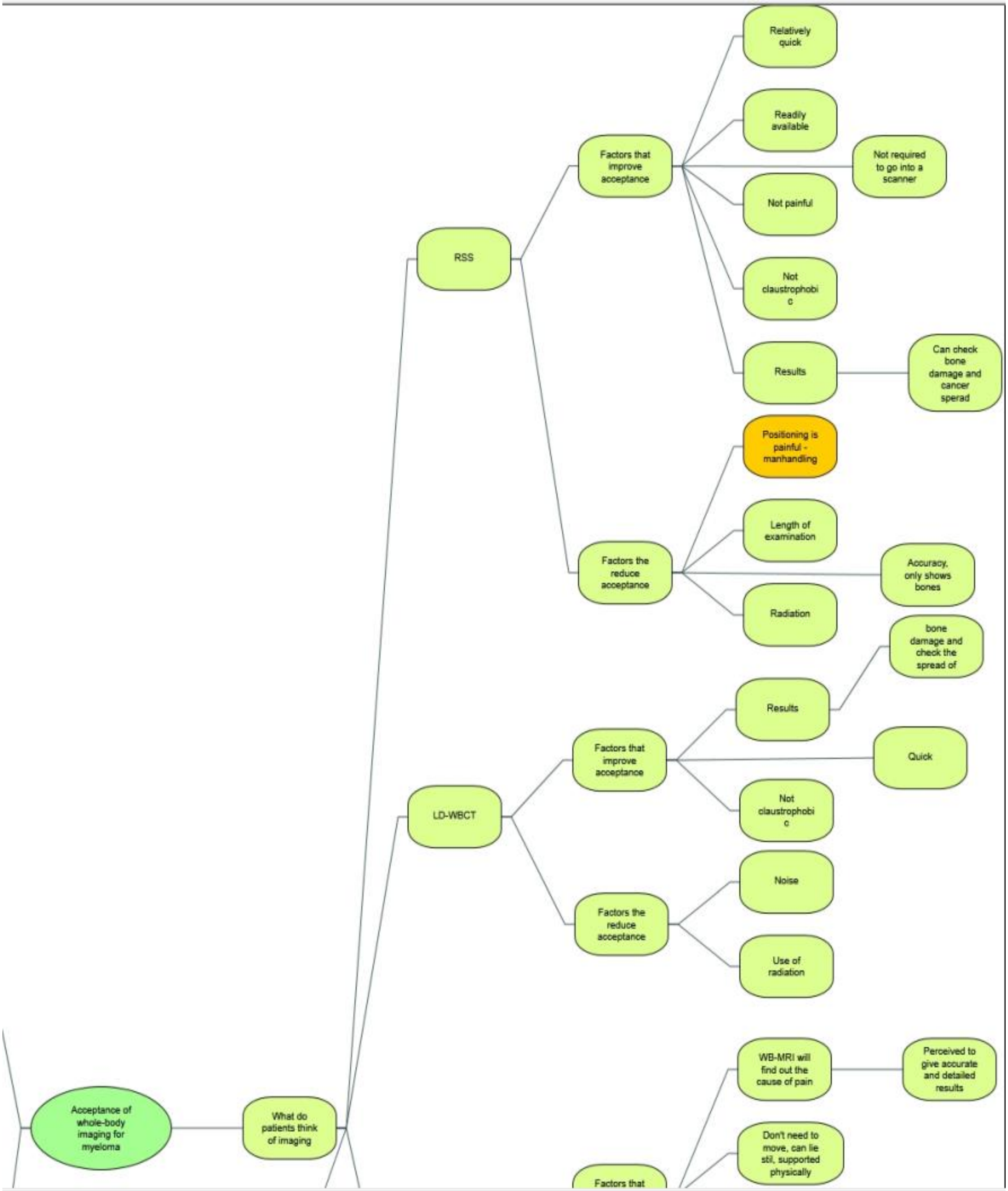
Word	Length	Count	Weighted Percentage (%)	Similar Words
scans	5	36	1.80	scan, scanned, scanning, scans
pain	4	30	1.50	pain, painful, painfully, pains
time	4	26	1.30	time, timely, times, timing
mri	3	20	1.00	mri
bone	4	17	0.85	bone, bones
claustrophobic	14	17	0.85	claustrophobic
results	7	15	0.75	result, results
myeloma	7	15	0.75	myeloma
see	3	15	0.75	see
needs	5	14	0.70	need, needed, needs
staff	5	13	0.65	staff, staffs
body	4	13	0.65	body
damage	6	12	0.60	damage
position	8	12	0.60	position, positioning, positions
provide	7	12	0.60	provide, provided, provides

