An Exploration of Factors Which Influence the Decision-Making Processes of Women Aged Sixty and Above When Individuals are Faced with a Medical Treatment Decision

Rachel Walton

Supervised by:

Dr Sarah Butchard and Dr Ste Weatherhead

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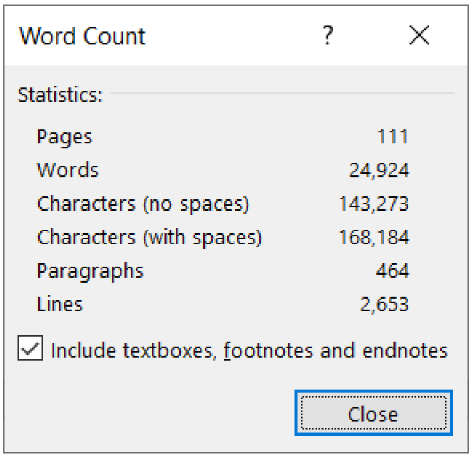

Word Count

Statistics:

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☑ Include textboxes, footnotes and endnotes

Introductory Chapter: Thesis Overview

This thesis consists of two chapters (1) a systematic review which explores older women's decision-making in relation to medical treatments; (2) an empirical paper which explores the decision-making processes of women aged sixty or above who have been offered Electroconvulsive Therapy (ECT). The empirical paper has been written for a planned publication in the Journal of Geriatric Psychiatry and Neurology and has therefore been written in line with their authors guidelines. These can be found in Appendix A. Also, in the near future the systematic review paper will be prepared for publication in the Journal of Age and Ageing and will be formatted in line with their authors guidelines. Currently the systematic review is formatted in line with APA formatting guidance.

Despite being individual papers, the two chapters aim to explore and obtain a greater understanding of older women's decision-making processes and factors which influence an individual's medical treatment decision-making. Such understanding enables clinicians to individualise treatment discussions and enhance educational strategies (Angarita, Elmi, Zhang, & Look Hong, 2018). This in turn increases the likelihood of person-centred care, as clinicians and service-providers alike are better able to develop and tailor interventions, based on their client or patient's goals, values and treatment preferences which positively influences patient satisfaction and clinical outcomes (Angarita et al., 2018; Ciambrone, 2006).

Throughout both papers, the researchers acknowledge that there is no consensus on what defines an "older woman" (Angarita et al., 2018). However, for the purpose of both the systematic review and the empirical paper a threshold of sixty years or above was used to classify the population being studied as 'older'. This threshold was chosen as the most recent dataset published by the ECT accreditation service (ECTAS) indicated that 1073 out of 1821 individuals to receive acute courses of ECT between April 2016 and March 2017 were aged sixty or above and the mean age of individuals to receive ECT within the same time frame was sixty-one years, the mode was seventy years and the median was sixty-four years, respectively (Buley, Copland, & Hodge, 2017). The researchers also wished to maintain consistency, where possible, across the two chapters although, they acknowledge that across the papers included within the systematic review authors use thresholds of sixty-five and seventy years to classify the population as ‘older’ (Husain, Collins, Reed, & Wyld, 2008; Schonberg et al., 2014).

Until this point, there has been a lack of synthesised data exploring factors which influence older women’s treatment decision-making, when they are faced with a decision around whether to receive or decline a medical treatment. The systematic review therefore identified, appraised and synthesised the existing literature which explores this phenomenon. A systematic search was conducted across six electronic databases and a total of nine papers were identified for review, with all but one paper exploring decision-making within the context of older women’s cancer treatment. The findings of this review suggested that the degree to which older women wish to be involved in their medical treatment decision-making varies between individuals. The review also highlighted a range of factors which influence this process. Thus, due to the individual and personal nature of older women’s medical treatment decision-making, it was recommended that clinicians take time to work with an individual to explore their concerns, values and personal circumstances to understand how the interplay between such factors influences their treatment decision-making as this is likely to improve collaboration and encourage a more person-centred approach. Several recommendations for future research were also made based on the findings of this review, particularly as throughout the review the researchers were only able to access research relating primarily to older women’s cancer treatment decisions and this limits the conclusions that can be made in relation to older women's medical treatment decision-making more generally.

The empirical paper explored the personal stories of seven females who had been offered ECT after they had become sixty years of age, in order to gather an increased understanding of their decision-making processes and factors which influenced their decision-making around the treatment. Data collected via seven individual interviews was analysed using Narrative Analysis as this allowed the researchers to explore each participants' own story, as influenced by any personal, ethical, social or political issues that the research may bring (Weatherhead, 2011). The research findings were synthesised into a grand narrative, or coherent story (Howitt, 2016), which is presented across five chapters within the results section of the empirical paper. The grand narrative highlighted a range of factors which influence older women's decision-making around ECT; participants difficulties with depression, feelings of desperation and their desire to "get rid" of distress appeared to be the most influential of these factors. From the research findings, a model highlighting factors which influence older women's decision making around ECT was developed. Several clinical recommendations and recommendations for future research were also made, including, the use of robust and comprehensive consent processes throughout an individual's course of ECT, as feelings of desperation and an individual's perception around their treatment choice are noted to influence an individual's ability to provide informed consent and the voluntariness of their decision (Clarke, Barnes, & Ross, 2018; Swift, 2011), and exploring the perspectives of family members, friends and carers who support individuals offered ECT.

The systematic review, empirical paper and their findings highlight the individualised and personal nature of older women's decision-making within the context of medical treatments for both physical and mental health difficulties. Older women's treatment decision-making has largely been neglected within medical and mental health research which in turn is likely to have resulted in clinicians, who work in physical and mental health services, making paternalised assumptions around older women's treatment preferences, their preferred decision-making style and their sense of autonomy and empowerment. Through disseminating the findings, and highlighting the clinical recommendations made it is hoped that clinicians are encouraged to have more open discussions around the physical and mental health treatments available to older women, older women's treatment preferences, their preferred decision-making style and factors which influence their treatment decision-making. This in turn is likely to improve the decision-making process experienced by older women and support more informed decision-making. It is also hoped that by addressing the recommendations for future research, researchers will continue to contribute to the growing evidence base relating to older women's health care decision-making to further increase understanding of factors which influence the decision-making process experienced by individuals when they are faced with a decision around whether to receive a medical treatment for varying physical and mental health concerns.

References

Angarita, F. A., Elmi, M., Zhang, Y., & Look Hong, N. J. (2018). Patient-reported factors influencing the treatment decision-making process of older women with non-metastatic breast cancer: a systematic review of qualitative evidence. *Breast Cancer Research and Treatment, 171*(3), 545-564. doi:10.1007/s10549-018-4865-0

Buley, N., Copland, E., & Hodge, S. (2017). *ECT Minimum Dataset 2016-2017*. London: ECT Accreditation Service The Royal College of Psychiatrists.

Ciambrone, D. (2006). Treatment Decision-Making Among Older Women with Breast Cancer. *Journal of women & aging, 18*(4), 31-47. doi:10.1300/J074v18n04_04

Clarke, K. A., Barnes, M., & Ross, D. (2018). I had no other option: Women, electroconvulsive therapy, and informed consent. *International journal of mental health nursing, 27*(3), 1077-1085. doi:10.1111/inm.12420

Howitt, D. (2016). *Introduction to Qualitative Research Methods in Psychology* (3rd ed.). Harlow: Pearson Education Limited.

Husain, L. S., Collins, K., Reed, M., & Wyld, L. (2008). Choices in cancer treatment: a qualitative study of the older women's (> 70 years) perspective. *Psycho-Oncology, 17*(4), 410-416. doi:10.1002/pon.1242

Schonberg, M. A., Birdwell, R. L., Bychkovsky, B. L., Hintz, L., Fein-Zachary, V., Wertheimer, M. D., & Silliman, R. A. (2014). Older women’s experience with breast cancer treatment decisions. *Breast Cancer Research and Treatment, 145*(1), 211-223. doi:10.1007/s10549-0142921-y

Swift, T. (2011). Desperation may affect autonomy but not informed consent. *AJOB neuroscience, 2*(1), 45-46. doi:10.1080/21507740.2010.537293

Weatherhead, S. (2011). Narrative analysis: An often overlooked approach. *Clinical Psychology Forum, 218*, 47-52.

Chapter One: Systematic Review

A Systematic Review of the Factors which Influence Older Women’s Medical Treatment Decision-Making

Abstract

Background

The population of the United Kingdom (UK) has steadily aged through the latter half of the twentieth century, which in turn has increased the risk of individuals experiencing one or more chronic health conditions. The growing need for interventions specifically developed for an ageing population has therefore been emphasised within the literature alongside the importance of identifying the physical and psychosocial phenomenon which influences treatment decision-making. Despite this, conflicting information regarding older people's health care decision-making preferences can be found and synthesised data exploring factors which influence older women's medical treatment decision-making is lacking.

Aims

To identify, appraise, and synthesise the existing literature that explores factors which influence the medical treatment decision-making of women aged sixty or above.

Methods

A systematic review was performed in accordance with Preferred Reporting Items for Systematic Review and Meta-analysis Protocols (PRISMA) principles. A search was conducted across six electronic databases and in total nine papers were identified for review, with all but one study exploring older women's decision-making within the context of cancer care. The quality of the articles identified was assessed through the Quality Assessment Tool for Studies with Diverse Design (QATSDD).

Results

Contrary to assumptions described in the medical literature, the results of this review indicated that many older women are keen to be involved in their medical treatment decision-making and employ a range of strategies to support their decision-making processes. However, the degree to which an individual wishes to be involved in such decision-making varies between individuals, along with factors found to influence treatment decision-making. Nonetheless, the study's findings highlighted the influence of the recommendations made by health care professionals (HCP's), participants personal circumstances, their knowledge of treatments and personal preferences as well as the influence of age-related health and life circumstances.

Conclusions

Older women's medical treatment decision-making is a highly personal and individualised process. Clinicians supporting older women, therefore, should not make assumptions around older women's treatment preferences or their preferred decision-making style. Instead it is recommended that clinicians take time to work with individuals to explore their concerns, values, social and personal circumstances to understand how the interplay between such factors influences an individual's treatment decision-making, as this is likely to increase collaboration between HCPs and older women, encourage a more person-centred approach and improve treatment satisfaction.

Introduction

‘Decision-making’; a fundamental and continuous process which impacts daily outcomes relates to the mental activities that occur when an individual is presented with multiple options (Galotti, 2002; McFall, 2015). The process typically involves a decision-maker undertaking several tasks including, goal setting, gathering information, decision structuring, and making and evaluating a final choice, even for the most minimally complex decisions. (Galotti, 2002). However, it is important to note that a decision-maker may perform multiple tasks simultaneously, may skip tasks and may perform the tasks in different orders, depending on the decision being made (Galotti, 2002).

Within health care settings, person-centred care and shared decision-making are increasingly advocated as a guide for how assessments, consultations, diagnoses and treatments should be performed (Sandman & Munthe, 2010). Shared decision-making, where both a patient / service-user and a clinician play an active role in the decision-making process around the patient’s treatment, is considered to be a key feature within a person-centred approach and has therefore been contrasted with other models of medical decision-making such as, paternalism and patient choice alone (Sandman & Munthe, 2010).

Researchers note that as shared decision-making involves integrating evidence into care and treatment discussions it enables patients to be better prepared to make informed, evidence-based health care decisions that are aligned with their treatment goals, values, and personal preferences (Cohen, 2017). Some of the positive outcomes associated with shared decision-making include increased treatment satisfaction and a reduction in unwarranted variation in care (Bradley & Green, 2018; Cohen, 2017). A 2014 systematic literature review suggested that interventions which support shared decision-making significantly improve outcomes for disadvantaged groups although, these findings should be interpreted with caution due to the varying quality and small sample sizes of the reviewed studies (Durand et al., 2014). It is, however, important to note that in addition to ethical and clinical arguments, there are also economic arguments which support a shared decision-making approach as this has been associated with reduced care costs which may be a result of reduced hospitalisation and increased adherence to medication (Bradley & Green, 2018; Cohen, 2017). Moreover, despite such supporting arguments clinicians should be aware that not all individuals wish to participate in their health care decisions. Engaging in shared decision-making generally requires knowledge, confidence, self-efficacy and high levels of health literacy (Chung, Lawrence, Curlin, Arora, & Meltzer, 2012; Durand et al., 2014). Evidence, therefore, suggests that treatment decision-making preferences vary between individuals and although many individuals prefer an active role others prefer such role to be more passive (Nicolai et al., 2016). With this, clinicians should not assume that shared decision-making is beneficial for all individuals as for some providing detailed information around treatment options or imposing a choice may significantly increase anxiety and may lead to decisional conflict (Nicolai et al., 2016).

Research exploring the relationship between ageing and decision-making is beginning to grow, with some researchers arguing that older adults prefer less autonomy and seek less information when making decisions on their own (Reed, Mikels, & Simon, 2014) and others suggesting that when faced with more than one option, older adults were more likely to choose options that involve shorter time delays or higher probabilities of experiencing an interaction with a close social partner (Seaman et al., 2016). There is also conflicting evidence around older people's desire to be involved in their health care decision-making, with some researchers suggesting that not all older people wish to engage in a shared decision-making process and prefer to simply receive information around their treatment and would prefer to participate in a doctor-led decision-making process (Husain, Collins, Reed, &

Wyld, 2008; Morgan et al., 2015; Vogel, Helmes, & Hasenburg, 2008). Whereas, for other individuals collaboration throughout the decision-making process is highly valued (Thomé, Dykes, Gunnars, & Hallberg, 2003). Nonetheless, the literature suggests that older adults have historically been less likely to participate in health care decisions and limited attention has been paid to how best engage older adults in their health care decision-making processes (Elliott et al., 2016; Schulman-Green, Naik, Bradley, McCorkle, & Bogardus, 2006) which in turn may negatively influence treatment outcomes and older adults’ well-being, particularly if their involvement is a consequence of older adults being less likely to be invited to participate in health care decisions, rather than individuals preferring a clinician-directed decision-making style.

The population of the United Kingdom (UK) has steadily aged throughout the latter half of the twentieth century which in turn has increased the risk of individuals experiencing one or more chronic health conditions (Fuller, Mindell, & Prior, 2016; Office for National Statistics, 2018) . Researchers have therefore emphasised the growing need for interventions which target older people and older women, specifically, however, they argue that such interventions cannot be adequately developed without obtaining an understanding of the physical and psychosocial phenomena which affect decision-making (Ciambrone, 2006). Despite this, synthesised data exploring factors which influence older women’s medical treatment decision-making is lacking.

An increased understanding of factors which influence older women’s medical treatment decision-making enables clinicians to individualise treatment discussions with patients and enables them to tailor educational strategies, reduces the risk of misinformation and has been found to improve a range of outcomes, including patient satisfaction (Angarita, Elmi, Zhang, & Look Hong, 2018). This systematic review was therefore conducted to identify, appraise, and synthesise the existing literature exploring factors which influence older women’s decision-making around whether to accept or decline a medical treatment. For the purpose of this review, a threshold of sixty years or above was used to classify the population being studied as ‘older’. However, the reviewers acknowledge that there is no consensus on what categorically defines an ‘older woman’ (Angarita et al., 2018).

Review Question

1. Which factors influence older women’s decision-making around whether to receive or decline a medical treatment?

Method

Throughout this mixed methods systematic review, a convergent integrated approach to synthesis and integration was utilised, as guided by the methodology outlined within The JBI Manual of Evidence Synthesis (Aromataris & Munn, 2019).This approach was chosen as the review question could be answered by qualitative, quantitative and mixed methodological approaches. Also, a convergent integrated approach is reported to provide a better understanding of the phenomenon under study as it allows reviewers to ‘sum up’ what is known about a target phenomenon and, can therefore direct both future practice and research (Lizardo et al., 2019; Sandelowski, Voils, & Barroso, 2006). Throughout this review the reviewers (1) used two tables, found in Table 3 and Appendix B, to extract data relevant to the review question; (2) ‘qualitised’ quantitative results highlighted within the quantitative and mixed methodological studies included in this review; (3) pooled together qualitative and ‘qualitised’ data based on their similarities in order to produce a set of integrated findings. A predetermined protocol which highlighted methods of analysis and inclusion criteria was followed throughout the mixed methods systematic review however, this was not formally published. Preferred Reporting Items for Systematic Review and Meta-analysis Protocols (PRISMA) guidelines were also followed.

Article Search Strategy

Articles were identified through an electrical search within several databases including, AMED, APA PsycINFO, CINAHL, MEDLINE, PubMed and Web of Science after a comprehensive search strategy was developed through consultation with an NHS librarian. The search terms used for each database included the following combinations: (old* OR aged OR geriatric OR ag?ing OR elderly) AND (woman OR women OR female*) AND (decision making OR decision-making OR decision making process OR decision-making process) AND (health OR health care OR healthcare).

Study Selection

After conducting the searches outlined above one reviewer (RW) began making inclusion decisions based on the review’s eligibility criteria, this process occurred in several stages. The reviewer initially removed all duplicate papers before independently reviewing the title and abstracts for initial eligibility. Once reasons for exclusion were recorded, the full texts of potential studies were reviewed in line with the review’s eligibility criteria. A second reviewer (SB) provided support throughout this stage to check reliability of the process. The PRISMA diagram, Figure 1, is utilised to highlight the process of screening and identifying eligible publications and to ensure transparency (Liberati et al., 2009).

Eligibility Criteria

The Population, Intervention, Comparison, Outcome and Study type (PICOS) framework was used to guide the development of this review’s eligibility criteria. Studies were identified for review if they satisfied the following eligibility criteria:

1) The population under investigation were women aged sixty or above who had been faced with a decision around whether to undergo a medical intervention such as pharmacotherapy and surgical procedures.
2) The population under investigation were being treated within westernised countries.
3) The studies explored participant-reported factors which influenced or were associated with their treatment decision-making at the time they were faced with a decision around whether to undergo a medical intervention.
4) The studies used qualitative, quantitative, or mixed methodologies.
5) The studies were published in English peer reviewed journals from the year 2000 onwards.

Studies were excluded from the review if:

1) The studies involved other age groups or genders and if a subgroup analysis for the population of interest was not conducted.
2) The studies explored older women’s decision-making around non-medical interventions, such as physiotherapy or chiropractic interventions.
3) The studies explored older women’s decision-making around assessment or screening procedures, such as mammography.
4) The studies explored secondary data, such as information recorded within medical records.
5) The studies utilised vignettes to explore hypothetical decision-making

6) The studies explored factors associated with participant decision-making style and communication preferences in isolation.

Narrative and systematic reviews, meta-analyses, protocols, dissertations, and case-reports were also excluded from this review. Further information highlighting how the PICOS framework was used to develop the inclusion and exclusion criteria of this review can be found in Table 1.

Table 1

The Review's Inclusion and Exclusion Criteria in line with the PICOS Framework

PICOS	Inclusion Criteria
Population	• Women aged sixty or above. • Women who had been offered a medical treatment within a Westernised country
Interest	• Factors which influence medical treatment decision-making
Context	• Medical treatments or medical interventions
Study Type	• Qualitative studies which were published in a peer reviewed journal since the year 2000 • Quantitative studies which were published in a peer reviewed journal since the year 2000 • Mixed methodological studies which were published in a peer reviewed journal since the year 2000

- Studies published in the English language

Data Extraction

At the point of data extraction, reviewers were not blinded to each study's author or the source of publication. One reviewer (RW) independently reviewed the identified studies and extracted qualitative and quantitative data by using the tables outlined in Table 3 and Appendix B. The data extracted included specific details which related to (1) the study's characteristics, including the author, year of publication and the country the study was conducted within; (2) participant information and characteristics, including the number of participants, their age and ethnicity; (3) study design and contextual information including data collection techniques and methods of analysis; (4) participant recorded information relating to their decision-making at the time they were faced with a decision around whether to undergo a medical intervention. Further details relating to the data extracted can be found in Table 3 and Appendix B.