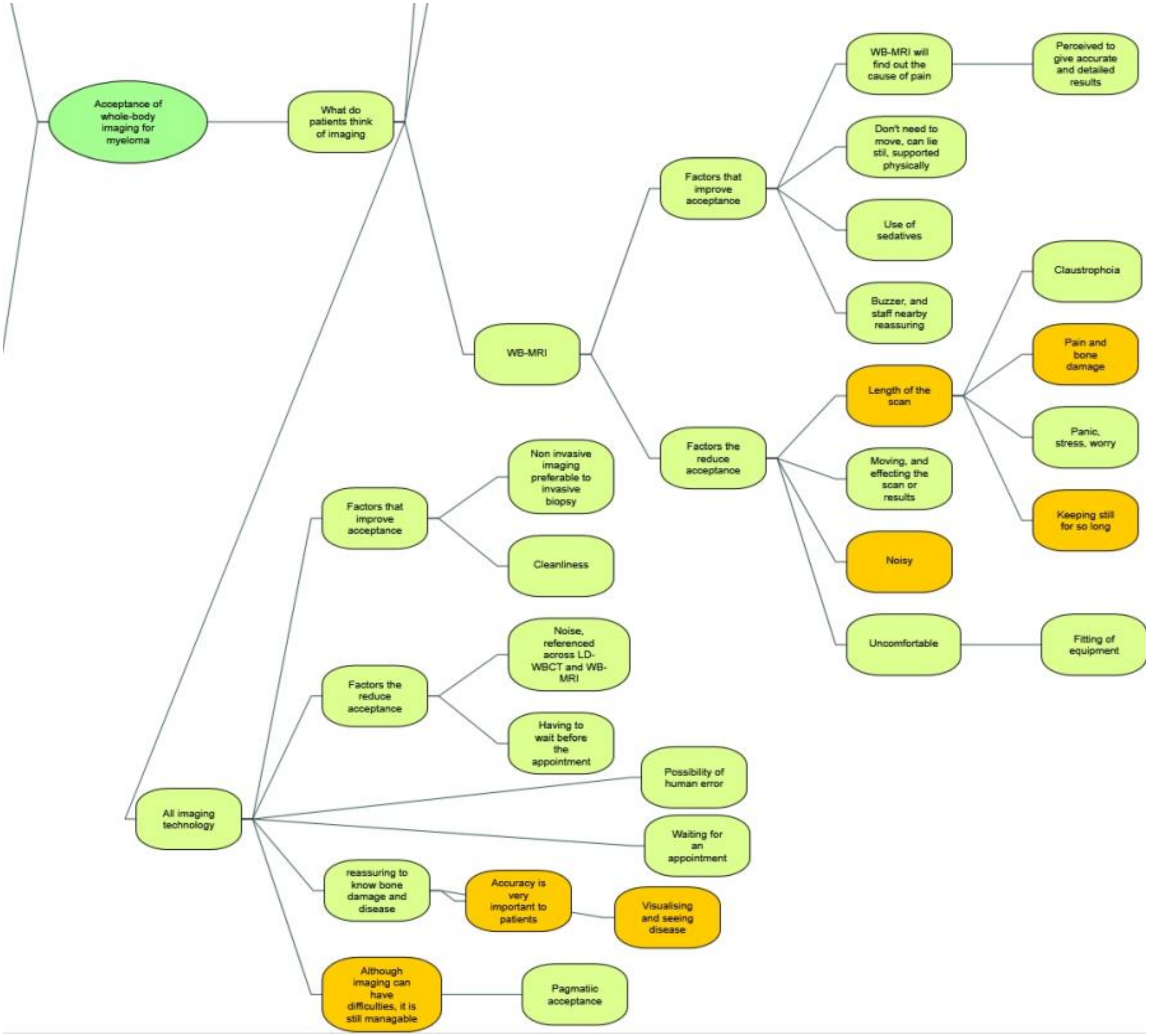
still	5	12	0.60	still
caused	6	12	0.60	cause, caused, causing
back	4	11	0.55	back
concerns	8	11	0.55	concern, concerned, concerning, concerns
currently	9	11	0.55	current, currently
good	4	11	0.55	good, goodness
long	4	11	0.55	long
none	4	11	0.55	none
uncomfortable	13	11	0.55	uncomfortable
useful	6	10	0.50	use, used, useful, using
difficult	9	10	0.50	difficult
lying	5	10	0.50	lie, lying
noise	5	10	0.50	noise, noises
quick	5	10	0.50	quick
scanner	7	10	0.50	scanner, scanners
less	4	9	0.45	less
problem	7	9	0.45	problem, problems
worrying	8	9	0.45	worried, worry, worrying

control	7	8	0.40	control
diagnosis	9	8	0.40	diagnosis
explained	9	8	0.40	explain, explained
feel	4	8	0.40	feel
give	4	8	0.40	give, gives
moving	6	8	0.40	move, moving
spinal	6	8	0.40	spinal
arthritis	9	7	0.35	arthritis
help	4	7	0.35	help, helped, helps
know	4	7	0.35	know
spine	5	7	0.35	spine
takes	5	7	0.35	take, takes, taking
test	4	7	0.35	test, testing, tests
cancer	6	6	0.30	cancer
chemo	5	6	0.30	chemo
claustrophobia	14	6	0.30	claustrophobia
length	6	6	0.30	length

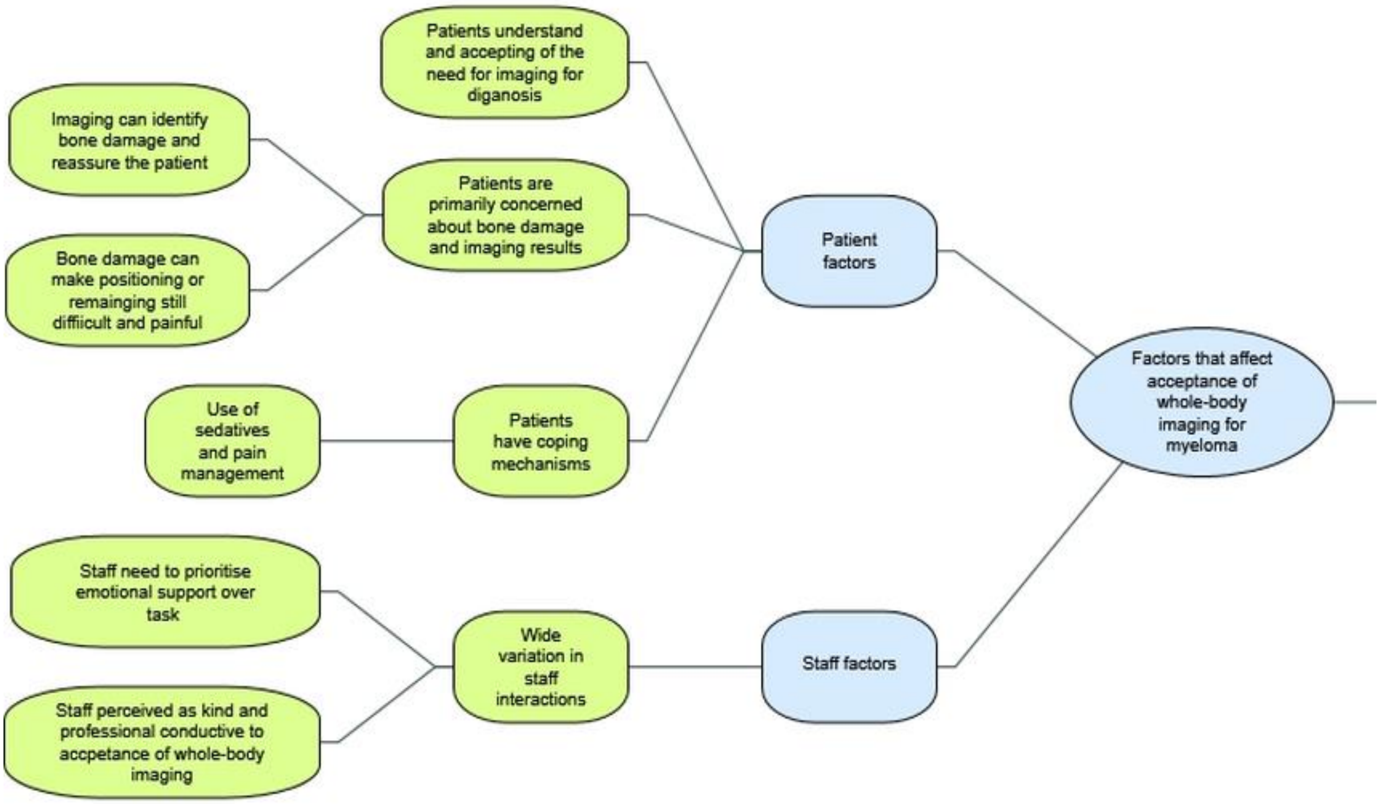
Appendix 8: Thematic Analysis Phase 3 Map