Data Transformation

Quantitative data was converted into 'qualitised data' as this allowed the reviewers to compare and contrast qualitative and quantitative findings. Throughout this process quantitative data, highlighted within quantitative and mixed methodological studies, was transformed into a textual description or narrative interpretation, through repeated examination and discussion between the two reviewers (RW and SB), in a way which answered the review question. Numerical figures or quantities highlighted within quantitative data were therefore removed throughout the 'qualitising' process to allow the data to be understood as standalone sentences which could be understood and compared against qualitative data. Table 3 includes two examples of qualitised data which demonstrate how the quantitative findings of Takase-Sanchez et al. (2015) were transformed into a textual description which could be compared against the qualitative findings of other studies.

Data Synthesis and Integration

A convergent integrated approach, as described by the JBI methodology for mixed methods systematic reviews (Lizardo et al., 2019) was used throughout this review as this allowed the reviewers to group eligible studies for synthesis by their findings and better highlights findings which answer the same research question and those that address the same aspects of a target phenomenon (Sandelowski et al., 2006). Qualitative data was therefore assembled with 'qualitised' data and pooled together based on their similarity in meaning in order to produce a set of integrated findings which highlight factors which influence older women's medical treatment decision-making. These integrated findings are highlighted within the results section of this review under relevant subject headings.

Quality Assessment

To determine the quality of the individual studies identified within this review, each study was scored using the Quality Assessment Tool for Studies with Diverse Design (QATSDD) (Sirriyeh, Lawton, Gardner, & Armitage, 2012). This 16-item tool was chosen as it allows reviewers to compare studies which utilise qualitative, quantitative, and mixed methods designs. The tool has also been assessed to determine its reliability and validity when used by health services researchers in the disciplines of psychology, sociology, and nursing. Cohen’s Kappa was used to assess test-retest reliability with scores falling within the good and substantial ranges (Sirriyeh et al., 2012).

When using the QATSDD reviewers are required to award each research paper a score between zero and three for each of the relevant criteria; fourteen of these criteria apply to qualitative studies, fourteen apply to quantitative studies however, all sixteen apply where studies have used a mixed methods design (Sirriyeh et al., 2012). A total quality score of up to forty-two can be obtained for qualitative and quantitative studies. A quality score of up to forty-eight can be obtained for studies which utilise a mixed methods approach (Sirriyeh et al., 2012). Each of the studies identified were reviewed by two reviewers (RW and SB). In line with recommendations made by Sirriyeh et al. (2012) each eligible paper was reviewed by the two reviewers independently in order to obtain an overall quality score for each paper. Any discrepancies between the reviewers’ scoring throughout the quality assessment were resolved through later discussions. A summary of each paper’s quality assessment can be found in Table 2.

Results

Study Selection

A total of 3,451 papers were identified through database searching and after duplicates were removed 2,730 were screened for eligibility. Of the 2,730 papers screened 2,680 failed to meet the reviews eligibility criteria based on their title and abstract alone. 50 articles were assessed for eligibility by review of the full text. 43 of these studies were excluded and 7 studies were included in the synthesis. An additional 2 papers were identified by reviewing the reference lists of the 7 eligible studies. In total 9 papers were included in the review. A PRISMA flow diagram highlighting this process can be found in Figure 1.

Figure 1- PRISMA Flow Diagram Highlighting Study Selection

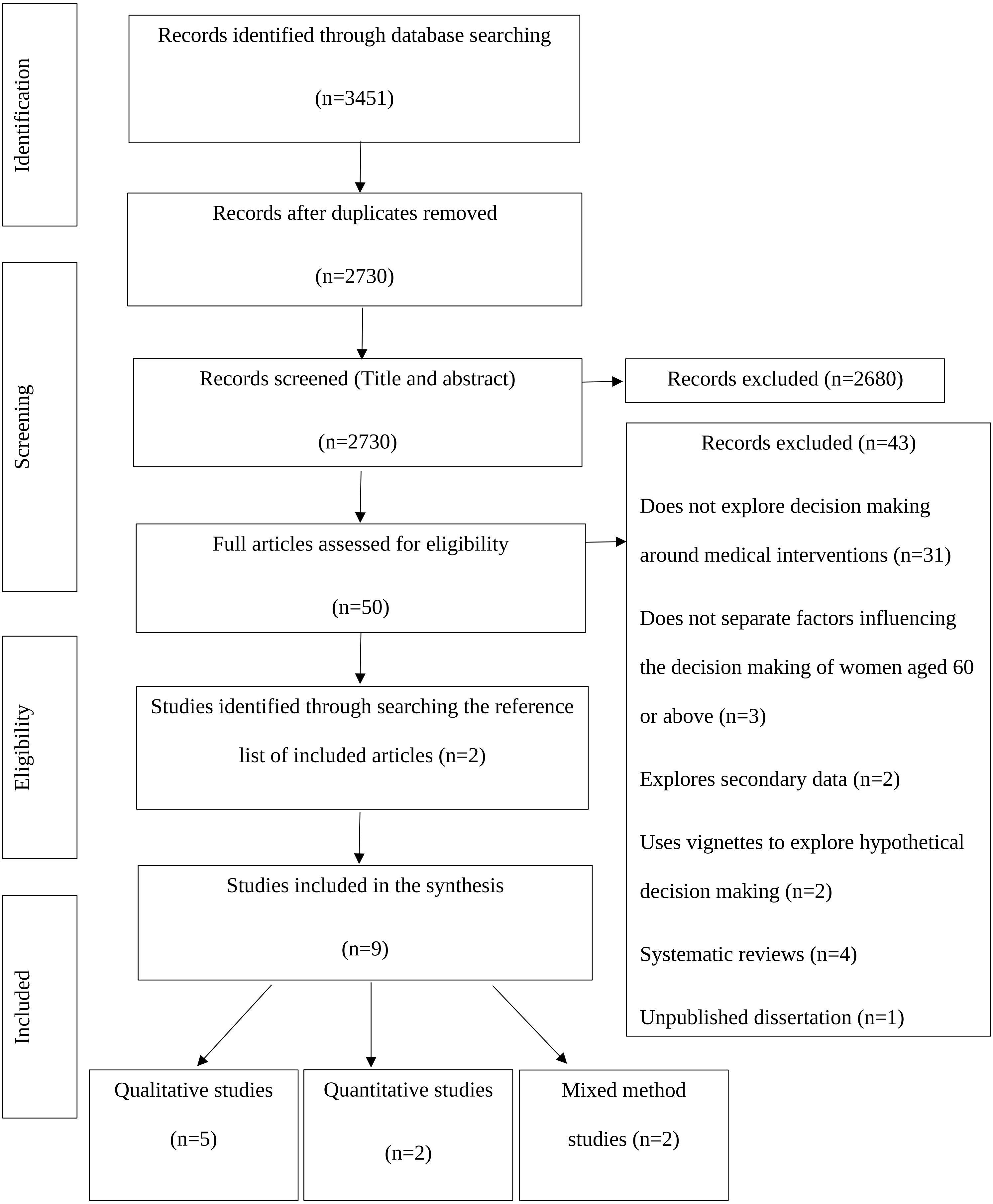


Table 2

Quality assessment of studies using the QATSDD tool

Selected articles identified by author and year. The score awarded to each criterion relate to 0=Not at all, 1=Very slightly, 2=Moderately, 3=Complete.

Quality Criteria	1.Ciambrone (2006)	2.Cyran, Crane & Palmer (2001)	3.Husain et al. (2008)	4.Lifford et al. (2015)	5.Morgan et al. (2015)	6.Pieters, Heilemann, Maliski, Dornig & Mentes (2012)	7.Schonberg et al. (2014)	8.Sinding, Wiernikowski & Aronson (2005)	9.Takase-Sanchez, Brooks, Hale & Heit (2015)
Explicit theoretical framework	2	1	2	3	2	2	2	2	2
Statement of aims/objectives in main body of report	3	2	3	2	3	3	3	2	3
Clear description of research setting	3	3	3	3	3	3	3	3	2
Evidence of sample size considered in terms of analysis	0	1	3	0	3	2	1	2	1
Representative sample of target group of a reasonable size	1	3	1	1	2	2	1	3	2
Description of procedure for data collection	2	3	3	3	2	2	2	3	2
Rationale for choice of data collection tool(s)	0	1	3	2	1	2	1	2	2
Detailed recruitment data	3	3	2	2	1	3	3	3	3
Statistical assessment of reliability and validity of measurement tools	N/A	3	N/A	N/A	0	N/A	0	N/A	1
Fit between stated research question and method of data collection (Quantitative)	N/A	2	N/A	N/A	2	N/A	2	N/A	3
Fit between stated research question and format and content of data collection tool	2	N/A	3	3	2	3	2	2	N/A
Fit between research question and method of analysis	2	3	3	3	3	3	2	2	3
Good justification for analytical method selected	0	1	2	3	1	3	1	3	2
Assessment of reliability of analytical process (Qualitative only)	0	N/A	2	2	2	2	2	3	N/A
Evidence of service user involvement in design	0	3	0	0	0	0	0	3	0
Strengths and limitations critically discussed	1	2	1	1	1	1	2	1	3
Qualitative Total Score	19	N/A	31	28	N/A	31	N/A	34	N/A
Quantitative Total Score	N/A	31	N/A	N/A	N/A	N/A	N/A	N/A	29
Mixed Methods Total Score	N/A	N/A	N/A	N/A	28	N/A	27	N/A	N/A

Quality Assessment

The outcome of each article's methodological quality assessment is presented within Table 2. This indicates that the nine articles included within this review are of varying quality and notes that six out of the nine articles provided minimal detail which highlights the strengths and limitations of the study. In contrast to this, the quality assessment demonstrated that the majority of studies provided a clear description of the research setting, all at least made broad reference to the study's aims and objectives in the main body of the report and most demonstrated an appropriate fit between the research question and the method of analysis utilised. On the whole, the eligible articles were deemed to be of reasonable quality, as measured by the QATSDD, and their quality was sufficient enough for each article to be included within this mixed methodological review. Although, it is important to note that caution was taken by the reviewers when synthesising the results in order to account for varying quality highlighted throughout the quality assessment.

During the quality assessment, the QATSDD highlighted several limitations with the paper written by Ciambrone (2006), this was therefore considered to have the poorest quality out of the nine papers included in this review. These limitations included the author not demonstrating whether the study's sample size had been considered in terms of analysis, not describing their rationale for the choice of data collection tool(s), them providing poor justification for the analytical method selected and them not highlighting the reliability of the analytical process. Additionally, the paper written by Ciambrone (2006), along with the papers written by Husain et al. (2008), Lifford et al. (2015), Morgan et al. (2015), Pieters et al. (2012), Schonberg et al. (2014) and Takase-Sanchez et al. (2015), did not demonstrate evidence of service-user involvement in their design. This was surprising to the authors, particularly as the area being explored related to decision-making, and was considered to be a major limitation of seven of the nine papers included in this review.

Study Characteristics

Out of the nine reviewed studies, five were conducted in the USA, three were conducted in the UK and one was conducted in Canada and all were published in academic journals between 2001 and 2015. All of the studies aimed to explore and identify factors which influenced or were associated with older women’s treatment decision-making, with the majority of studies exploring such phenomenon within the context of breast cancer treatment. However, one study also explored older women’s treatment decision-making in relation to either breast or gynaecologic cancer and a final study explored patient-reported reasons for selecting obliterative surgery for the treatment of pelvic organ prolapse. Several of the studies also had additional aims which included (1) exploring factors associated with older women’s breast cancer surveillance decision-making and adherence; (2) identifying the attitudes of older women in relation to primary endocrine therapy (PET) and surgery in the context of breast cancer treatment; (3) understanding the experiences of older women who have undergone PET or surgery as a treatment for breast cancer; (4) exploring the concordance between health care professionals (HCP’s) and patient views regarding the process of decision-making in relation to treatment of operable breast cancer; (5) understanding how older women’s decision-making processes may contribute to treatment decision regret or satisfaction.

The sample size varied across studies, in line with each study’s methodology. The sample size of the qualitative studies included in this review ranged between 15 and 35. The two quantitative studies had sample sizes of 198 and 77, respectively. Moreover, the sample size of the two mixed methodology studies were 729 and 70 although, in the paper written by Morgan et al. (2015) only 33 women who had undergone treatment for breast cancer participated in qualitative interviews in addition to an initial questionnaire relating to their decision-making preferences.

In relation to analysis, three of the qualitative studies which were written by Ciambrone (2006), Pieters et al. (2012) and Sinding et al. (2005) drew upon grounded theory to analyse the data obtained through qualitative interviews. The paper written by Husain et al. (2008) used framework analysis and within their paper Lifford et al. (2015) used the Coping in Deliberation (CODE) framework to gain insight into decision-making and coping processes. Cyran et al (2001) and Takase-Sanchez et al. (2015) used quantitative methodologies within their articles which involved bivariate analyses by means of χ^2 tests, t-tests or analysis of variance, multivariate logistic regression and spearman rank correlation coefficients. The paper written by Morgan et al. (2015) used mixed methodologies; the concordance between participants' preferred and actual decision-making preferences was assessed using Cohen's Kappa, associations between age, treatment and decision making style were identified using χ^2 tests and framework analysis was used to analyse data gathered through qualitative interviews. Finally, Schonberg et al. (2014) utilised χ^2 tests, a two-sample t-test or the Wilcoxon Rank-Sum test for the quantitative component of the study and progressive coding techniques were used to identify themes within the qualitative component.

Participant Characteristics

In line with the review's eligibility criteria, participants in all nine articles were women who were aged sixty or above. Most papers reported the age range of participants at the time they participated in the study, with participant ages ranging between sixty-five and ninety-eight years. Most papers also reported the average age of participants at the time they participated in this study, by highlighting either the "average age", median age or mean age; such figures ranged between seventy-six and eighty-three years. However, the papers written by Schonberg et al. (2014) and Sinding et al. (2005) did not report the full age range of participants and did not provide information around the mean of participants. Instead the authors highlighted age brackets of interest such as, '65 to 74 years' and then '74+ years'. Also, rather than reporting the age of participants at the time they took part in the study, Cyran et al. (2001) reported the age range and mean age of participants at the time they had received a diagnosis of breast cancer, with participants being between sixty-five and eighty-four years and had a mean age of seventy-two years at the time they were diagnosed with breast cancer.

All studies reported either the time frame between participants receiving a physical health diagnosis, them completing treatment or undergoing a particular surgical procedure. Of the eight papers that reported the timeframe between participants receiving a physical health diagnosis and later participating in the research study, seven reported that such time frame was between three months and ninety-six months. The exception to this was the paper written by Ciambrone (2006) which noted that most participants received a diagnosis of breast cancer six years prior to participating in the research study. However, this time frame ranged from two years to twenty years. Pieters et al. (2012) reported that the mean time between participants completing their primary treatment for primary-stage breast cancer and participating in their research interview was eight and a half months and although Takase-Sanchez et al. (2015) did not report the duration between participants undergoing obliterative surgery as a treatment for pelvic prolapse and them later taking part in the study they did however, explore the time since such procedure and its relationship between surgical decision regret.

Six of the nine papers eligible for this review included information relating to participants' ethnicity and highlighted a poor representation of individuals from Black, Asian and Minority Ethnic (BAME) backgrounds. Across the six studies individuals who self-identified as white or Caucasian represented between 61% and 100% of participants. Also, of the three studies which included no information regarding participant ethnicity Ciambrone (2006) was the only author to acknowledge that studies exploring the decision-making of "women of colour" are needed.

Finally, the studies included in this review reported participant information relating to their educational status and their marital status. Six out of the nine studies included information regarding participants educational status. The papers written by Pieters et al. (2012), Sinding et al. (2005) and Takase-Sanchez (2015) provided the most detail in this domain by highlighting the proportion of people who had obtained grade 8 education or less, had completed some or all of their high school education, had completed some college, had obtained an associate's degree, a bachelor's degree or a graduate degree. In relation to participant marital status, six studies provided at least some information in relation to the proportion of participants who were married, had been widowed, were living alone or had never been married. However, Cyran et al. (2001) did not report a full data set in relation to this, suggesting that not all participants provided information relating to their marital status. Within their articles Lifford et al. (2015), Morgan et al. (2015) and Sinding et al. (2005) did not report data relating to participant marital status. Instead, Sinding et al. (2005) provided detail around participant household status and indicated the proportion of participants who lived alone, lived with at least one other person, or lived within a senior resident's facility.

Treatment Characteristics

All of the nine studies included in this review had interviewed or surveyed women who had decided on or completed their treatment. The majority of studies explored the decision-making in the context of breast cancer treatment, with participants either being offered or undergoing breast conserving surgery or lumpectomy, radiation therapy, mastectomy, chemotherapy, PET, wide local excision, PET or surgery with endocrine therapy and proton therapy across the seven papers. Sinding et al. (2005) explored decision-making in the context of both breast and gynaecologic cancer however, it does not report the treatments offered to older women or those which they had received. Moreover, Takase-Sanchez et al. (2015) specifically explored factors which influenced older women's decision to receive obliterative surgery for the purpose of pelvic organ prolapse.

Decision-Making Styles

Three types of decision-making styles were described by researchers throughout the nine articles including clinician-based decision-making, patient-based decision-making and shared decision-making approaches. Morgan et al. (2015) explored both participants preferred and actual decision-making styles and identified a moderate agreement between the two phenomena. The authors also noted that such styles were associated with participants final treatment type, with surgery being associated with clinician-centred decisions and PET with patient-centred decisions. Several papers also reported participants actual decision-making style and their perceived involvement around their treatment decision-making; Schonberg et al. (2014), for example, reported that 41% of participants reported making treatment decisions with physicians and their family, 34% reported sharing their decision with their clinician and 17% made their final treatment decision alone. Similarly, Pieters et al. (2012) note that although participants felt supported by their physicians, many had felt confident that they had made their own treatment decisions and had emphasised that they had not made treatment decisions just to gain their physician's approval. In contrast to this, Ciambrone (2006) writes that 60% of participants perceived their treatment decision to be driven by their physician, Cyran et al. (2001) noted that 24% of participants recalled that they did not have a choice of procedure and Lifford et al. (2015) reported that many participants did not perceive that they had a choice to make, because they were either not offered a choice by their health care professional or they believed that the decision was instantly obvious. Specifically, Ciambrone (2006) noted how participant’s language was indicative of their non-participation in treatment decision-making as women emphasised how they “did what they told me to do”.

Husain et al. (2008), Sinding et al. (2005) and Takase-Sanchez et al. (2015) did not specifically report participants preferred or actual decision-making style and did not report how participants experienced their involvement in their treatment decision-making. However, Husain et al (2008) reported that participants relied heavily on ‘expert’ medical advice when deciding on their treatment and Takase-Sanchez et al. (2015) highlighted the influence of clinicians as “a need to follow my doctor’s recommendations” was concluded to be the most influential factor when participants were faced with a decision around whether to receive obliterative surgery. Moreover, Sinding et al. (2005) noted that for some individuals, making treatment decisions which were not aligned with the advice received by their clinician resulted in awkward interactions with their health care professionals and negatively influenced their care and treatment.