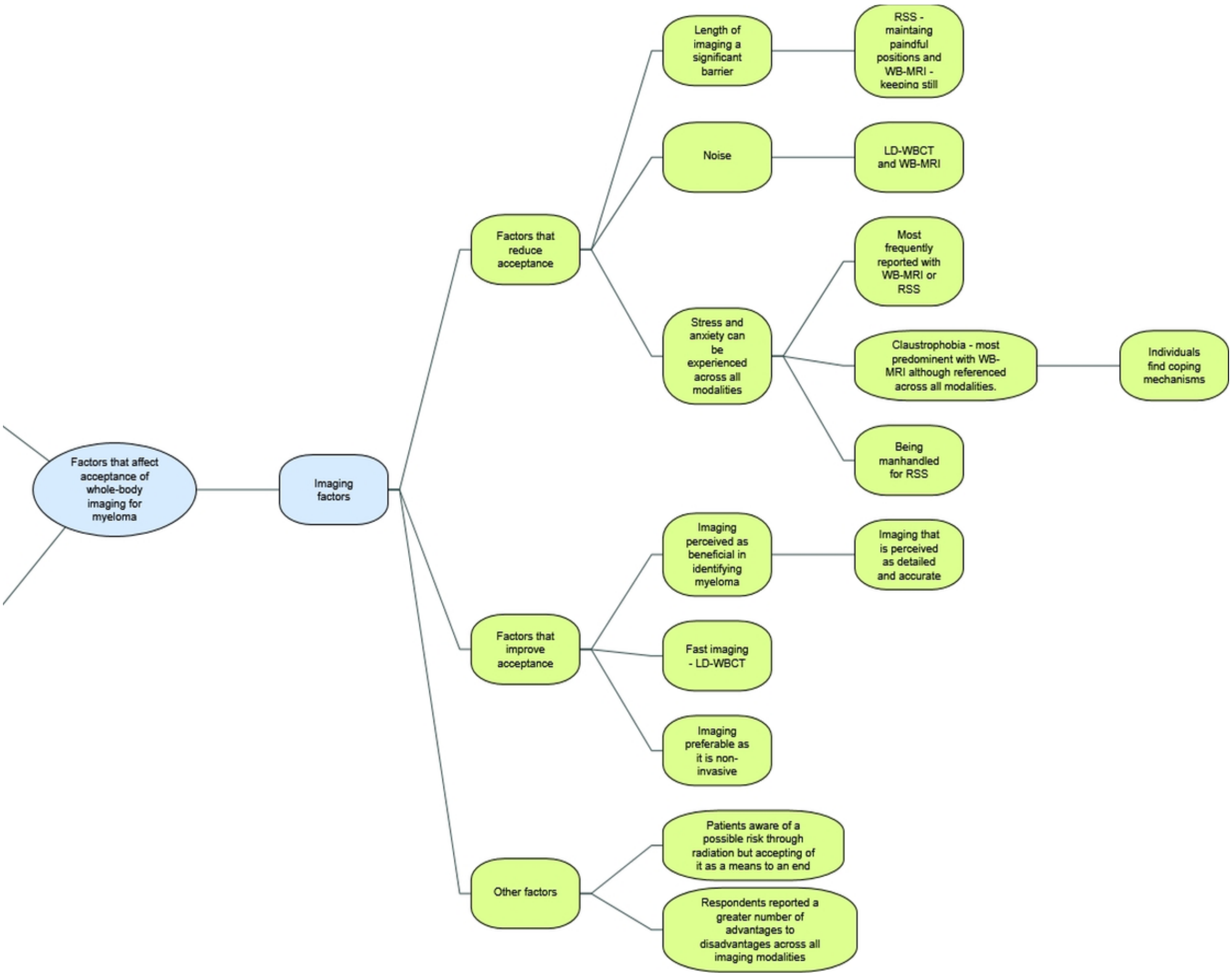



Acceptance of whole-body imaging for myeloma
What do patients think of imaging
RSS
Factors that improve acceptance
Relatively quick
Readily available
Not required to go into a scanner
Not painful
Not claustrophobic
Results
Can check bone damage and cancer sperad
Factors the reduce acceptance
Positioning is painful - manhandling
Length of examination
Accuracy, only shows bones
Radiation
LD-WBCT
Factors that improve acceptance
Results
bone damage and check the spread of
Quick
Not claustrophobic
Factors the reduce acceptance
Noise
Use of radiation
WB-MRI will find out the cause of pain
Perceived to give accurate and detailed results
Don't need to move, can lie stil, supported physically
Factors that