Participant-reported factors which influence treatment decision-making

Table 3

Factors reported by participants as influencing their treatment decision-making

Participant-reported factors	Illustrative Quote	Contributing studies
Perceptions of risk	“Cancer immediately was associated with death, uncertainty (e.g., “What are they going to do to me?”) and suffering”(Pieters et al., E12). “Women’s cognitive appraisals of breast cancer were mainly focussed on their chances of survival and the potential for cancer control or cure” (Lifford et al., 2015, p7)	Ciambrone (2006), Cyran et al. (2001), Husain et al. (2008), Lifford et al. (2015), Pieters et al. (2012), Schonberg et al. (2014).
Physician recommendations	“Most women described their treatment as their physician’s choice and they were happy to leave the decision-making to the “experts”” (Ciambrone, 2006, p36) “A need to “follow my doctor’s recommendations” made the most difference in selecting obliterative surgery” (Takase-Sanchez et al., 2015, p327).	Ciambrone (2006), Cyran et al. (2001), Husain et al. (2008), Morgan et al. (2015), Schonberg et al. (2014), Sinding et al. (2005), Takase-Sanchez et al. (2015).
Faith in their physician’s judgement	“These women had confidence in their oncologists and trusted that they would make the best treatment decisions for their individual cases (Ciambrone, 2006, p38)	Ciambrone (2006), Pieters et al. (2012), Schonberg et al. (2014).

The perspectives of significant others	"Many women were pleased that their significant others did not have much to say regarding treatment as they felt it would make their life more difficult" (Ciambrone, 2006, p37)	Ciambrone (2006), Lifford et al. (2015), Pieters et al. (2012), Schonberg et al. (2014).
Knowledge of treatments and personal preferences	"Two of the women, however, did voice a strong preference for a particular treatment option regardless of the advice from the medical team. They based their decision on the experiences of close family members who themselves had suffered from breast cancer" (Husain et al., 2008, p413). "Most formed a preference relatively quickly based on their past experiences and personal goals and values" (Lifford et al., 2015, p7).	Ciambrone (2006), Husain et al. (2008), Lifford et al. (2015), Morgan et al. (2015), Pieters et al. (2012) , Schonberg et al. (2014), Takase-Sanchez et al. (2015).
Attitudes towards hospitalisation and surgery	"Reasons why they [participants] had chosen PET, other than that it was the doctor's recommendation included having undergone painful biopsies and consequently not wanting any further interventional procedure" (Husain et al., 2007, p17).	Cyran et al. (2001), Husain et al. (2008), Lifford et al. (2015).
Co-morbidities and perceptions around health, age and strength	"Some women considered whether they were strong or healthy enough to recover from surgery and explored whether there were additional coping strategies they could employ" (Lifford et al. 2015, p9). "Participant's narratives revealed how age-related health and life circumstances, intersecting with key features of cancer care and broader social structures affecting older people, shaped treatment decisions and experiences of treatment" (Sinding et al., 2005, p1171).	Husain et al. (2008), Lifford et al. (2015), Morgan et al. (2015), Schonberg et al. (2014), Sinding et al. (2005).

Potential side effects and how these may influence participants' quality of life	"The most important aspect of treatment outcome for these women appeared to be the ability to carry on life as before" (Husain et al., 2005, p414) "Another patient's decision to forego chemotherapy was driven by concern that side effects would jeopardise her ability to continue living at home independently, which for her was an overriding priority" (Sinding et al., 2005, p1172).	Ciambrone (2006), Husain et al. (2008), Lifford et al. (2015), Morgan et al. (2015), Schonberg et al. (2014), Sinding et al. (2005).
Personal Circumstances	"Clinicians frequently were unaware of these personal characteristics, such as women who were caregivers of spouses with dementia, that had a profound effect on decision-making (Pieters et al., 2012, E16) "Patient-reported reasons that predicted more satisfaction with the decision for obliterative surgery included "No longer sexually active and/or did not plan to be" (Takase-Sanchez et al., 2015, p328)	Pieters et al. (2012), Schonberg et al. (2014), Sinding et al. (2005), Takase-Sanchez et al. (2015).
Practicalities of receiving treatment	"Other women considered their lack of financial and social support when they made decisions" (Pieters et al., 2012, E16) "A concern with "getting around" threaded through participants' accounts and drew attention to practical aspects of cancer care associated with older age" (Sinding et al., 2005, p1173)	Pieters et al. (2012), Schonberg et al. (2014), Sinding et al. (2005).

As demonstrated in Table 3, a range of factors were reported by participants as influencing their treatment decision-making, including participant perceptions of risk, the advice of their HCP's, trust, the perspectives of significant others, personal knowledge, experience and treatment preferences, the negative consequences associated with particular treatments, co-morbid health conditions, attitudes towards hospitalisation and surgery and participant's personal and social circumstances.

Participant Thoughts and Feelings After Receiving a Physical Health Diagnosis.

Husain et al. (2008) and Schonberg et al. (2014), who both explore treatment decision-making in the context of breast cancer, describe the varying experiences of participants at the time they received a diagnosis of breast cancer. On hearing their diagnosis, Husain et al. (2008) note that the opinions expressed by participants was varied, with some individuals being unsurprised at hearing the diagnosis, some accepting that they had already had a long life and others being fearful and anxious due to the potential implications of the cancer diagnosis. Husain et al. (2008) and Pieters et al. (2012) noted that for participants cancer was associated with death, uncertainty, suffering and leaving loved ones behind. Across the paper’s participants, therefore, described an urgency to receive treatment in order to get rid of the cancer as soon as possible, prevent cancer spread and reduce the risk of re-occurrence. Risk was also a factor considered by the participants involved in Takase-Sanchez et al’s. (2015) study; minimising surgical risks was reported as a reason to undergo such treatment.

The Influence of HCPs.

Participants spoke of how their HCP played a role in their decision-making. Several participants involved in the study conducted by Morgan et al. (2015) stated that they wanted their clinician to make recommendations around their treatment. Similarly, Cyran et al. (2001) highlighted that physician recommendations were reported by 41% of participants as influencing their decision to undergo a mastectomy procedure and 37% of participants who underwent a lumpectomy. Similarly, “To follow my doctor’s recommendations” was reported as making the most difference in participants decision to undergo obliterative surgery (Takase-Sanchez et al., 2015). Moreover, Schonberg et al. (2014) and Sinding et al. (2005)

highlighted how participants had felt pulled by their HCPs judgement and felt the 'shoud of their physician's recommendations.

Participants involved in the studies conducted by Ciambrone (2006), Pieters et al. (2012) and Schonberg et al. (2014) spoke of how they trusted and had faith in their HCPs recommendations. Some individuals described how they trusted their clinician with their life (Ciambrone, 2006) and others reported how they had faith with whatever the surgeon had told them and how they had left their decision-making up to the doctor (Schonberg et al., 2014). Additionally, Pieters et al. (2012) detailed how participants determined the trustworthiness of HCPs and care providers and noted that this was influenced by their experience of interacting with HCPs, whether HCPs were able to provide satisfactory answers to participants' questions, and whether the power balance was noted during consultations. In particular, participants appreciated that physicians did not form a coalition with their spouse or support person when such individuals accompanied them to their appointment, but instead primarily related with themselves and specifically provided them with treatment options. Pieters et al. (2012) reported how participants deeply valued the empowerment and agency that they had received whilst relating with the surgeon.

The Influence of Significant Others.

The influence of participant's significant others on the older women's decision-making varied across the papers. Pieters et al. (2012) and Schonberg et al. (2014) noted that the perspectives of significant others were helpful for some participants, as individuals involved in their studies described how it was "important for women to get together and talk" and others described how their family members input had helped to confirm their decisions. However, in contrast to this Ciambrone (2006) reported that some individuals had described themselves as pleased that their significant others did not have much to say with regards to their treatment and preferred informal support systems to provide emotional support rather than consultation. Moreover, some individuals involved in Pieters et al's. (2015) study described how their support systems would pressurise them into asking their HCPs questions and explained that this was often unhelpful for them as often they did not know what questions to ask.

Across seven of the nine articles, participants expressed treatment preferences which were influenced by their own treatment experiences, the experience of close friends and family members, their gut instinct and knowledge of their own personal goals and values (Ciambrone, 2006; Husain et al., 2008; Lifford et al., 2015; Morgan et al., 2015; Pieters et al., 2012; Schonberg et al. 2014; Takase-Sanchez et al., 2015). Lifford et al. (2015) described how participants formed treatment preferences relatively quickly and Ciambrone (2006) noted how respondents knew the types of treatment they did not want and based their decisions on this. Participant attitudes towards hospitalisation and surgery as well as the potential implications of undergoing a particular procedure also influenced participants' treatment decision-making. Husain et al. (2008) noted that participants all had previous experience of hospitalisation, and many had undergone painful biopsies which influenced their wish to avoid further surgical procedures. Similarly, in relation to breast cancer treatment participants spoke of their desire to keep their breast, fear of being left disfigured and concerns around post-operative scaring and hear thinning when considering their treatment options (Cyran et al., 2001; Husain et al., 2008; Lifford et al., 2015) . However, Husain et al., (2008) noted that participants involved in their study had chosen to undergo less invasive treatments, such as PET, as they were aware that they could later undergo surgical procedures.

Age-Related Health and Life Circumstances.

Finally, Sinding et al. (2005) explain how participant data revealed how age-related health and life circumstances alongside key features of care and broader social structures which affect older individuals had shaped treatment decision-making, a statement which applies to all of the papers included in this review. The influence of co-morbidities, which for some participants had pre-dominated their thoughts, had to be taken into consideration (Husain et al. 2008). Participants' perceptions around their age, health and strength were also influential, as some individuals described themselves as too old or too frail to undergo or recover from particular treatments and others weighed up their changes of survival in addition to treatment side-effects (Lifford et al., 2015; Morgan et al., 2015; Schonberg et al., 2014). Some participants emphasised that the risk of side-effects "weren't worth it" at their age (Ciambrone, 2006) and across several papers participants considered how their quality of life would be affected and associated this with their ability to carry on as before, their independence, their ability to cope with tasks of daily living and their ability to enjoy hobbies (Husain et al., 2008; Lifford et al., 2015; Morgan et al., 2015; Schonberg et al., 2014; Sinding et al., 2005). Additionally, some individuals emphasised that they had prioritised their quality of life over quantity of life (Morgan et al., 2015; Schonberg et al., 2014). Moreover, participants considered the practicalities of treatment and how treatment decisions would affect significant others. Pieters et al. (2012) and Schonberg et al. (2014) noted how participants had caring responsibilities for their spouses and grandchildren so would therefore try and make decisions which were in the best interest of loved ones. Schonberg et al. (2014) also raised issues around the practicalities of receiving treatment, particularly in relation to the availability of transportation and financial costs. For many women they relied on significant others to support them to hospital and whilst they were receiving care. However, many individuals disliked being a burden on others and some participants emphasised how participants felt the need to protect vulnerable loved ones from frank discussions with their clinicians (Husain et al., 2008; Lifford et al., 2015; Pieters et al., 2012; Sinding et al., 2005).

Discussion

This systematic review explored and obtained a greater understanding of factors which influence the medical treatment decision-making of older women in relation to a range of health conditions. It has previously been demonstrated that such understanding can enable clinicians to provide more person-centred care, which in turn can improve clinical outcomes and patient satisfaction (Angarita et al., 2018). Similarly, scarcity of evidence regarding the perspectives and experiences of older women is likely to result in HCPs making paternalistic assumptions around older women’s treatment preferences (Chouliara et al., 2004).

Following a systematic search nine studies were identified for review, with eight of these studies exploring older women’s treatment decision-making within the context of cancer care. Across the nine papers, a range of factors were identified as influencing older women’s medical treatment decision-making including the recommendations made by HCPs, participant’s personal circumstances and their knowledge of treatments and personal preferences. The studies eligible for this review also highlighted the influence of age-related health and life circumstances and demonstrated how factors such as co-morbidities, the risk of side-effects, perceptions around age, health and strength, caring responsibilities and an individual’s desire to remain independent, maintain their current quality of life and avoid burdening others, had influenced their decision to either receive or decline treatment. The nine papers also demonstrated the wide range of strategies employed by older women when they are faced with a decision around whether to receive a medical treatment, including drawing upon the advice of their clinician, speaking to loved ones and considering their advice and medical treatment experiences and considering their own goals and preferences. Thus, emphasising the truly personal nature of medical treatment decision-making.

Despite older adults being reported to have less involvement in clinical decision-making in comparison to other populations (Schulman-Green et al., 2006) the findings of this review highlighted involvement in three types of decision-making styles including clinician-based decision-making, patient-based decision-making and shared decision-making approaches, which often depended on their personal preferences. However, across the nine papers the influence of HCPs was highlighted, as a ‘need’ to follow physician’s recommendations was described alongside the pull of a HCPs judgement. Pieters et al. (2012) noted that many individuals found their HCPs recommendations helpful as they had trusted their clinician and had experienced positive doctor-patient interactions although for others this may have been influenced by paternalistic views (Angarita et al., 2018). Sinding et al’s (2005) paper highlighted how individuals experienced a sense of obligation to their clinicians counsel and how some older women had to assert their decision to decline treatment, despite believing that this would be in their best interest, which suggested that for some individuals their treatment preferences were not held as equal as their HCPs judgement, as recommended within a shared-decision making approach. This in turn is likely to negatively influence an individual’s health care experiences and their well-being and increase the risk of decisional conflict and the risk of decisional regret (Nicolai et al., 2016). The match between an individual’s preferred decision-making role and their actual decision-making role relating to cancer treatment is reported to be negatively associated with treatment decision regret (Nicolai et al., 2016)

Perception of risk and their wish to minimise risk in relation to cancer spread, cancer re-occurrence, the surgical procedure and future treatments was also highlighted as influencing treatment decision-making. For many individual’s, cancer was associated with death, uncertainty, suffering and leaving loved ones behind. An urgency to receive treatment was therefore evident throughout several studies as some individual’s felt required to make rapid decisions about treatments which had long-term and short-term consequences, despite HCPs encouraging individuals to carefully consider their treatment options (Morgan et al., 2015; Pieters et al., 2012). Themes of taking responsibility were also evident as Ciambrone (2006) and Sinding et al. (2005) spoke of how individuals knew the course of action that they ‘had’ to take to avoid dealing with cancer again which may not be surprising as within the cancer literature fear of spread and re-occurrence is not only reported to influence the decision-making of individuals with cancer it also influences the quality of life and wellbeing of cancer survivors of varying age (Chouliara et al., 2004) as well as older women’s cancer screening behaviour (Schonberg, Ramanan, McCarthy, & Marcantonio, 2006).

Concerns were experienced by older women relating to their body image and changes to this if they were to undergo a medical intervention. Across the studies included in this review, concerns around an individual’s hair thinning, individuals being left with post-operative scaring and individuals being left disfigured were described which in turn influenced older women’s decision-making around whether to receive a mastectomy, lumpectomy, chemotherapy (Cyran, Crane, & Palmer, 2001; Husain et al., 2008; Lifford et al., 2015). Such fears are reported to be the same as those held by younger individuals who have received a diagnosis of cancer, however, studies comparing this fear between older and younger individuals is lacking (Angarita et al., 2018). Moreover, Cyran et al. (2001) noted that older women treated by female physicians were more likely than those treated by male physicians to raise concerns about their appearance, despite recent research suggesting that older women with breast cancer are keen to preserve their body image ideal, irrespective of age and would consider breast reconstruction surgery if this was offered to them (Fenlon et al., 2013). Thus, further demonstrating how an individual’s HCP, whose own judgement may be influenced by ageist stereotypes around older women’s body image, can influence an older woman’s medical decision-making.

The quality assessment of this review identified that many of the eligible studies lacked service-user involvement throughout the development of their design; only two of the reviewed papers demonstrated evidence of service-user involvement. Thus, highlighting a major limitation to seven papers, as UK policy recommends that service-users, including patients, carers and the public should be involved in all publicly funded health and social care research (Smith et al., 2008). Within the literature it is argued that including service-users in research processes can help achieve better quality research, which in turn may lead to better quality health services (Smith et al., 2008). Involving service-users as co-researchers or interviewers has been found to positively influence recruitment, as potential participants often feel less intimidated by the experience which in turn facilitates the exploration of issues and outcomes that are most relevant to service-users (Minogue, Boness, Brown, & Girdlestone, 2005). The lack of service-user involvement identified throughout this review, therefore, not only influences the quality of research studies included in this review, it is also likely to negatively influence the quality of care available for older people. By not consulting with individuals with lived experience, many researchers are likely to have missed valuable opportunities for people with lived experience to share their thoughts and experiences around their decision-making processes, and factors which were paramount to their medical treatment decision-making. This in turn is likely to have prevented an in-depth exploration of issues and factors which are most relevant to service-users and may have resulted in researchers replicating the paternalistic patterns and assumptions described in the literature around older women’s treatment needs, their decision-making preferences and factors which influence their decision-making, particularly as the data collection tools utilised may not have explored the issues of most concern to service-users (Chouliara et al., 2004). Also, as involving individuals with lived experience throughout the research process has been shown to positively influence recruitment and data collection, their lack of involvement throughout many studies may have influenced the number of participants recruited and the information shared by individuals, particularly if individuals recruited felt wary of the research process.

This systematic review also highlighted significant gaps in the literature relating to older women's health care decision-making. The aim of this review was to identify, appraise and synthesise the existing literature to better understand factors which influence older women's decision-making around whether to accept or decline a medical treatment. The reviewers also noted the importance of exploring such phenomenon in relation to a range of medical treatments and in the context of varying health conditions. Despite this, only one paper conducted by Takase-Sanchez et al. (2015) explored decision-making outside the context of older women's cancer treatment which was surprising to the reviewers, particularly as with increased age comes an increased risk of individuals experiencing one or more chronic health conditions and findings from this review highlighted how participants were required to consider the influence of co-morbidities alongside other factors when faced with a decision around whether to receive a medical treatment (Fuller et al., 2016; Office for National Statistics, 2018). It is thought that an increased understanding of factors which influence treatment decision-making for a range of health care conditions will enable clinicians to tailor their treatment discussions and will encourage clinicians to explore the needs and decision-making preferences of older women as well as the influence of factors outside of the condition being treated when individuals are faced with a decision around whether to receive a medical treatment. Thus, positively influencing the care provided by increasing the likelihood of person-centred discussions and care.

Finally, this systematic review highlighted an additional gap in the literature relating to the medical treatment decision-making of older women from BAME populations. Some papers included within this review have made attempts to ensure that their sample was representative. However, only four out of nine papers slightly met this criterion and three papers moderately met this criterion throughout the quality assessment. Moreover, across the six papers which included information relating to participants’ ethnicity participants who self-identified as white or Caucasian represented between 61% and 100% of individuals. Within the literature it is well established that there are ethnic inequalities in health within the UK, and although historically such inequalities later in life have been relatively under researched, it has more recently been shown that after controlling for social and economic disadvantage BAME older people are still more likely than white British to report limiting health and poor self-rated health (Evandrou, Falkingham, Feng, & Vlachantoni, 2016). Thus, as an increased understanding of treatment decision-making has been shown to improve clinical outcomes and patient satisfaction further exploration of medical treatment decision-making of older women from BAME backgrounds is required. Currently, it is unclear whether the decision-making styles and preferences as well as factors which influence the medical treatment decision-making of individuals from BAME backgrounds differs from those of individuals from white or Caucasian backgrounds. However, researchers are beginning to acknowledge that an individual’s cultural background may influence their ability or desire to engage in a shared decision-making process, particularly as certain cultural backgrounds lack a tradition of individuals making autonomous decisions (Elwyn et al., 2012; Hawley & Morris, 2017) and recent literature suggests that people from BAME backgrounds appraise their treatment decision-making less favourably than individuals from white or Caucasian backgrounds (Johnson Polacek, Ramos, & Ferrer, 2007).