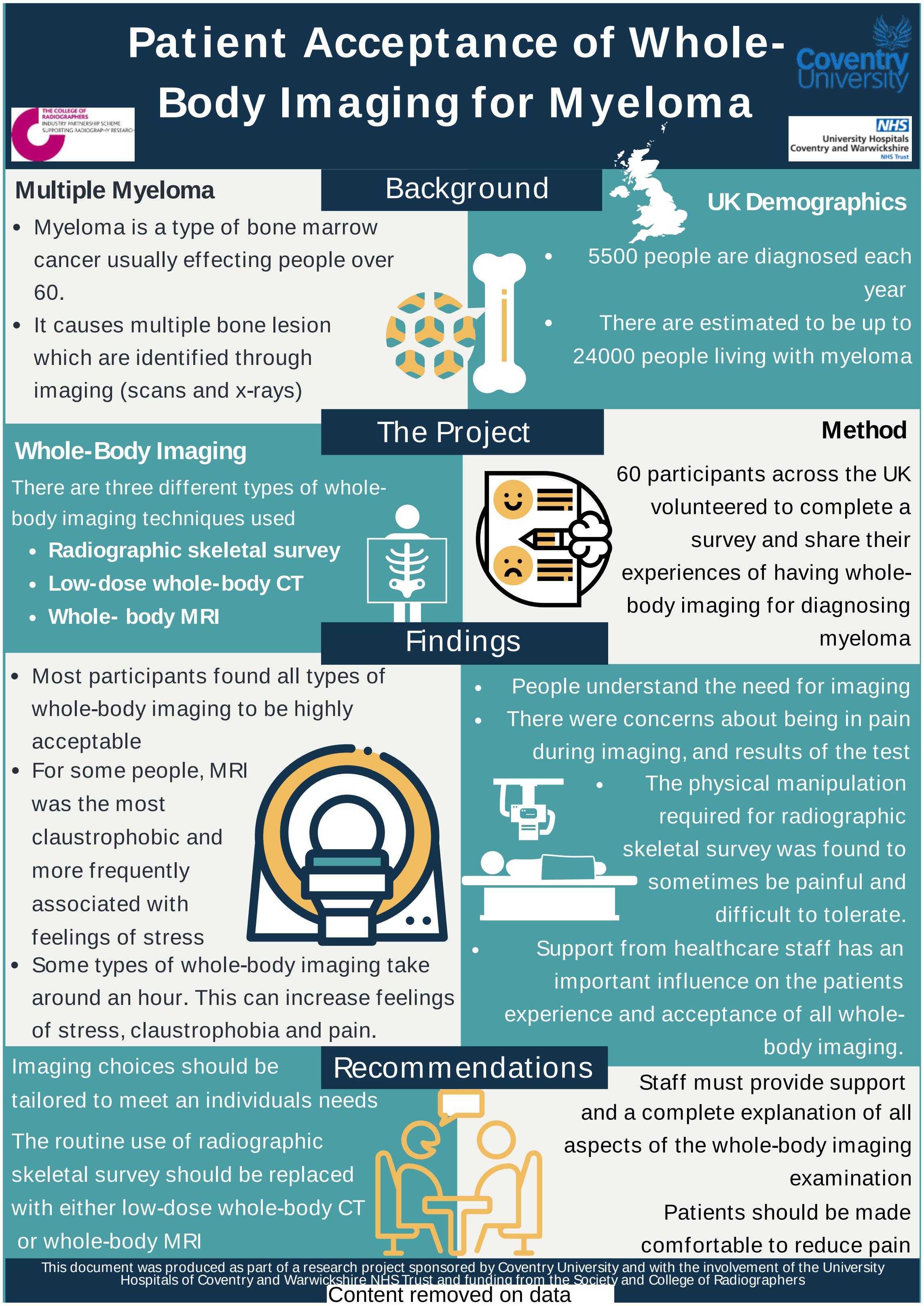

Acceptance of whole-body imaging for myeloma
What do patients think of imaging
WB-MRI
Factors that improve acceptance
WB-MRI will find out the cause of pain
Perceived to give accurate and detailed results
Don't need to move, can lie stil, supported physically
Use of sedatives
Buzzer, and staff nearby reassuring
Factors the reduce acceptance
Length of the scan
Claustrophoia
Pain and bone damage
Panic, stress, worry
Keeping still for so long
Moving, and effecting the scan or results
Noisy
Uncomfortable
Fitting of equipment
All imaging technology
Factors that improve acceptance
Non invasive imaging preferable to invasive biopsy
Cleanliness
Factors the reduce acceptance
Noise, referenced across LD-WBCT and WB-MRI
Having to wait before the appointment
Possibility of human error
Waiting for an appointment
reassuring to know bone damage and disease
Accuracy is very important to patients
Visualising and seeing disease
Although imaging can have difficulties, it is still managable
Pagmatiic acceptance

Appendix 8: Thematic Analysis Phase 4 Map




Factors that affect acceptance of whole-body imaging for myeloma
Imaging factors
Factors that reduce acceptance
Length of imaging a significant barrier
RSS - maintaing paindful positions and WB-MRI - keeping still
Noise
LD-WBCT and WB-MRI
Stress and anxiety can be experienced across all modalities
Most frequently reported with WB-MRI or RSS
Claustrophobia - most predominent with WB-MRI although referenced across all modalities.
Individuals find coping mechanisms
Being manhandled for RSS
Factors that improve acceptance
Imaging perceived as beneficial in identifying myeloma
Imaging that is perceived as detailed and accurate
Fast imaging - LD-WBCT
Imaging preferable as it is non-invasive
Other factors
Patients aware of a possible risk through radiation but accepting of it as a means to an end
Respondents reported a greater number of advantages to disadvantages across all imaging modalities

Appendix 9: Project Infographic



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Back Cover

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