Clinical Implications

Within the literature understanding factors which influence an individual's medical treatment decision-making has increased the likelihood of person-centred care, as HCPs are better able to individualise treatment discussions and tailor educational strategies (Angarita et al., 2018). This, in turn, has been found to positively influence an individual's understanding of their treatment, clinical outcomes and patient satisfaction (Angarita et al., 2018). The findings of this review, therefore, have significant clinical implications which could positively influence the care and support available to older women and in turn could enable older women to make more informed decisions around lifesaving and life enhancing treatments which fit in line with their personal values, goals and preferences.

In the past, clinicians may have assumed that older women could not, or perhaps preferred not to, be involved in decisions regarding their health care and treatment (Crooks, 2001) when in fact the findings of this review suggest that some older women are keen to be involved in their treatment decision-making, are happy to be involved in treatment discussions and are able to draw upon various strategies to support their decision-making process. However, it is important to note that the degree to which older women wish to be involved in their treatment decision-making is variable. Thus, clinicians should not make blanket assumptions around their patient's preferences and should not assume that shared decision-making is beneficial for all, as for some individuals imposing a choice may significantly increase anxiety and may lead to decisional conflict (Nicolai et al., 2016).

The findings of this review also demonstrate how age-related health and life circumstances influence older women's decision-making. Co-morbidities, the risk of side-effects and participants perceptions around their health, age, and strength were shown to influence participants decision-making. However, participants also expressed concerns around how their body image, independence, caring responsibilities and quality of life would be affected if they were to undergo a particular treatment, which also played a significant role in their treatment decision-making. When supporting older women, clinicians should therefore ensure that time is taken to discuss and explore the influence of factors associated with the personal and social circumstances of the individual receiving care, as well as their treatment preferences and concerns. In doing this, clinicians are likely to reduce the risk of making paternalistic assumptions around a patient's best interest, factors they believe do not apply to older women, such as body image, or those they feel are most significant to their treatment decision-making, which in turn will increase the likelihood of collaborative decision-making and person centred care.

Strengths, Limitations and Recommendations for Future Research

By identifying, appraising and synthesising the existing literature which explores factors that influence older women's medical treatment decision-making this review brings together previously disparate research in a coherent and rigorous manner. The findings highlight the individuality and personal nature of older women's medical treatment decision-making and provides contradictory evidence against several ageist assumptions described within the literature including those which state that (1) older women could not or preferred not to make decisions regarding their care and treatment; (2) in the context of cancer care women are better off to receive extensive surgery; (3) appearance and body image is insignificant to older women (Crooks, 2001). The review also highlights gaps within the literature relating to the medical treatment decision-making processes and preferences of older women from BAME backgrounds, individuals who have been found to appraise their treatment decision-making less favourably than white and Caucasian individuals (Johnson

Polacek et al., 2007). The reviewers therefore recommend that future research should further explore the treatment decision-making of individuals from BAME backgrounds to establish whether such decision-making differs from individuals from white or Caucasian backgrounds and to address both the gaps identified within the literature and the health inequalities experienced by individuals from BAME backgrounds. Moreover, within the context of breast cancer some of the fears and concerns around the impact of particular treatments described by older women in this review are also experienced by younger women (Angarita et al., 2018). However, despite this studies comparing the impact of such fear and concerns between age groups is lacking (Angarita et al., 2018). Thus, it is recommended that future research addresses this area and further compares the decision-making processes of older and younger women.

It is, however, important to note that this review is not without limitations. Throughout the review a second reviewer (SB) provided support throughout aspects of the article screening process. However, to further increase the reliability of such process the reviewers acknowledge that it would be preferable if the second reviewer were able to screen all articles identified through the systematic search. Additionally, although The QATSDD has previously been assessed in relation to its reliability and validity and had provided valuable information regarding the quality of the nine studies, the tool in fact assesses mixed methodological studies alongside those that only use one method of analysis which results in the overall quality scores of studies with a mixed methodological design being artificially inflated.

Moreover, a major limitation of the review relates to the studies identified. Researchers were only able to access research relating primarily to older women’s cancer treatment decisions, which limits the conclusions that can be made in relation to older women’s medical treatment decision-making more generally. The reviewers therefore recommend that future research should explore older women's treatment decision-making within the context of varying health conditions to further understand the psychosocial phenomena of treatment decision-making and to increase the likelihood of person-centred care, particularly as co-morbidities were one of many factors described by older women as influencing their treatment decision-making. Although, when making such recommendation the reviewers acknowledge that papers, not included within this review, which explore older women's decision-making in relation to mammography screening and their complementary and alternative medicine use, factors which influence advanced care planning and practitioner choices for back pain care as well as those that explore the perspectives of older women who did not attend screening for diabetes (Dahl et al., 2018; Kirby, Broom, Adams, Sibbritt, & Refshauge, 2014; Kwak & Ellis, 2019; Murthy et al., 2017; Schonberg, McCarthy, York, Davis, & Marcantonio, 2007; Schonberg et al., 2006) are also likely to provide important and clinically relevant insights into older women's perspectives around their health, care, and treatment, as well as what is important for them. Future reviews should therefore not only explore and synthesise literature relating to older women's decision-making in relation to medical treatments, as done within this review. The current literature relating to older women's decision-making in other health care contexts as well as their screening behaviour and advanced care planning should be explored and synthesised to further understand the perspectives of older women and improve the health care and support available to this population.

Conclusions

Despite predominantly exploring older women's medical treatment decision-making within the context of cancer care this systematic review highlighted the individuality and personal nature of older women's medical treatment decision-making. Contrary to previous assumptions, the findings suggest that many older women are keen to be involved in their treatment decision-making and are able to draw upon varying strategies to support such process. However, the degree to which an individual wishes to be involved in their treatment decision-making is variable and factors which influence such decision-making vary considerably. It is therefore recommended that clinicians do not make assumptions around older women's treatment preferences and their preferred decision-making style. Instead, clinicians should take time to work with an individual to explore their concerns, values, social and personal circumstances to understand how the interplay between such factors influence treatment decision-making as doing this is likely to improve collaboration, encourage a more person-centred approach and improve patient satisfaction. Moreover, clinicians should take time to provide good and accessible information around the medical treatments available to older women to ensure that individuals are able to provide fully informed consent as treatment decision-making, whether this is patient led, clinician led or shared cannot take place without fully informed consent.

References

Angarita, F. A., Elmi, M., Zhang, Y., & Look Hong, N. J. (2018). Patient-reported factors influencing the treatment decision-making process of older women with non-metastatic breast cancer: a systematic review of qualitative evidence. *Breast Cancer Research and Treatment, 171*(3), 545-564. doi:10.1007/s10549-018-4865-0

Aromataris, E. & Munn, Z. (2019), *Joanna Briggs Reviewer's Manual*: The Joanna Briggs Institute 2019.

Bradley, E., & Green, D. (2018). Involved, inputting or informing: "Shared" decision making in adult mental health care. *Health Expectations, 21*(1), 192-200. doi:10.1111/hex.12601

Chouliara, Z., Miller, M., Kearney, N., Stott, D., Molassiotis, A., & Twelves, C. (2004). Older people with cancer: Perceptions and feelings about information, decision-making and treatment - A pilot study. *European Journal of Oncology Nursing, 8*(3), 257-261. doi:10.1016/j.ejon.2003.12.010

Chung, G. S., Lawrence, R. E., Curlin, F. A., Arora, V., & Meltzer, D. O. (2012). Predictors of hospitalised patients' preferences for physician-directed medical decision-making. *Journal of Medical Ethics, 38*(2), 77. doi:10.1136/jme.2010.040618

Ciambrone, D. (2006). Treatment Decision-Making Among Older Women with Breast Cancer. *Journal of women & aging, 18*(4), 31-47. doi:10.1300/J074v18n04_04

Cohen, M. D. (2017). Engaging patients in understanding and using evidence to inform shared decision making. *Patient Education and Counseling, 100*(1), 2-3. doi:10.1016/j.pec.2016.11.013

Crooks, D. L. (2001). Older women with breast cancer: New understandings through grounded theory research. *Health Care for Women International, 22*(1-2), 99-114. doi:10.1080/073993301300003108

Cyran, E. M., Crane, L. A., & Palmer, L. (2001). Physician Sex and Other Factors Associated With Type of Breast Cancer Surgery in Older Women. *Archives of Surgery, 136*(2), 185-191. doi:10.1001/archsurg.136.2.185

Dahl, M., Lindholt, J., Søgaard, R., Frost, L., Andersen, L. S., & Lorentzen, V. (2018). An interview-based study of nonattendance at screening for cardiovascular diseases and diabetes in older women: Nonattendees' perspectives. *Journal of Clinical Nursing, 27*(5-6), 939-948. doi:10.1111/jocn.14018

Durand, M.-A., Carpenter, L., Dolan, H., Bravo, P., Mann, M., Bunn, F., & Elwyn, G. (2014). Do Interventions Designed to Support Shared Decision-Making Reduce Health Inequalities? A Systematic Review and Meta-Analysis. *PLoS ONE, 9*(4), 1-13. doi:10.1371/journal.pone.0094670

Elliott, J., McNeil, H., Ashbourne, J., Huson, K., Boscart, V., & Stolee, P. (2016). Engaging Older Adults in Health Care Decision-Making: A Realist Synthesis. *The Patient, 9*(5), 383-393. doi:10.1007/s40271-016-0168-x

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., . . . Rollnick, S. (2012). Shared Decision Making: A Model for Clinical Practice. *Journal of general internal medicine, 27*(10), 1361-1367. doi:10.1007/s11606-012-2077-6

Evandrou, M., Falkingham, J., Feng, Z., & Vlachantoni, A. (2016). Ethnic inequalities in limiting health and self-reported health in later life revisited. *Journal of Epidemiology and Community Health, 70*(7), 653-662. doi:10.1136/jech-2015-206074

Fenlon, D., Frankland, J., Foster, C. L., Brooks, C., Coleman, P., Payne, S., . . . Addington-Hall, J. M. (2013). Living into old age with the consequences of breast cancer. *European Journal of Oncology Nursing, 17*(3), 311-316. doi:10.1016/j.ejon.2012.08.004

Fuller, E., Mindell, J., & Prior, G. (2016). *Health Survey for England 2016*. London: NHS Digital

Galotti, K. M. (2002). *Making Decisions That Matter : How People Face Important Life Choices*: Psychology Press.

Hawley, S. T., & Morris, A. M. (2017). Cultural challenges to engaging patients in shared decision making. *Patient Education and Counseling, 100*(1), 18-24. doi:10.1016/j.pec.2016.07.008

Husain, L. S., Collins, K., Reed, M., & Wyld, L. (2008). Choices in cancer treatment: a qualitative study of the older women's (> 70 years) perspective. *Psycho-Oncology, 17*(4), 410-416. doi:10.1002/pon.1242

Johnson Polacek, G. N. L., Ramos, M. C., & Ferrer, R. L. (2007). Breast cancer disparities and decision-making among U.S. women. *Patient Education and Counseling, 65*(2), 158-165. doi:10.1016/j.pec.2006.06.003

Kirby, E. R., Broom, A. F., Adams, J., Sibbritt, D. W., & Refshauge, K. M. (2014). A qualitative study of influences on older women's practitioner choices for back pain care. *BMC health services research, 14*(1), 131-140. doi:10.1186/1472-6963-14-131

Kwak, J., & Ellis, J. L. (2019). Factors related to advance care planning among older African American women: Age, medication, and acute care visits. *Palliative & supportive care*, 1-6. doi:10.1017/S1478951519001007

Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P. A., . . . Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *PLOS Medicine, 6*(7), 1-28. doi:10.1371/journal.pmed.1000100

Lifford, K. J., Witt, J., Burton, M., Collins, K., Caldon, L., Edwards, A., . . . Brain, K. (2015). Understanding older women's decision making and coping in the context of breast cancer treatment. *BMC Medical Informatics & Decision Making, 15*(1), 1-12. doi:10.1186/s12911-015-0167-1

Lizardo, L., Stern, C., Carrier, J., Godfrey, C., Reiger, K., Salmond, S., . . . Loveday, H. (2019). Chaper 8: Mixed methods systematic reviews. In E. Aromataris & Z. Munn (Eds.), *Joanna Briggs Reviewer's Manual*: The Joanna Briggs Institute 2019.

McFall, J. P. (2015). Directions Toward a Meta-Process Model of Decision Making: Cognitive and Behavioral Models of Change. *Behavioral Development Bulletin, 20*(1), 32-44. doi:10.1037/h0101038

Minogue, V., Boness, J., Brown, A., & Girdlestone, J. (2005). The impact of service user involvement in research. *International Journal of Health Care Quality Assurance, 18*(2), 103-112. doi:10.1108/09526860510588133

Morgan, J. L., Burton, M., Collins, K., Lifford, K. J., Robinson, T. G., Cheung, K.-L., . . . Wyld, L. (2015). The balance of clinician and patient input into treatment decision-making in older women with operable breast cancer. *Psycho-oncology, 24*(12), 1761-1766. doi:10.1002/pon.3853

Murthy, V., Adams, J., Broom, A., Kirby, E., Refshauge, K. M., & Sibbritt, D. (2017). The influence of communication and information sources upon decision-making around complementary and alternative medicine use for back pain among Australian women aged 60-65 years. *Health & social care in the community, 25*(1), 114-122. doi:10.1111/hsc.12275

Nicolai, J., Buchholz, A., Seefried, N., Reuter, K., Härter, M., Eich, W., & Bieber, C. (2016). When do cancer patients regret their treatment decision? A path analysis of the influence of clinicians' communication styles and the match of decision-making styles on decision regret. *Patient Education and Counseling, 99*(5), 739-746. doi:10.1016/j.pec.2015.11.019

Office for National Statistics. (2018). *Overview of the UK Population: November 2018*. London: Office for National Statistics

Pieters, H. C., Heilemann, M. V., Maliski, S., Dornig, K., & Mentes, J. (2012). Instrumental Relating and Treatment Decision Making Among Older Women With Early-Stage Breast Cancer. *Oncology Nursing Forum, 39*(1), E10-E19. doi:10.1188/12.ONF.E10-E19

Reed, A. E., Mikels, J. A., & Simon, K. I. (2014). Older Adults Prefer Less Choice Than Young Adults. *Translational Issues in Psychological Science, 1*(S). doi:10.1037/2332-2136.1.S.5

Sandelowski, M., Voils, C. I., & Barroso, J. (2006). Defining and Designing Mixed Research Synthesis Studies. *Research in the Schools, 13*(1), 29-40.

Sandman, L., & Munthe, C. (2010). Shared decision making, paternalism and patient choice. *Health Care Analysis, 18*(1), 60-84. doi:10.1007/s10728-008-0108-6

Schonberg, M. A., McCarthy, E. P., York, M., Davis, R. B., & Marcantonio, E. R. (2007). Factors influencing elderly women's mammography screening decisions: implications for counseling. *BMC geriatrics, 7*(1), 26-33. doi:10.1186/1471-2318-7-26

Schonberg, M. A., Ramanan, R. A., McCarthy, E. P., & Marcantonio, E. R. (2006). Decision Making and Counseling around Mammography Screening for Women Aged 80 or Older. *Journal of general internal medicine, 21*(9), 979-985.

Schonberg, M. A., Birdwell, R. L., Bychkovsky, B. L., Hintz, L., Fein-Zachary, V., Wertheimer, M. D., & Silliman, R. A. (2014). Older women's experience with breast cancer treatment decisions. *Breast Cancer Research and Treatment, 145*(1), 211-223. doi:10.1007/s10549-0142921-y

Schulman-Green, D. J., Naik, A. D., Bradley, E. H., McCorkle, R., & Bogardus, S. T. (2006). Goal setting as a shared decision making strategy among clinicians and their older patients. *Patient Education and Counseling, 63*(1), 145-151. doi:10.1016/j.pec.2005.09.010

Seaman, K. L., Gorlick, M. A., Vekaria, K. M., Hsu, M., Zald, D. H., & Samanez-Larkin, G. R. (2016). Adult Age Differences in Decision Making Across Domains: Increased Discounting of Social and Health-Related Rewards. *Psychology and Aging, 31*(7), 737-746. doi:10.1037/pag0000290

Sinding, C., Wiernikowski, J., & Aronson, J. (2005). Cancer Care From the Perspectives of Older Women. *Oncology Nursing Forum, 32*(6), 1169-1175. doi:10.1188/05.ONF.1169-1175

Sirriyeh, R., Lawton, R., Gardner, P., & Armitage, G. (2012). Reviewing studies with diverse designs: the development and evaluation of a new tool. *Journal of evaluation in clinical practice, 18*(4), 746-752. doi:10.1111/j.1365-2753.2011.01662.x

Smith, E., Ross, F., Donovan, S., Manthorpe, J., Brearley, S., Sitzia, J., & Beresford, P. (2008). Service user involvement in nursing, midwifery and health visiting research: A review of evidence and practice. *International Journal of Nursing Studies, 45*(2), 298-315. doi:10.1016/j.ijnurstu.2006.09.010

Takase-Sanchez, M. M., Brooks, H. M., Hale, D. S., & Heit, M. H. (2015). Obliterative Surgery for the Treatment of Pelvic Organ Prolapse: A Patient Survey on Reasons for Surgery Selection and Postoperative Decision Regret and Satisfaction. *Female pelvic medicine & reconstructive surgery, 21*(6), 325-331. doi:10.1097/SPV.0000000000000198

Thomé, B., Dykes, A.-K., Gunnars, B., & Hallberg, I. R. (2003). The Experiences of Older People Living with Cancer. *Cancer Nursing, 26*(2), 85-96. doi:10.1097/00002820-200304000-00001

Vogel, B. A., Helmes, A. W., & Hasenburg, A. (2008). Concordance between patients' desired and actual decision-making roles in breast cancer care. *Psycho-Oncology, 17*(2), 182-189. doi:10.1002/pon.1215

Chapter Two: Empirical Paper

A Narrative Exploration of the Decision-Making Processes of Women Aged Sixty and Above Who Are Offered Electroconvulsive Therapy (ECT) as a Treatment for Severe Depression.

To be submitted to: Journal of Geriatric Psychiatry and Neurology. Author guidelines can be found in Appendix A.

Older Women's Decision Making in the Context of Medical Treatments

Abstract

This research study explored the personal narratives of seven females who had been offered ECT, after they had turned sixty years of age, in order to obtain an increased understanding of their decision-making processes, and factors which influenced their decision-making around whether to receive the treatment. Data collected through individual interviews was analysed using Narrative Analysis and the findings were synthesised into a grand narrative which is presented across five chapters. The grand narrative highlighted several themes which influenced participants' decision-making at the time they were offered ECT including, the impact of their all-consuming difficulties, desperation, being at the end of the road and hope. The clinical implications of the findings are discussed alongside clinical recommendations, including the use of thorough and robust consent procedures when supporting individuals who have experienced longstanding mental health difficulties. The study's limitations and areas that warrant further exploration are also discussed.

Older Women's Decision Making in the Context of Medical Treatments

Introduction

Electroconvulsive therapy (ECT); a treatment developed in the late 1930's for mental health conditions such as schizophrenia and catatonia, involves passing an electrical current through the brain to induce seizure activity.[1] Since its development, ECT has been described as an effective medical treatment for severe and persistent psychiatric disorders.[2] The Royal College of Psychiatrists holds the position that ECT is a well-established and safe treatment option for depressed individuals who have had an inadequate response to, or tolerability of, anti-depressant medication[3] and in the past has argued that ECT remains the most effective treatment for severe depressive disorder.[4] It is, however, important to note that ECT remains controversial due to unfavourable media portrayals, its history of abuse, increased scrutiny by the legal system and powerful and vocal ECT activists.[5] The literature surrounding ECT is often polarised,[6] with some authors arguing that the treatment causes damage similar to a traumatic brain injury, significantly increases risk of death and that the cost-benefit analysis for ECT is so poor that its use cannot be scientifically justified.[7,8] In contrast to this others have concluded that ECT is significantly more effective than simulated or 'sham' ECT, is probably more effective than drug therapy and remains an important treatment option for the management of severe depression.[9] However, a more recent review exploring the quality of ECT versus 'sham' ECT trials and meta-analyses concluded that the quality of most 'sham' ECT versus ECT studies is so poor that the meta-analyses were wrong to conclude anything about efficacy, either during or beyond the treatment period, and argued that there is no evidence that ECT is effective for its target demographic or its target diagnostic group. [10] The authors of this review have therefore argued that ECT should be suspended immediately until a series of well-designed randomised, placebo-controlled studies have investigated whether there are any significant benefits which the proven significant risks can be weighed. [10] In the United Kingdom (UK) a group of professionals, individuals who have received ECT and carers have also contacted the Secretary of State for Health and Social Care to request an urgent review into the use of ECT, a request which has been supported by MIND, a leading mental health charity within the UK.

Within the UK, The National Institute for Health and Care Excellence (NICE) currently considers ECT in the treatment of depressive illness, schizophrenia, catatonia and mania.[11] In relation to depressive illness, NICE recommends that ECT should be considered for acute treatment of severe depression that is life-threatening and when a rapid response is required but should not be used routinely for people with moderate depression. Instead, NICE advises that in cases of moderate depression, ECT could be considered if an individual’s depression has not responded to multiple pharmacotherapy treatments and psychological treatment,[12] and highlights the increased risks associated with ECT during pregnancy, in older people and in children so therefore, advises clinicians to exercise particular caution when considering ECT in these populations.[11] However, it is important to note that within a multidisciplinary team the decision to give ECT is dependent on many different factors including a clinician's professional identity, how a person understands the evidence base and how much power such clinicians have in the decision-making process.[6] This, in turn, has resulted in individuals experiencing differing decision-making processes around ECT depending on the personal views of the clinicians involved in their care.[6]

Despite NICE guidance advising that caution should be taken when considering ECT as a treatment for older adults, ECT is reported to be widely used in old age psychiatry clinical practice in Australia, The United States of America, New Zealand and the UK.[13] Also, within their writings Burstow[14] and Newnes[15] note that in every country where ECT is administered women consistently receive ECT between two and three times more than men, a ratio which in the past been defended by clinicians arguing that ECT is most commonly administered for depression and women are diagnosed with depression approximately two to three times more than men.[14] Such argument has been supported by historical prevalence figures,[16,17] however, more recent research conducted in Sweden has suggested that the prevalence of depression is similar in men and women across all age groups.[18] Also, women over the age of sixty are shown to account for half of the statistics in relation to the use of ECT, despite evidence suggesting that older women sustain the most damage from the treatment.[15,19]

The ECT Accreditation Service (ECTAS), established to improve standards of practice in ECT services in England, Wales, Northern Ireland and the Republic of Ireland, collects data relating to the use of ECT in order to observe trends over time. Within their most recent minimum data set report ECTAS notes that 1114 individuals who received acute ECT between April 2016 and March 2017 were female, a figure which has remained constant since 2012.[20] Also, within the same time period, 1073 out of 1821 individuals who received acute ECT were over the age of sixty, with the mean age being 61 years and the most common age being 71 years.[20] Thus, although ECTAS did not specifically report data relating to the proportion of women over sixty to receive ECT within their 2016-2017 minimum dataset report, the data available suggests that women over sixty were the largest population to receive both acute and maintenance ECT between April 2016 and March 2017. However, it is important to note that the true figures relating to the use of ECT between such time period are likely to be higher than those listed above as the 2016-2017 minimum dataset report did not include data from 46 out of 117 ECT clinics across the four countries.

Within the literature the use of ECT has been explored extensively; researchers have explored the cognitive side effects of ECT,[21] the subjective experiences of older women who have received ECT,[22] and the decisional capacity of older adults with depression to consent to ECT.[23] Despite this, research exploring the decision-making processes experienced by individuals when they are faced with a decision around whether to receive ECT is sparse.[24]

Similarly, the underlying reasons behind the large difference in ECT use between men and women have largely been neglected.[25]

'Decision-making' relates to the mental activities that occur when an individual is presented with multiple options[26] and is a frequent and essential process in everyday life.[24] Within health care settings, researchers have argued that integrating evidence into care and engaging patients in understanding and using such evidence facilitates an individual's decision-making processes and helps clients to make evidence-based decisions that are aligned with their treatment goals, values and personal preferences.[27] Also, the guiding principles of the Mental Capacity Act,[28] a legal framework designed to protect and empower people who may lack the mental capacity to make their own decisions around their care and treatment, note that (1) an individual should be assumed to have capacity unless it is established that they lack capacity; (2) a person should not be treated as unable to make a decision unless all practicable steps to help them to do so have been taken; (3) an individual should not be treated as unable to make a decision merely because they make an unwise decision, which in turn brings what could be understood as good clinical practice into the law. However, it is important to note that ECT holds a difficult position in being the only mental health treatment covered by both the Mental Capacity Act[28] and the Mental Health Act.[29]

Within mental health services, shared decision-making, where an individual and their care team work collaboratively, share information and discuss treatment options to reach a joint decision about an individual's treatment, is viewed as an ethical model of health communication which recognises the skills and experiences offered by all participants involved in making health care decisions and positively influences health outcomes.[30] However despite this, the current evidence base predominately explores decision-making and decision-making processes for the treatment of medical or physical health conditions;

literature relating to an individual's decision-making in relation to the treatment of mental health conditions is lacking and therefore warrants further exploration as mental health conditions, along with evidence based treatments for these conditions, differ considerably to physical health conditions. [24] In relation to ECT, only one study conducted in The United States of America has explored the experience and decision-making processes of older adults.[24] Two studies conducted in Australia have explored the experiences of individuals', of varying age,[31] and the specific experiences of women[25] who have received ECT in order to better understand what helped or hindered their decision-making process and what could be done to improve such process.

Due to the disproportionate number of women over sixty receiving ECT in the United Kingdom and because the decision-making processes of this population are yet to be explored, this study aimed to gather and analyse the personal narratives of women aged sixty and above who have been offered ECT in order to obtain a greater understanding of their decision-making processes and factors which influenced their decision-making around whether to receive the treatment. An increased understanding of factors which influence medical treatment decision-making has been shown to facilitate more personalised treatment discussions between health care professionals and service-users, reduces the risk of misinformation and can enable clinicians to tailor educational strategies which in physical health settings has improved patient satisfaction and clinical outcomes.[32] From an economic perspective shared-decision making has also been associated with reduced hospitalisation and increased adherence to medication which may in turn positively influence care costs. [27,30] It is therefore thought that the findings from this study will help support the planning of future clinical practice and improve the support available to older women, when they are faced with a decision around whether to receive ECT as in the past the strong and often polarised views around ECT are likely to inhibit open discussions around the treatment, which in turn may influence an individual’s ability to make the best-informed treatment decisions.[31]

Method

Throughout this study a qualitative design which adopted a narrative approach was utilised to explore the experiences of women who had been offered ECT after they had turned sixty years of age. Such approach was considered to be the most appropriate approach to achieve the study’s aims as it allows an in-depth exploration of an individual’s experiences and enabled the researcher to explore each participant’s personal narrative, as influenced by any personal, ethical, social or political issues that the research may bring.[33]

Participant Characteristics

Women, who were residing in England and had made a decision around whether to receive ECT as a treatment for severe depression since becoming sixty years of age, irrespective of whether they opted to receive or decline the treatment, were invited to participate in this research project. In total seven individuals, all of whom had opted to receive ECT since becoming sixty years of age, participated in this study. Further information relating to participant characteristics and their demographics were not collected throughout this study in order to further protect participant anonymity. It was felt that this was particularly important as participants were predominantly recruited from one NHS Foundation Trust.

Procedure

The study was advertised across multiple sites within one NHS Foundation Trust in the North West of England, as well as via third sector organisations and social media. Clinical staff, who worked across the NHS recruitment Trust, approached individuals who met the study’s inclusion criteria and provided them with information about the study and also advised whether it would be appropriate for the researcher to contact potential participants. Depending on the potential participants preference, individuals were then either encouraged to contact the researcher if they wished to participate or, with permission, their contact details were shared with the researcher in order to allow the researcher to provide more information about the study.

Table 1. Potential Participants Identified from the NHS Recruitment Trust

Potential Participants Identified	**N**
Individuals identified from the NHS recruitment Trust who met the research study’s inclusion criteria	43
Individuals who were contacted in relation to the research by either clinicians working within the NHS recruitment Trust or the researcher	18
Individuals who, when contacted, advised that they did not wish to participate in the research	12
Individuals who, when contacted, were interested in participating in the research	6

Table 1 highlights the proportion of potential participants identified from the NHS recruitment Trust and those contacted in relation to the study by either the researcher or clinicians working within the NHS recruitment Trust. Not all potential participants identified from the NHS recruitment Trust were contacted, because for some the lead clinician involved in their care felt participating in research would be too demanding due to their current physical, psychological or personal circumstances. Of the eighteen potential participants contacted, twelve were not interested in participating in the research and provided reasons for this. Such reasons included personal circumstances such as the individual experiencing difficulties with their mood or them having caring responsibilities. Whereas, other individuals explained that they “could not really remember anything” from that time in their life, had “found ECT frightening” and did not wish to speak more about their experiences, and believed they “didn’t really have a choice” so felt they couldn’t comment on decision-making.

The six potential participants who, when approached, advised that they were interested in participating in the research either contacted the researcher by telephone or email or, if the researcher was advised by the potential participant’s clinician, were contacted by the researcher in order to confirm eligibility, to establish the best way for the researcher to provide potential participants with the study’s participant information sheet (Appendix C) and to answer any questions relating to the research.

Table 2. Potential Participants who Contacted the Researcher Directly

Potential Participants who Contacted the Researcher Directly	**N**
Individuals who also contacted the researcher in relation to the study	6
Individuals who were ineligible to participate in the research	5
Individuals who were eligible to participate in the research	1

Also, in addition to the potential participants identified through the NHS recruitment Trust, six individuals, who had seen the study advertised via social media and through third sector organisations, contacted the researcher directly, either by telephone or email, to discuss their interest in the study. Following a telephone call with each of these individuals, the researcher confirmed that five individuals were ineligible to take part but thanked them for their interest. One individual who contacted the researcher directly was eligible to participate, in line with the study's inclusion criteria. Table 2 highlights the proportion of people who contacted the researcher directly to discuss their interest in the study.

In total, seven research interviews were arranged and were conducted in person. The researcher travelled either to the participant's home or a place of their choice which would maintain their security and confidentiality. Before conducting each interview, the researcher obtained written informed consent from each participant, through using the study's consent form (Appendix D). Also, throughout each interview the researcher utilised an interview guide (Appendix E) which began with an open question in order to increase the likelihood of participants describing their experiences and sharing their personal narrative. However, clarifying questions and additional prompts were also used throughout the interview to encourage expansion. When considering the target population for this research, the researchers believed that the use of clarifying questions and additional prompts within each research interview would be particularly important as cognitive impairment, in the form of persistent and significant memory dysfunction, has been shown to be related to ECT.[8] All interviews were audio recorded and later transcribed verbatim.

Following the research interview, participants were provided with a debrief form (Appendix F) and an opportunity to ask questions about the research. A summary letter, which aimed to capture the key events, experiences, people and places detailed within participants' personal narrative as well as their significance to the participant at the time they were offered ECT, was also sent to six out of seven participants following their research interview in order to increase the trustworthiness of the data. Unfortunately, it was not possible to share a written summary letter with one participant as she was experiencing difficulties with her physical health. All six participants, who received a summary letter provided feedback in relation to this, either by letter, email or telephone. Within their feedback, most participants advised that the summary letters captured their experiences well. Several individuals also recalled further detail around their experiences and concerns at the time they were offered ECT, as well their experience of other treatments for depression. This information was used by the researcher, alongside participant's transcripts and their summary letters, to support the data analysis process and to support the development of the grand narrative.

Reflexivity Statement

All qualitative research is contextual and occurs within a particular time and place between two or more people.[34] The actions of the researcher or those hearing an individual's narrative are, therefore, argued to be as central to the narrative as the narrator themselves, as the researcher is considered to be a co-creator of meaning.[35] With this in mind, it is important for narrative researchers to consider their personal, professional and epistemological positioning and the impact that this may have on the research. When completing this research, the primary researcher, and the individual completing each research interview was employed by the National Health Service (NHS) as a Trainee Clinical Psychologist. Such positioning in the NHS may have influenced the narratives described by participants. Also, in the past, the primary researcher had also volunteered in a country whose cultural understanding of mental health and distress was significantly different to her own. Whilst in such country the researcher observed the frequent use of ECT and was provided with an opportunity to observe the treatment. This experience had resulted in the researcher holding a negative view of ECT, a view which had been perpetuated as the researcher had been exposed to highly critical narratives around the use of ECT throughout her career and professional training in clinical psychology, and this in turn increased the risk of bias.

To reduce the risk of bias several steps were taken by the researcher, in line with credibility guidelines developed for qualitative research studies in psychology and other related fields.[36] Such steps included (1) the researcher being aware of her own perspective and how this may influence her interpretation of the research data; (2) the researcher using participant quotes throughout the results section in order to highlight specific examples of each theme; (3) the researcher using several methods to in order to check the credibility of the themes identified, such as the researcher obtaining feedback from participants in relation to their individual summary letters, and the researcher discussing such themes during frequent meetings with her research supervisors, one of whom met the inclusion criteria for this research project; (4) the researcher presenting the key themes identified within the data across several chapters to ensure that the research findings are presented in a concise and coherent manner. To increase the researcher’s awareness of her own perspective and how this may influence her interpretation of the research data a reflective diary was used.

Service User Consultation

Throughout this research, one of the three research supervisors was a woman who had been offered ECT after she had turned 60 years of age and therefore met the study’s inclusion criteria. This shaped the research in a range of ways as the researcher was able to gain a greater understanding of the experiences of someone who had lived experience of the phenomena of interest. Along with their supervisors, the researcher was therefore able to adapt the interview guide utilised throughout the research interview to ensure that they adequately explored areas and factors which held significance to the individual with lived experience. The researcher also adapted the recruitment poster used throughout the study (Appendix I) to ensure that this caught the attention of potential participants, whilst reducing the risk of the content being intimidating for viewers, after considering the individual with lived experience’s feedback. Additionally, the supervisor with lived experience was involved with a range of service user and survivor networks and generously made links with these networks to advertise the study which, in turn facilitated the recruitment process. Moreover, as described in the reflexivity statement, the researcher attended frequent meetings with all of their research supervisors, including the individual who had lived experience of the topic of interest. During these meetings the researcher frequently discussed the themes identified throughout the data analysis process in order to reduce the risk of bias and to check the credibility of their research findings.

Ethical Considerations

Ethical approval for this study was granted by an NHS Research Ethics Committee in the North West of England, the Health Research Authority (HRA) in England and Health and Care Research Wales (HCRW) in September 2019. Evidence of this approval can be found in Appendix G. Prior to taking part, all participants were provided with the study's information sheet (Appendix C) which highlighted the aims of the study, what taking part would involve, how participant data would be used and stored, any risks associated with taking part including, the risk of emotional distress and the risk of participant's narratives being identified as direct quotes would be used within the write up and, the participants right to withdraw from the study. To maintain participant anonymity, all identifying information was removed at the point of transcription and all participants were provided with pseudonyms. Upon reading the participant information sheet, all participants provided written informed consent. Also, due to the risk of participants experiencing emotional distress through their participation in this research, the researcher followed a distress protocol (Appendix H) throughout participant interviews. This highlighted an appropriate course of action for the researcher to take, should a participant experience distress through their involvement in this study.

Data Analysis

To obtain a rich understanding of participant experiences and other factors which influenced the decision-making processes experienced by individuals at the time participants were offered ECT a narrative approach to analysis was utilised by the researcher. Narrative analysis (NA), a qualitative approach dependent on the ideas developed in narrative psychology, refers to many different styles of work.[37] There is, therefore, no one way to conduct NA or no definitive framework to follow[35,38] However, ultimately the methodology relates to the exploration of a person's own narrative as influenced by any personal, cultural, ethical, social or political issues that the research can bring.[33]

This research was guided by several narrative methods and frameworks including those described by Crossley[38], Reissman[35] and Weatherhead.[33] Initially each interview was listened to and transcribed verbatim. The transcript was then read several times to familiarise the researcher with the data.[38] Once familiarised, the researcher then explored each transcript; Narrative tone, characters and key themes were noted[38] as well as the order in which participants discussed and described each of the key themes in order to explore both the structure and the content of participant's personal narratives. NVivo 12 software was utilised by the researcher to support this process. Summary letters were then written for each participant in order to highlight key events, experiences, people, places and their significance to the participant at the time they were offered ECT. Participants provided feedback on these summary letters, any requested changes or additional reflections, were included in the final version of these letters to ensure the analysis captured their experiences and the significance of these.

Once participants had provided feedback on the summary letters, the researcher examined each transcript for shared themes, characters, experiences and narratives. Commonalities across the transcripts were amalgamated and synthesised to develop a grand narrative or what Howitt describes as a coherent story,[37] which was described by participants across the seven interviews. This approach has the potential to shift away from the larger pedagogic and emancipatory aims of qualitative research, if not done sensitively[39]. However, as there were many similarities across participant narratives it was felt that a grand narrative approach would enable the researcher to present the extensive data gathered through individual interviews in a concise and coherent manner. To reduce the risk of losing the uniqueness of each participant's narratives and key elements of their experience the grand narrative developed was compared against each participant's summary letter and their feedback. Also, to further increase the trustworthiness, reflexivity and rigour in the analytical process, supervisors remained involved in the analytic process and provided feedback on participant summary letters and throughout the development of the grand narrative. The researcher also maintained a full paper trail and compared coding with her research supervisors to further increase the rigour of the study.[40]

Findings

The findings outlined below represent the grand narrative which emerged through the seven interviews, the participant summary letters, and the feedback provided by participants. The grand narrative is organised into five chapters with chapters one and two exploring the difficulties experienced by participants prior to them being offered ECT and the alternative treatments tried. Chapters three and four explore participants thoughts and feelings when they were offered ECT as well as their experiences when they received the treatment. Finally, chapter five describes participants reflections after receiving the treatment.

Chapter One- Difficulties experienced prior to being offered ECT, "people say it's a black hole and it really was black"

Within this chapter, the difficulties experienced by participants prior to being offered ECT were explored. Across the seven narratives, participants described themselves as experiencing longstanding or chronic difficulties with depression prior to them being offered ECT, which for some individuals *"peaked and troughed, but didn't really go away* *completely"* (June) and had left individuals feeling *"really poorly"* (Kay) and *"absolutely dreadful in myself"* (Tania). One participant described herself as *"going around seriously ill for two years"* (Nancy). Participants used imagery and metaphors and described their experience of depression as being like *"a big black hole"* (Nancy) and *"looking through the world through dark glasses"* (June). Whereas, others described how their experiences had impacted their life. Tania described that time in her life as a "*dreadful, dreadful time"* and explained *"my life wasn't functioning right at all, no interests, couldn't do anything".* Similarly, when speaking of her experience of depression Ruth said *"It's a weird thing, that you just can't… you can't visualise getting through a day, you can't be bothered with anything, you don't want to eat, you just wander around the village, just wander aimlessly around [like a] lost soul".*

As participants described the impact of their difficulties on themselves and others, themes of loss and burden became evident across the narratives as *"the world is just not the same place. It's a horrible [place]"* (June) and others were *"bearing the brunt of it"* (Kathryn).

"It affected all sorts of things, you know, family, friendships. I suppose I felt worthless and I didn't want to make other people depressed either, so I felt I didn't want to speak to other people or see them. I wasn't very good company, so I didn't want to inflict it on anyone else" (Kay).

Participants held different understandings of factors which had influenced their difficulties. Across the seven narratives participants described the potential influence of circumstantial factors.

"I know I'm usually in pain, that's usually the start of it and I start getting a lot of nightmares at night and they're very bloody in their [nature]" (Celia).

However, the notion of chemicals in the brain and genetic factors contributing to participants' difficulties were also evident within participants' understanding of their difficulties.

"But in your brain, it's a chemical imbalance. It's the clinical depression or a circumstantial depression. They said mine was clinical, people [and] circumstances hadn't changed"
"Other people get the circumstantial depression, bereavement or loneliness, but mine wasn't like that" (June).

"See I don't know whether it is hereditary, depression, because my father suffered from depression lots and I don't know whether that came down to me or it was totally different circumstances that gave me depression. I've no idea" (Kathryn).

Chapter Two- *Experience of other treatments, "Before you know where you are, you're taking a cocktail full of stuff"*

Throughout their narratives, participants spoke of their experience of mental health treatments prior to them being offered ECT and several individuals understood or believed that ECT was not offered as a first response *"It's down the line, if you know what I mean. If things aren't progressing or working"* (June). Tania explained that *"you have to wait for the right time to be offered it"*. However, Celia spoke with frustration around her consultant's willingness to offer ECT and believed that because her consultant leaves ECT as a last resort, it has in the past resulted in her requiring a more intensive course of treatment. Celia explained that her consultant *"does not listen to the wishes of his patient".*

Consistently across the narratives, participants described their experience of pharmacotherapy and explained that either their psychiatrist or general practitioner (GP) *"had tried all sorts of different medications and combinations of medications, but nothing* *seemed to help"* (Kay). Ruth spoke with frustration and concern when she said *"I mean I'd been on so many drugs. I've got stuff to make me go to sleep, and they're not working. The sleeping tablets didn't work at all. I still wasn't sleeping, up and down all night long and these antidepressants… They certainly weren't anti-depressing me, I was just as bad as ever. Then I was putting all these things down my neck and I was well aware [of] what I was putting down my neck".* Also, participants spoke of their medication being changed which *"meant kind of starting again from scratch, getting those funny feelings in your head that you can get until your body gets used to them"* (June) and going through *"this wean off period, a start-up period [whilst] all the time you're full of hope."* (Ruth).

Participants described varying experiences of psychiatric support, with some individuals describing positive experiences, *"It helped so much that people were listening to me. See before, people weren't listening to what I was saying. Know what I mean?"* (Nancy). Whereas, others described having time limited appointments with their psychiatrist, an individual that would change frequently from appointment to appointment. June, in particular, spoke with disappointment about her clinician frequently changing and explained that the psychiatrist *"didn't even know you as a person. It's such a personal illness really, you know"* and wondered whether there was a shortage of psychiatrists or her experience was influenced by the way the government funded mental health services.

In addition to psychiatric support, participants described varying experiences of other mental health treatments prior to being offered ECT. Three individuals explained that they had not been offered any other treatments, such as psychological therapy prior to being offered ECT. Kathryn explained "*there's not anything particular that I do or feel that I feel talking therapies would get me over."* Whereas, Nancy and Kay had both engaged in psychological therapies after receiving ECT and Kay had wondered *"Maybe if I'd had more* *help-talking therapies, years ago, but it wasn't nearly as common then, that would have helped, and maybe I wouldn't have needed ECT. But it just wasn't around".*

In contrast, all other participants described engaging in a range of therapeutic interventions prior to being offered ECT, including group interventions and one to one therapy. Since her 40's Tania, explained that she had seen a range of professionals and when discussing this reflected *"Did I see those many people? Yes, yes I did because somehow I couldn't get out of this place".* Similarly, Celia explained that in the past she had "*done so many different therapies"* and Ruth advised that she had attended psychological therapies, had paid privately to receive ECT and Transcranial Magnetic Stimulation (TMS) and had engaged in hypnotherapy, she said that *"this whole thing cost me a fortune".*

Chapter Three- Thoughts and feelings when offered ECT, "If I don't do this, I'm at the end of the road"

Within this chapter, participants described their experiences at the time that they were offered ECT, factors which had influenced these thoughts and feelings, people who were available to provide them with support and what it was like for them to make a decision around whether to receive ECT. Common themes across participant narratives included feelings of desperation and being at the end of the road, not knowing what to do, taking responsibility, hope and trust. June described how she felt towards the depression and explained *"I just wanted it to kind of stop, you know, to be finished and feeling well".* However, participants reported mixed feelings when they were initially offered the treatment. Kathryn explained *"I was going to have it before I had it and I said that they would fry my brains and I wouldn't have it.* Similarly, Kay described initial feelings of reluctance but explained *"although I had said I wouldn't have ECT again, it got to the point, you know, I* *was quite desperate really to have some help because the medication just wasn't doing anything".* Kay also noted *"when the subject of ECT came up-I was reluctant, but I thought that was all there was left to do; and you get to the point when you feel that staff will give up on you if you don't anyway. So, it seemed the option really".* Whereas, Tania felt glad to be offered ECT but *"hoped that erm which sounds awful, but I hoped that I would die on the bed and then it would have been taken out of any-body's hands"*

Participants described being encouraged to speak to family members and friends at the point they were offered ECT. Nancy recalled that the psychiatrist supporting her had said "*what we're going to have to do, you're so badly depressed and all that happened we think we've got to give you ECT. So, have a word with your family, or they can come and see us, you know, and they can see what's going on, or we'll explain everything. It was all very good"*. Overall, participants spoke positively about the support provided by family members throughout the decision-making process and many recalled their family members being 'for ECT' or encouraging them to receive the treatment *"Oh, they were all very supportive. Yes, and it was my decision, ultimately, but they all… there was my two children and my husband. Yes, they were wanting to support me. It did seem the best thing to do"* (Kay).
Moreover, several participants described how they trusted and valued their husband's opinion so were appreciative of their husband's support throughout the decision-making process *"I sort of trust [Husband's name]'s judgement. I always have because he's not a panicker, he's level-headed, sort of thing. So, I thought he's going to be supportive and if he thinks it's going to help. He'll be with me… He'll stand by me"* (June).

However, some participants described differing views across family members and friends who have supported them in the past. Celia, in particular, explained that her sibling had been against her receiving ECT in the past and described how she had managed this more recently.

"My family don't know that I go for it [ECT] now, because they thought it was too degrading, me being in hospital and the forgetfulness. So they don't know the last twice I've had the outpatient one [course of ECT]. It's only my friend and my partner that knows"

Participants had varying knowledge of ECT at the point they were most recently offered the treatment and one strategy used by some individuals was to draw upon their previous experiences. Kay explained that she had first received ECT when she was coming up for thirty "*I was an inpatient then, which was quite different anyway, and the way people were treated was very bad actually. No compassion, it seemed to me. Just treated like cattle, yes. And coming around afterwards, you feel really groggy and not really any support around, as I recall".* Whereas, Nancy recalled the conversations she had held with other people and the information she had seen in the media around ECT *"People were so against [ECT] at the time, do you know what I mean? It was in the papers and everything, you know what I mean. Said you shouldn't treat people…[in that way]"* . She explained that this knowledge had increased her feelings of anxiety prior to her receiving her first few treatments.

Participants also described receiving varying information around ECT, from the psychiatrist who had offered them the treatment and the service supporting them with some individuals being advised of both the benefits and risks associated with the treatment and others being advised that ECT would only affect an individual's memory on a short-term basis.

"I don't remember anyone talking to me about the good things about ECT, alright, but I do remember them saying it would only affect your memory when you have it, short term. Yes, like not remembering what was happening over the treatment". (Kathryn)

Kay described receiving written information around ECT and explained "*we were able to go home and talk about it as a family, read about it, and discuss it, and come to a decision. So, it was completely different [than the first time]".*

Kay described what it was like for her to weigh up her experiences, the information provided and what she knew of ECT.

"There was quite a lot of negativity about it; some staff didn't want to take part in this treatment and didn't agree with it at all. So, it's a lot to take on board and to mull over when you know some staff don't want to do it. I don't know now how much controversy there is about ECT nowadays. I know they don't offer it nearly as often. Well I know I read at the time, earlier on. I've read that people had different views about it, and if the staff can't agree, you think… "How can you know really?" But as I've said, I was desperate really. So, that was the decision I made"

In contrast to this, Ruth advised that her decision to receive ECT *"didn't take much deciding"* despite knowing that it is such an extreme treatment. Ruth reported that at that time in her life she was in such a state and *"just wanted that feeling of being at peace with myself and what I was doing".* She explained that *"nothing else had worked and at least after trying ECT, I knew[that] I had tried everything".* A sense of taking responsibility for one's own health was also evident throughout Tania's narrative, who when faced with the decision had thought *"I don't know anything else. You know to not try it, at least if I've tried it erm.. I kind of can see if it helps me".* However, June described how throughout this process she had leaned on her husband and thought *"I don't know if I'd have done it without [husband] quite honestly, or I would have been more nervous anyway."* She explained *"he was very good. I felt [through trying ECT] there was hope for both of us really. I knew [husband's name]* *would be there for me because he's the kind of person who would be there for people as it's his nature."*

Chapter Four- *Experiences when receiving ECT, "the staff really were marvellous and had made me feel safe"*

Throughout their narratives, participants discussed their experiences when receiving ECT and spoke about the support they received from clinicians, their thoughts and feelings when they received the treatment and how they experienced ECT. Participants described initial feelings of nervousness and anxiety prior to receiving the treatment

"I had to be wheeled down and go into this room and you had to have things on your head so…until you went out it was done… right up until the last minutes you're awake. Do you know what I mean? I think that made me more nervous than anything. Know what I mean?" (Nancy)

However, participants described the support provided by clinicians as helpful and reassuring. "*they [the ECT clinicians] were nice and they explained everything they were doing, and they sort of put the needle in and the nurse was holding my hand and it does make a difference. It really makes a difference. I didn't feel I had to put on a show, that erm I'm tough. I said this is how I feel, how I truly feel and I'm desperate. And umm it takes a lot to say that, you know. But it's best to"* (Tania).

Kay compared her most recent experience of ECT, to when she had first received the treatment and explained *"it was a completely different experience. I mean it's not pleasant but it's much better; everyone was treated individually and helped and supported. So, it was very different"*

Participants described how they had found ECT and whether this had influenced their mood. All but one participant described ECT as helpful. Nancy explained that *"it lifts your mood, slowly, but very surely. You know what I mean. It wasn't an overnight success. It was very, very slow".* Similarly, Celia explained that after receiving ECT *"I start to plan more positively and think of the future".* She also noted that the nightmares she experiences start to reduce and *"I can put the suicidal thoughts into a box, rather than have them in my head all the time".* However, in contrast to this June had declined her final scheduled ECT treatment.

" I had 16, well they booked 16 in, which actually is quite a lot. I can remember being upset and they said you'd only got one more to go and I said I've had enough; I'm not having anymore. I can remember feeling down because I don't think I did feel any better…I just remember being upset. I just felt like I'd had enough, tired of it, going every week."

June also described feeling under pressure and out of control at the time she declined her final ECT treatment.

"*I can remember them saying oh come on, you'll have to have the…this could be the one….and [my husband] was saying this could be the one that's a turning point. Why come this far and not have the last one? And the psychiatrists saying…the more they went on, the more I went against it. So I didn't have the last one because I don't think out of 16 one would have made a difference." "It was like bullying in a way, not bullying. I felt like it was a pressure and I didn't want it and I sort of dug my heels in I think." " I just felt I'd had enough. I was scared to be honest. If I'm truthful. I felt frightened of what was happening to me. And the feeling of being out of control is horrible as if you can't control, they'd be controlling me and this thing was controlling me to a certain degree."*

Chapter 5- Experiences and reflections following ECT, "I'm on the road to recovery here, through my own perseverance"

Throughout their narratives, participants shared their experiences, as well as their thoughts and feelings around ECT after receiving the treatment. Participants also reflected on their experience of mental health care. Consistent across several narratives was the experience of memory difficulties following ECT. Celia explained that she experienced significant memory difficulties *"for the time before I start it [ECT], as well as about 6 months after"* and explained that *"it's the price you pay for it, really and that's the only price I pay for it, is the memory [difficulties]."* Similarly, Tania explained that following ECT she believed that her memory had worsened. However, she thought it was *"best to have lost a bit of memory and be here to see friends, family".* In contrast, Kathryn described experiencing much more significant memory impairments following ECT, which were highlighted throughout the interview. Kathryn explained *"It's the funny things that have gone, you know, things I should remember but I don't remember. Erm, I just put up with it now.* However, Kathryn described this as *"not as natural"* and a problem, particularly due to her family circumstances.

When sharing their thoughts on ECT after receiving the treatment, participants described different views. June said disappointedly "*I thought it [ECT] was going to make me better, but then it just wasn't. I wouldn't want it again, put it that way. It's not because of anything painful, because you're asleep. I don't really like hospitals to be truthful. I don't like being away from home, unless I'm going somewhere I want to go"* and wondered about the long-term consequences of receiving ECT. However, Tania believed that ECT had been helpful to her and explained *"If anybody ever asked me what I knew [about ECT], what I think about it, I would say well if you're really at what I call the end of the road and you're going to tip away then erm… I would say give it a try".* When she opted to receive ECT, Tania described herself as *"definitely, at the end of the road".* Moreover, Ruth described herself as *"on the road to recovery here through my own perseverance"* following ECT. However, she explained that she was cross about the psychiatric care that she had received as her community psychiatrist *"could not make a decision around ECT"* and whilst staying in an informal inpatient facility a psychiatrist had informed her that she *"did not have depression"* so therefore would not be considered for ECT. Ruth reported that she had paid a considerable sum of money to receive ECT on a private basis, something she was entitled to on the NHS, and therefore described feeling let down and annoyed as "*I've, had no kids, no maternity benefit"* and had had a very long working career.

Two participants reflected on their experience of trying different treatments prior to ECT. Kay wondered *"Maybe if I'd had more help, talking therapies, years ago, but it wasn't nearly as common then, that would have helped, and maybe I wouldn't have needed ECT. But it just wasn't around".* Whereas, Celia believed *"they delay giving me the ECT, [when] I would have benefitted from it earlier"* and noted *"If only I'd had the opportunity to have it earlier, then I think 6 to 8 sessions may well have been enough and I think the memory loss and that wouldn't have been as bad….That's only because I know me, do you know what I mean? And I know what's worked in the past I think".* Finally, Kay reflected on the information she had received around ECT, the second time she had received the treatment and although she was grateful to receive this *"it would have been much nicer to be able to talk to someone who had had the treatment, or someone else, a member of staff telling you a bit more about it, rather than the consultant who was saying "would you like to have this or not?". To talk to someone a bit more about it and the actual physical sort of way it worked".* Overall, Kay reported that her most recent experience of ECT *"was so much better than the previous occasion, so I didn't think too much about it. But latterly, I think it could have been much better, with hindsight".*

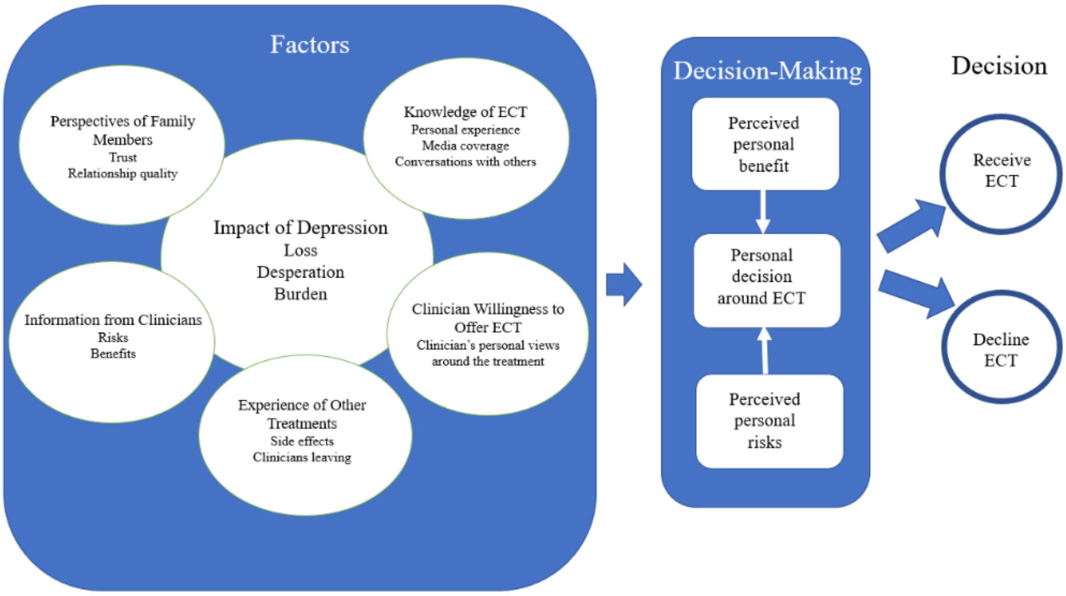
Discussion

This research explored the personal narratives of seven women who were offered ECT after they had turned sixty years of age, in order to obtain a greater understanding of their decision-making process and factors which influenced their decision to receive the treatment. Prior to this investigation, the evidence base predominantly explored decision-making and decision-making processes in the context of medical or physical health conditions.[24] Literature relating to an individual's decision-making in relation to the treatment of mental health conditions, and research specifically exploring the decision-making processes experienced by individuals when they are offered ECT, was sparse and therefore warranted further exploration as mental health conditions, along with evidence based treatments for these conditions, differ considerably to physical health conditions.[24]

A range of commonalities were identified throughout the seven participants' narratives. These were therefore amalgamated to develop a grand narrative which consists of five distinct chapters and details the difficulties experienced by participants prior to them being offered ECT, their experience of other treatments, participant's thoughts and feelings at the time they were offered ECT, their experiences when receiving the treatment and their reflections. The grand narrative also demonstrates the range of factors which influence older women's decision-making around ECT; including their experience of different mental health treatments, personal knowledge and experience of ECT, information provided by clinicians, perspectives of family and friends, and the quality of older women's relationships with those individuals. However, the impact of their difficulties with depression alongside feelings of desperation and their desire to "get rid" of distress, appeared to be the most influential. This was emphasised by several themes including a sense of being at the end of the road and participants taking responsibility for their health and well-being. The decision-making processes experienced by older women when faced with a decision around whether to receive

ECT is highly individualised and personal. However, further information regarding this process, as well as factors which influenced participants decision-making is outlined within Figure 1.

Figure 1: A model highlighting the decision-making processes experienced by participants when faced with a decision around whether to receive ECT, adapted from the model developed by Angarita and colleagues.[32]



Prior to being offered ECT participants described themselves as experiencing longstanding and all-consuming difficulties with depression and had used powerful imagery and metaphors to describe how such difficulties were like being in a "big black hole". Participants also described how their difficulties had impacted both themselves and others, as at that time in their lives participants interests and functioning were significantly affected which, in turn, resulted in participants relying on others for support and loved ones "bearing the brunt" of participant difficulties or being required to make "sacrifices". Thus, highlighting themes of loss and burden. Moreover, participants spoke of varying experiences of mental health treatments prior to them being offered ECT with participants consistently describing their experience of pharmacology but describing varying experiences of psychiatric care, psychological therapy and accessibility to such support. One participant in particular described herself as frustrated and cross about the mental health care she had received and had in fact paid privately to receive ECT, TMS and hypnotherapy, which had significant financial implications. Also, across several of their narrative's participants spoke of how they were required to hold onto hope whilst trying different medications and trying to 'get rid of their depression'.

In line with NICE guidance, which advises that ECT should not be used routinely for people with moderate depression and instead clinicians should consider the treatment if an individual's depression had not responded to multiple drug or psychological treatments,[12] several participants understood that ECT was not offered as a first response and that individuals "have to wait for the right time to be offered it". Two participants spoke with frustration in relation to their clinician's willingness to offer the treatment. One individual believed that in the past she has required a more intensive course of ECT because her consultant leaves this as a last resort and the other individual described herself as having to fight for her health and well-being because her clinician could not make a decision around the ECT. These experiences provide support for the findings made by Duxbury and colleagues[6] who noted that individuals are likely to experience differing decision-making processes around ECT, depending on the personal perspectives of clinicians involved in their care and the power such individuals hold within an MDT. However, despite such experiences, the paternalistic view of the 'doctor knows best' was present throughout several participants narratives as individuals described how they cannot argue with professionals and how the professionals "know what they are talking about", views which have been linked to individuals engaging in clinician-driven decision-making styles and individuals taking a more passive role in their treatment decision making.[41]

Common themes across participant narratives when they described their experiences at the point they were offered ECT included feelings of desperation, being at the end of the road, not knowing what to do, taking responsibility hope and trust. Participants spoke of their desire to get rid of the depression and to be feeling well again. However, they reported mixed feelings when they were initially offered ECT, with some individuals feeling reluctant and others feeling glad. Participants recalled being encouraged to speak to their family and friends about their treatment options and many individuals spoke positively of the support and advice provided by their family and friends. In particular, several individuals spoke of how they had trusted their husband's judgement and associated this trust with aspects of their husband's personality, the quality of their relationship with their husband and how well they perceived their husband to know them. They, therefore valued their thoughts around ECT, which in turn influenced their decision-making. Moreover, throughout the decision-making process additional strategies used by individuals included drawing upon their previous experiences of ECT, considering the conversations they had held with others and recalling discussions held in the media around ECT, which for some increased feelings of reluctance and anxiety, and considering the verbal or written information their psychiatrist had provided them with around ECT. However, participants described themselves as receiving varying information around the treatment with some individuals. Several individuals noted that such information had highlighted the benefits and risks associated with ECT, with the risks highlighting the potential of memory difficulties following ECT. Whereas, one individual could not recall being informed of the benefits to ECT and was told that ECT would only cause short-term memory difficulties, when in fact the memory difficulties she had experienced were much greater than this, which in turn raises ethical concerns as it is likely that some participants were not provided with sufficient information around ECT, as well as the risks associated with the treatment, to provide fully informed consent.

With regards to decision-making, two participants described what it was like to weigh up their experiences, the information provided and what they knew of ECT. One participant described the amount she had to consider, whereas the other individual described the decision as "not taking much deciding". Nonetheless, both individuals explained that their feelings of desperation had, ultimately, influenced their decision and consistently participants described a sense of responsibility to try ECT as they didn't know what else to do and had hoped that ECT "would work" both for themselves and their loved ones, factors which have been considered to influence an individual's ability to provide informed consent. Within their paper Clarke and colleagues[25] note that coercion, even when passive, can exert a strong influence over someone, and consider passive coercion to be present when a person signs a consent form based on the belief that they do not have any other option. Whereas in contrast to this, Swift[42] proposes that desperation does not affect capacity to consent but instead influences voluntariness, which in terms of informed consent is legally defined in relation to external constraints imposed by others in forms such as, coercion, undue influence, force or fraud. It is, however, important to note that in this study despite experiencing feelings of desperation and participants receiving support from loved ones throughout the decision-making process, participants emphasised that they had perceived the decision to receive ECT as their own although, these decisions may not have been fully informed which in itself is a major ethical concern.

Throughout their narrative's some participants understood their difficulties with depression as being caused or influenced by genetic factors or chemicals in the brain and this may have influenced their decision-making around whether to receive ECT. The notion that chemicals in the brain or genetic factors influence difficulties with depression sits in line with a strong interpretation of the medical model of mental illness. This interpretation argues that mental illness is caused primarily by brain abnormalities, such as an imbalance in neurotransmitters, the presence of lesions or abnormal neural connectivity, and is therefore treatable exclusively by intervening in the brain or nervous system.[43,44] By potentially having greater exposure to the medical model and understanding their difficulties in line with this explanation, participants may have been more likely to choose treatments which intervene in the brain, such as ECT, over other evidence-based treatments such as talking therapies, which are supported by the psychological model or biopsychosocial model of distress. It is, however, important to note that some individuals reported that they had not been offered alternative treatments such as talking therapies and may have therefore been denied the opportunity to engage in other evidence based treatments for depression, which have been described as being less intrusive and less "extreme" than ECT. Additionally, some individuals explained that they had limited opportunity to speak with clinicians about ECT, the mechanisms involved in the treatment and how these treat depression which further demonstrates that individuals may not have received sufficient information to make a fully informed choice around the treatment.

Participants shared their experiences at the time they had received ECT, their experiences following the treatment and their reflections. Participants consistently described experiencing initial feelings of anxiety and nervousness prior to them receiving ECT, which for some individuals was influenced by their previous experiences of ECT and negative portrayals of ECT presented by the media. However, such finding is likely not to be surprising as Chakrabarti et al.'s review paper[45] reports that on average 63% of participants involved in research studies have reported feeling anxious or fearful before ECT. Nonetheless, participants described the support provided by clinicians as helpful and re-assuring. All but one participant believed that they had found ECT helpful but emphasised that it was “not an overnight success”. One individual, however, reported that she did not believe that ECT had improved her difficulties and therefore, declined her final scheduled treatment despite feeling under pressure from clinicians who were encouraging her to undergo this; a finding which highlights that decision-making around ECT is an ongoing process, particularly as a course of ECT on average consists of between six and eight treatments.

Memory difficulties following ECT were consistently understood by participants as one of the risks associated with the treatment and several individuals reported that their memory had worsened after the treatment. For some individuals, the memory difficulties they experienced following the treatment were viewed as less significant than their difficulties with depression. They, therefore, considered undergoing ECT to be worthwhile. However, one individual experienced extensive memory difficulties which significantly impacted her life and were problematic due to her familial circumstances. This individual wondered whether her decision around ECT would have been different if she had been aware of the true extent of her memory difficulties following ECT, rather than believing that her memory would only be affected on a short-term basis. Finally, participants held mixed views around whether they would opt to receive ECT again in the future, views which again were influenced by their difficulties prior to ECT, their experiences when receiving the treatment and their experiences following ECT, particularly experiences relating to memory difficulties and their previous difficulties with depression. Moreover, one participant wondered whether she would have needed ECT if more talking therapies had been available to her when she was younger.

Clinical Implications and Recommendations for Clinical Practice

By exploring the narratives of older women who have been offered ECT and obtaining a greater understanding around their decision-making processes and factors which influence their decision-making, several clinical recommendations can be made to improve the support available for older women who experience mental health difficulties and older women who are faced with a decision around whether to receive ECT, in particular. It may be helpful for clinical services to utilise a clear model which highlights factors which influence the decision-making process experienced by individuals when they are offered ECT, such as the one outlined in Figure 1, as this is likely to positively influence the understanding of clinicians, which in turn may encourage more personalised discussions around ECT and improve the decision-making process for those offered the treatment. Moreover, as the impact of desperation has been discussed within the research literature in relation to its influence on an individual's ability to make informed treatment choices clinical services should, therefore, ensure that they have robust and comprehensive consent procedures in place when supporting individuals throughout every treatment of ECT as findings from this research emphasised that decision-making around ECT is an ongoing process and individuals referred for the treatment are often, in essence, powerless in comparison to the impact of their difficulties. Ensuring that individuals are provided with accurate and accessible information relating to depression, factors which influence depression, available evidence based treatments and how these can be of benefit to individuals, the risks, benefits and mechanisms of ECT as well as how ECT 'works', is just one aspect required within robust and comprehensive consent procedures as neglecting to provide such information significantly impacts an individual's ability to provide informed consent and this in itself would be a serious ethical issue.

An additional recommendation relates to the use of in-depth cognitive assessments to explore an individual's cognitive functioning prior to, during and following their treatment of

ECT. NICE guidance recommends that the cognitive functioning of individuals receiving ECT should be monitored on an ongoing basis and at a minimum at the end of each course of treatment.[11] However, given the persistent and significant memory impairments associated with ECT and as research evidence suggests that older women are at greatest risk of harm from the treatment,[8,19] the importance of thorough and ongoing cognitive assessment for this population, in particular, should be emphasised. Moreover, it feels important to provide individuals with information around rehabilitation opportunities and the support available to for individuals who experience cognitive difficulties, should cognitive assessments indicate that ECT has affected an individual’s cognitive functioning.

A final recommendation comes from the reflections of one participant who noted that throughout her decision-making it would have been helpful to talk to someone who had received ECT in recent years. It may, therefore, be helpful for clinical services to consider whether a peer support worker, who has lived experience around ECT, could support individuals who are considering whether to undergo ECT. Within the literature, people in recovery have experienced increased hope, an increased social network and increased motivation when supported by a peer support worker.[46] Moreover, individuals have been found to build rapport more easily with peer support workers than with non-peer clinicians.[46]

Strengths, Limitations and Recommendations for Future Research

As far as the author is aware, this research is the first study conducted in the UK to explore the decision-making processes experienced by women over sixty when they are offered ECT so therefore makes important contributions to the current literature exploring decision-making around whether to receive ECT. The findings highlighted the influence of several important factors which influence older women’s decision-making which, in turn, have enabled the researcher to make several recommendations that are relevant for future clinical practice. It is, however, important to note that this study is not without its limitations. Despite initially aiming to explore the narratives of individuals who had been offered ECT, this study in fact only explored the narratives of women who had opted to receive ECT when they were aged sixty and over. The narratives and experiences of women who had declined ECT at the point they were offered the treatment were not captured in this research and this is likely to have significance as individuals who have received ECT appear to hold more favourable views around the treatment, than those who have declined ECT,[45] although, the researcher notes that the seven participants interviewed as part of this study held varying views around ECT following the treatment. Also, due to the methods of recruitment individuals whose lead clinician believed that participating in the research would be too demanding due to their current physical, psychological or personal circumstances, were by default excluded from participating in the research. Similarly, several individuals who advised "they could not remember anything", from that time in their life, those who believed that they "didn't really have a choice" and individuals who had "found ECT frightening" were not willing to speak about their experiences around ECT. However, as one of the additional aims to the research was to improve the support available and the healthcare experiences of individuals offered ECT the researchers believed that interviewing individuals who were willing to speak about their experiences around ECT would best achieve their research aims whilst also reducing the risk of distress or harm through an individual's involvement in the research process.

Throughout the research process the researcher had also been unable to share a written summary letter with one participant due to the individual experiencing significant physical health difficulties. This resulted in the researcher being unable to obtain feedback from the participant in relation to their understanding of the participant's narrative.

Consequently, the interpretation of this participant's narrative may have been influenced by the researchers own biases which, in turn, could have influenced the trustworthiness of the analysis despite the researcher taking additional steps to reduce the risk of bias.

A final limitation relates to the study's small sample size, however, this supports the methodology utilised as NA is considered to be a useful qualitative methodology, particularly when sample sizes are small and where the focus of enquiry is upon the relationship between self and culture.[33] Moreover, all but one of the seven participants recruited had, in the past, received care from one NHS Trust in England, which is likely to significantly influence the generalisability of this study's findings as the decision-making processes of all but one participant is likely to be influenced by not only the personal views of individuals involved in their care, but also the availability of support and treatments within such Trust. Nonetheless, despite these limitations this research provides an important contribution to the current literature around older women's decision-making around ECT by highlighting how individualised and highly personal such decision-making is. From the research findings several recommendations have been made which, should ECT continue to be available as a treatment for depression, could improve the support available to older women when they are faced with a decision around whether to receive the treatment Also, as the findings suggest that decision-making around ECT is highly personal, older women's decision-making around mental health treatments is worthy of further exploration, particularly as the participants interviewed as part of this study held varying views around their treatment and experience preferences and the availability of mental health support. Moreover, as the present research specifically explores older women's experiences of decision-making in ECT and as previous research has explored the perspectives of professionals,[6] future research should complete the triangle of perspectives by seeking the views of family members and carers who support individuals offered ECT, particularly as this study highlighted how the views of family members and friends can influence the decision-making of those offered ECT.

Conclusions

Despite its limitations, as the only study conducted in the UK, this research provides an important contribution to the current literature around older women's decision-making around ECT by exploring the personal narratives of seven women who had received ECT after they had become sixty years of age. The findings highlighted several key factors which influenced participants decision-making at the time they were offered ECT and emphasised the significant influence of participants difficulties and the impact of these. From the research findings several clinical recommendations have been made relating to the use of a clear model within clinical services to increase understanding around factors which influence decision-making around ECT, the use of robust and comprehensive consent processes throughout an individual's course of ECT which ensure that individuals are provided with accurate and accessible information around ECT and alternative treatments for depression, and the frequent and consistent use of cognitive assessments. It is, therefore, felt that this study contributes to the growing body of literature which looks beyond individuals' personal experiences of ECT and instead hopes to improve the decision-making process and support available for individuals faced with a decision around whether to undergo ECT.[31] It is noted by the researchers that in the UK a group of professionals, individuals who have received ECT and carers are campaigning for ECT to be suspended and their request for an urgent review into the use of ECT has been supported by MIND, a leading mental health charity. However, whilst ECT continues to be offered as a treatment for depression we have a moral, ethical and professional responsibility to ensure that people are provided with clear, accurate and accessible information and are supported throughout the decision-making process in a way that enables fully informed choice about what could be a life altering treatment. It is hoped that the recommendations made through the findings of this research will encourage more open discussions around ECT, will support a clinicians moral, ethical and professional responsibility, will facilitate more informed decision-making and will improve experiences for older women who are considering whether to undergo ECT.

References

1. Brooks WB. Electroconvulsive Therapy in Older Adults. *Medicine & Health Rhode Island.* 2011 April;94(4):107-109.
2. Fink M. *Electroconvulsive therapy: A guide for professionals and their patients.* Oxford: Oxford University Press; 2009.
3. Ferrier IN, Waite J. *The ECT Handbook.* 4th ed. Cambridge: Cambridge University Press; 2019.
4. Waite J, Easton A. *The ECT Handbook.* 3rd ed. Cambridge: Royal College of Psychiatrists; 2013.
5. Kelly KG, Zisselman M. Update on Electroconvulsive Therapy (ECT) in Older Adults. *Journal of the American Geriatrics Society.* 2000 May;48(5):560-566.
6. Duxbury A, Smith I, Mair-Edwards B, et al. What is the process by which a decision to administer electroconvulsive therapy (ECT) or not is made? A grounded theory informed study of the multi-disciplinary professionals involved. *Social Psychiatry and Psychiatric Epidemiology.* 2018 June 8;53(8):785-793.
7. Read J, Cunliffe S, Jauhar S, McLoughlin DM. Should we stop using electroconvulsive therapy? *BMJ (Online).* 2019 January 30;364:1-3.
8. Read J, Bentall R. The effectiveness of electroconvulsive therapy: A literature review. *Epidemiology and Psychiatric Sciences.* 2010 March 14;19(4):333-347.
9. The UK ECT Review Group. Efficacy and safety of electroconvulsive therapy in depressive disorders: a systematic review and meta-analysis. *Lancet.* 2003 March 8;361(9360):799-808.
10. Read J, Kirsch I, McGrath L. Electroconvulsive Therapy for Depression: A Review of the Quality of ECT versus Sham ECT Trials and Meta-Analyses. *Ethical Human Psychology and Psychiatry.* 2020.
11. The National Institute for Health and Care Excellence. *Guidance on the use of electroconvulsive therapy.* London: The National Institute for Health and Care Excellence; 2003.
12. The National Institute for Health and Care Excellence. *Depression in adults: recognition and management.* London: The National Institute for Health and Care Excellence; 2009.
13. Plakiotis C, George K, O'Connor DW. Is Electroconvulsive Therapy Use Among Young-Old and Old-Old Adults Comparable? A 10-Year Population-Level Analysis of Service Provision. *The Journal of ECT.* 2014 September;30(3):232-241.
14. Burstow B. Electroshock as a Form of Violence Against Women. *Violence Against Women.* 2006 April;12(4):372-392.
15. Newnes C. *Inscription, Diagnosis, Deception and the Mental Health Industry : How Psy Governs Us All.* Basingstoke Hampshire: Palgrave Macmillan; 2016.
16. Culbertson FM. Depression and Gender: An International Review. *American Psychologist.* 1997 January;52(1):25-31.
17. Kuehner C. Why is depression more common among women than among men? *The Lancet Psychiatry.* 2017 February;4(2):146-158.
18. Höglund P, Hakelind C, Nordin S. Severity and prevalence of various types of mental ill-health in a general adult population: age and sex differences. *BMC Psychiatry.* 2020 May 11;20(209):1-11.
19. Sackeim HA, Prudic J, Fuller R, Keilp J, Lavori PW, Olfson M. The Cognitive Effects of Electroconvulsive Therapy in Community Settings. *Neuropsychopharmacology* 2007;32(1):244-254.

20. Buley N, Copland E, Hodge S. *ECT Minimum Dataset 2016-2017.* London: ECT Accreditation Service The Royal College of Psychiatrists; 2017 July.
21. Ingram A, Saling MM, Schweitzer I. Cognitive Side Effects of Brief Pulse Electroconvulsive Therapy: A Review. *The Journal of ECT.* 2008 March;24(1):3-9.
22. Orr A, O'Connor D. Dimensions of Power: Older Women's Experiences with Electroconvulsive Therapy (ECT). *Journal of Women & Aging.* 2005;17(1/2):19-36.
23. Lapid MI, Rummans TA, Pankratz VS, Appelbaum PS. Decisional Capacity of Depressed Elderly to Consent to Electroconvulsive Therapy. *Journal of Geriatric Psychiatry and Neurology.* 2004 March;17(1):42-46.
24. Amazon J, McNeely E, Lehr S, Marquardt MG. The Decision Making Process of Older Adults Who Elect to Receive ECT. *Journal of Psychosocial Nursing.* 2008 May;46(5):45-52.
25. Clarke KA, Barnes M, Ross D. I had no other option: Women, electroconvulsive therapy, and informed consent. *International Journal of Mental Health Nursing.* 2018 June;27(3):1077-1085.
26. Galotti KM. *Making Decisions That Matter: How People Face Important Life Choices.* New Jersey: Lawrence Erlbaum Associates Inc.; 2002.
27. Cohen MD. Engaging patients in understanding and using evidence to inform shared decision making. *Patient Education and Counselling.* 2017 January;100(1):2-3.
28. Department of Health. *The Mental Capacity Act.* London: HMSO; 2005.
29. Department of Health. *The Mental Health Act.* London: HMSO; 1983.
30. Bradley E, Green D. Involved, inputting or informing:“Shared” decision making in adult mental health care. *Health Expectations.* 2018 February;21(1):192-200.
31. Wells K, Newton Scanlan J, Gomez L, et al. Decision making and support available to individuals considering and undertaking electroconvulsive therapy (ECT): a qualitative, consumer-led study. *BMC Psychiatry.* 2018;18(1):1-9.
32. Angarita FA, Elmi M, Zhang Y, Look Hong NJ. Patient-reported factors influencing the treatment decision-making process of older women with non-metastatic breast cancer: a systematic review of qualitative evidence. *Breast Cancer Research and Treatment.* 2018 July;171(3):545-564.
33. Weatherhead S. Narrative analysis: An often overlooked approach. *Clinical Psychology Forum.* 2011 February;218:47-52.
34. Dodgson JE. Reflexivity in Qualitative Research. *Journal of Human Lactation.* 2019 May;35(2):220-222.
35. Riessman CK. *Narrative analysis.* London: SAGE Publications Ltd.; 1993.
36. Elliott R, Fischer CT, Rennie DL. Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology.* 1999 September;38(3):215-229.
37. Howitt D. *Introduction to Qualitative Research Methods in Psychology.* 3rd ed. Harlow: Pearson Education Limited; 2016.
38. Crossley M. Narrative Analysis. In: Lyons E, Coyle A, eds. *Analysing Qualitative Data in Psychology.* London: SAGE Publications Limited; 2007:131-144.
39. Sandelowski M, Docherty S, Emden C. Qualitative Metasynthesis: Issues and Techniques. *Research in Nursing & Health.* 1997 August;20(4):365-371.
40. Yardley L. Demonstrating Validity in Qualitative Psychology. In: Smith J, ed. *Qualitative Psychology: A practical guide to research methods.* Vol 2. London: SAGE Publications Limited; 2008:235-251.
41. Sandman L, Munthe C. Shared Decision Making, Paternalism and Patient Choice. *Health Care Analysis.* 2010;18(1):60-84.

42. Swift T. Desperation may affect autonomy but not informed consent. *AJOB neuroscience.* 2011 January;2(1):45-46.
43. Murphy D. Psychiatry and the Concept of Disease as Pathology. In: Broome M, Bortolotti L, eds. *Psychiatry as Cognitive Neuroscience: Philosophical Perspectives.* Oxford: Oxford University Press; 2009:103-117.
44. Sullivan J. Medical Models of Mental Illness. 2016.
45. Chakrabarti S, Grover S, Rajagopal R. Electroconvulsive therapy: A review of knowledge, experience and attitudes of patients concerning the treatment. *The World Journal of Biological Psychiatry.* 2010;11(3):525-537.
46. Walker G, Bryant W. Peer Support in Adult Mental Health Services: A Metasynthesis of Qualitative Findings. *Psychiatric Rehabilitation Journal.* 2013 March;36(1):28-34.

Appendices

Appendix A

Author Guidelines for the Journal of Geriatric Psychiatry and Neurology

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Journal of Geriatric Psychiatry and Neurology, please ensure you have read the Aims & Scope.

1.2 General Instructions

Manuscripts should be submitted electronically to https://mc.manuscriptcentral.com/jgpn. Authors will be required to set up an online account on the SageTrack system powered by ScholarOne. Manuscripts will be sent out anonymously for editorial evaluation. Obtaining permission for any quoted or reprinted material that requires permission is the responsibility of the author. Submission of a manuscript implies commitment to publish in the journal. Authors submitting manuscripts to the journal should not simultaneously submit them to another journal, nor should manuscripts have been published elsewhere in substantially similar form or with substantially similar content. Authors in doubt about what constitutes prior publication should consult the Editor: James M. Ellison, MD, MPH, James.M.Ellison@ChristianaCare.org.

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All material (abstracts, keywords, text, tables, and figure captions) should be typed double-spaced. Computer preparation is mandatory. Subheading should be used to designate the different sections of the text. References should be numbered consecutively throughout the text. Provide a list of three to six keywords to assist indexing of the article.

Articles of any length are considered.

Title page: The title should be brief and meaningful. The authors’ first and last names, academic or medical degrees, and affiliations should follow the title. Authorship should be limited to direct participants, although technical assistance can be acknowledged as a footnote. A separate paragraph should identify where the work was done, if supported by a grant or otherwise, and the meeting, if any, at which the paper was presented.

Abstract: An abstract of approximately 150 words should be provided on. This abstract should be factual and should present the reason for the study, the main findings, and the principal conclusions.

Text: This should follow the usual format for scientific articles. Pages should be numbered consecutively. All abbreviations should be spelled out at first mention. Only generic names of drugs should be used.

Figures and tables: Special care should be given to the preparation of figures and tables, including captions and explanatory information. Technical excellence is stressed. Lettering and arrows, where applicable, should be done in a professional manner. Color illustrations are unacceptable for publication without prior permission of the publisher. Recognizable photographs of patients must be masked and must carry with them written permission for publication. Captions for all figures should be typewritten double-spaced, with numbers corresponding to those on the figures themselves.

Tables should be numbered consecutively according to their in-text citation. Each should be typed double-spaced and should be no larger than a single page. Include a brief descriptive title and an indication of its position in the text.

References: Authors are responsible for correctness and completeness of references. References should be typed double-spaced on separate pages. They should be arranged according to their order of appearance in the text, and indicated by superscript numbers. References should be typed in accordance with the style shown below for book and journal articles. Up to four authors should be listed; when there are more than four, only the first three should be listed, followed by "et al." Abbreviations of journal names should conform to the style in Index Medicus. Abstracts, editorials, and letters to the editor should be noted as such. Personal communications, unpublished manuscripts submitted but not yet accepted, and similar unpublished items should not appear in the reference list. Such citations may be noted in the text. Some basic information regarding references and the reference list has been listed below.

References List

Basic rules for the reference list:

- The title "References" is centered at the top of a separate page at the end of the document.
- Entries are preceded by their number and are given in numerical order.
- The reference list should be single-spaced. Single-space between entries.
- The second line and all subsequent lines of each item in the reference list should be indented (hanging indent).
- Do not use "et al." in the Reference list at the end; names of all authors of a publication should be listed there.

Here are a few examples of commonly found references. For more examples please check AMA (11th Ed).

- **Books Author(s) separated by commas.**
  - ***Title of Book*. Place of publication: Publisher; year.**
  - Goldberg L, Elliot DL. *Exercise for Prevention and Treatment of Illness*. Philadelphia, Pa: FA Davis Co; 1994.
- **Edited book.**
  - **Author(s), eds. *Title of Book*. Place of publication: Publisher; year.**
  - Armitage JO, Antman KH, eds. *High Dose Cancer Therapy: Pharmacology, Hematopoietins, Stem Cells*. Baltimore, Md: Williams & Wilkins; 1995.

- **Chapter or article from a book Author(s) of article.**
  - **Title of article. In: Editor's name, ed. *Title of Book*. Place of publication: Publisher; Year: Chapter or page number.**
  - Gamble VN. On becoming a physician: a dream not deferred. In: White EC, ed. *The Black Women's Health Book: Speaking for Ourselves*. Seattle, Wash: Seal Press; 1990:52-64.
- **Articles in journals**
  - AMA style requires the use of standard abbreviations for all references, when applicable. Abbreviations for many common medical journals can be found in the AMA Manual of Style (pp.473-479). Additional abbreviations can be searched in the PubMed Journal Database (http://www.ncbi.nlm.nih.gov/nlmcatalog/journalbs).
- **One author** (do not include issue number or month unless volumes are not consecutively numbered)
  - Author. Article title. *Journal Title*. Month Year;Volume:Inclusive page numbers.
  - Angelo J. A survey of persons who use integrated control devices. *Assist Technol*. 1998;10:77-83.
- **Articles in Online Journals**
  - The preferred citation style for an electronic journal uses a DOI (digital object identifier). The DOI provides a persistent link to the electronic item and is considered to be more stable than a URL. If the DOI is not given on the full text article or in the citation, use a DOI lookup tool to locate it (http://www.crossref.org/guestquery/) or use the format for an article without a DOI.
- **Article from online journals with DOI available.** Note that when using a DOI, no access date or URL are used.
  - **Author. Title of article. *Name of Journal*. Year;vol(issue):pages. doi:xx.xxxx.**
  - Florez HR, Martinez RL. Outdoor exercise reduces the risk of hypovitaminosis D in the obese. *J Steroid Biochem Mol Bio.* 2007;103(3-5):679-681. doi:10.1016 /j.jsbmb.2006.12.032.
- **Article from online journals without DOI available**. The accessed date will often be the only date available.
  - **Author. Title of article. *Name of Journal*. Year;vol(issue);pages. URL. Published date. Updated date. Accessed date.**
  - Hay PJ. Understanding bulimia. *Aust Fam Physician*. 2007;36(9):708-712. http://www.racgp.org.au/afp/200709/18554. Accessed October 11, 2009.
- **Web pages**
  - **Author or responsible body. Title of item cited. Name of website. URL. Published date. Updated date. Accessed date.**
  - World Health Organization. Saving the future generation in Darfur. World Health Organization. http://www.who.int/features/2007/child_health/en/index.html. Published July 7, 2007. Accessed October 11, 2009.
- **Other Media.** Use for DVDs, videos, cd-roms, and other media formats.
  - **Author. Title [format]. Publisher place: Publisher; Year.**
  - Holzknect J. *History of physical therapy in the United States* [DVD]. New York, NY: Insight Media; 2007.

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1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

For information and guidance on how to make your article more discoverable, visit our Gateway page on How to Help Readers Find Your Article Online

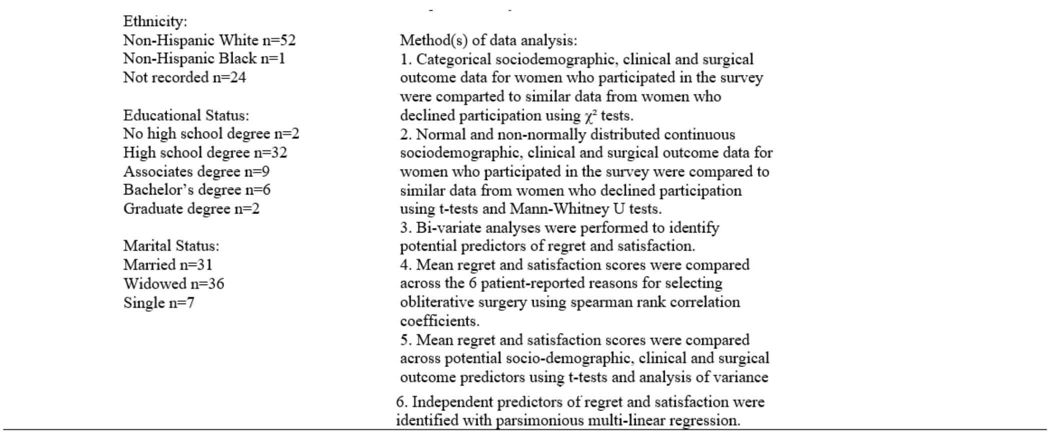
Appendix B

Data Extracted from the Nine Studies Included in the Systematic Review

Author, Year, Country	Participant Information: N, Study population, Age, Ethnicity, Educational Status, Marital Status	Study Characteristics: Design, Aims, Data collection techniques, Method(s) of analysis	Treatment type	Participant's treatment decision-making style
1. Ciambrone (2006), USA	N=30 Study population: Older women who have been diagnosed or have undergone treatment for breast cancer Age Range: 67 to 90 years Average=77 years Ethnicity: Not reported Educational Status: Not reported Marital Status: Married n=13 Widowed n=11 Never married n=3 Divorced n=3	Design: Qualitative Aims: 1. To identify factors associated with older women's breast cancer primary therapy decision- making processes 2. To identify factors associated with older women's breast cancer surveillance decision-making and adherence 3. To ascertain how women's primary support persons influence decision-making processes and women's choices Data collection Techniques: Open ended interviewing Method(s) of data analysis: Grounded Theory	Breast conserving surgery, Radiotherapy, Mastectomy, Chemotherapy	60% of participants perceived their treatment decision to be physician driven 40% of participants perceived their treatment decision to be shared where both themselves and their physician were involved
2. Cyran, Crane and Palmer (2001), USA	N=198 Study population: Older women from Colorado who were surgically treated for early-stage breast cancer Age Range: 65 to 84 years Mean age at diagnosis= 72 years Ethnicity: White n=160 African American n=12 Hispanic n=26 Educational Status: Obtained less than high school education n=104 Obtained greater than high school education n=94 Marital Status: Married n=95 Not married n=80 N=21	Design: Quantitative Aims: To describe factors associated with the type of surgical procedure performed in older women with early-stage breast cancer Data collection Techniques: A computer-assisted telephone interview which was guided by a survey instrument containing open and closed questions Method(s) of data analysis: 1. Bivariate analysis by means of χ^2 tests were performed to compare proportions 2. Continuous data was analysed with a standardised t-test or analysis of variance 3. Multivariate logistic regression tests were performed to determine factors independently associated with the outcome of lumpectomy	Lumpectomy, Mastectomy	74% of participants recalled that they were involved in their treatment decision making 22 women reported that the size or stage of their tumour determined their treatment 26 women reported that their physician led their treatment decision
3. Husain, Collins, Reed and Wyld (2008), UK	Study population: Women over 70 years who were diagnosed with primary operable breast cancer within the past 15 years who had been offered and treated with either PET or surgery as initial therapy for their breast cancer Age Range: 76 to 91 years Mean age= 83.4 years Ethnicity: All participants were Caucasian Educational Status: All participants received high school education to the age of 14 years. Marital Status: Married n=6 Widowed n=15 N=35	Design: Qualitative Aims: To identify: 1. The factors that influenced older women's treatment choice 2. The attitudes of older women to PET and surgery 3. The experiences of older women having undergone treatment with PET or surgery Data collection Techniques: Semi-structured interview Method(s) of data analysis: Framework analysis	Mastectomy, Widelocal excision, PET	Not recorded
4. Lifford et al. (2015), UK	Study population: Women aged 75 years and older who had been diagnosed with oestrogen receptor positive breast cancer and had been offered a choice of PET or surgery with endocrine therapy	Design: Qualitative Aims: To understand women's treatment decision-making, information needs and preferred media for information	PET, surgery with endocrine therapy	Specific detail around participant decision-making styles were not recorded. However, many participants

	Age Range: 75 and 98 years Median age= 83 years Ethnicity: Not recorded Educational Status: Not recorded Marital Status: Not recorded	Data collection Techniques: Audio-recorded semi-structured interviews Method(s) of data analysis: Transcripts were coded according to the CODE framework phrases		did not perceive that they had a choice to make either because: 1. They were not offered a choice by their health care professional 2. The decision felt instantly obvious.
5. Morgan et al. (2015), UK	Decision making preferences questionnaire N=729 Study population: Women aged over 70 years who had been diagnosed with operable primary breast cancer since February 2013 Age Range: 70 to 96 years Median age= 77 years Ethnicity: Not recorded Educational Status: Not recorded Marital Status: Not recorded 2. Patient interviews N=33 Study population: Women aged over 70 years who had been diagnosed with operable primary breast cancer since February 2013 Age Range: 75 to 94 years Median age=83 years Ethnicity: Not recorded Educational Status: Not recorded Marital Status: Not recorded 3. Health Care Professional Interviews N=34 Surgeons n=30 Breast Care Nurses n=13 Geriatrician n=1	Design: Convergent Mixed Methods with three components. Aims: To explore the interaction between health care professionals and older patients in the decision-making process, as well as the concordance between health care professionals and patient views regarding the processes of decision-making about treatment operable breast cancer. Data collection techniques: 1. Questionnaires about decision-making styles administered to a large cohort of older women recruited as part of a multicentre UK cohort study of older women with breast cancer. 2. Interviews with older women previously diagnosed with operable oestrogen receptor positive breast cancer, to explore their decision-making preferences about the choice between surgery or PET. 3. Interviews with health care professionals involved in the care of older women with breast cancer to explore their views about older women's involvement in decision-making. Method(s) of analysis: 1. Concordance between preferred and actual decision-making preferences was assessed using Kappa 2. Associations between age, treatment and decision-making style were identified using χ^2 tests. 3. Qualitative interviews were assessed using framework analysis.	Surgery, PET	Three types of participants preferred, and actual decision-making styles were recorded: 1. Doctor-centred 2. Shared 3. Patient-Centred Both preferred and actual decision-making styles were associated with final treatment type, with surgery being associated with more doctor-centred treatment decisions and PET with more patient-centred decision ($p<0.001$ and $p=0.002$) A moderate agreement between participants preferred and actual decision-making style was found (Kappa=0.60, $p<0.001$) Increasing age was also associated with more patient-centred decision-making styles, both preferred and actual ($p<0.001$)
6. Pieters, Heilemann, Maliski, Dornig and Mentes (2012), USA	N=18 Study population: Women aged 70 years and older who had recently undergone treatment for early-stage breast cancer and had experienced treatment decision making Age Range: 70 to 94 years Average age= 76 years Ethnicity: White n=11 Latina n=2 Other n=5 (African American/Black, Chinese, Filipino, Indian, Persian) Educational Status: Completed some high school n=2 Graduated from high school n=9 Completed some college n=2 Obtained a bachelor's degree n=1 Completed some graduate school n=1 Obtained a graduate degree n=3 Marital Status: Married/Living as Married n=6 Divorced n=6 Widowed n=5 Never married n=1	Design: Qualitative Aims: To understand how women aged 70 years and older who had recently undergone treatment for early-stage breast cancer experienced treatment decision-making Data collection Techniques: Semi-structured interviews Method(s) of data analysis: Constructionist grounded theory	Lumpectomy, Radiotherapy, Mastectomy: Lateral, Mastectomy: Partial, Mastectomy: Double, Proton Therapy, Chemotherapy	Not recorded

7. Schonberg, et al. (2014), USA	N=70 Study population: Women aged 65 years and older who had been diagnosed with ductal carcinoma in situ (DCIS) or invasive breast cancer Age Range: Full age range was not reported. However, participants were separated into two groups those aged between 65 and 74 and those aged 75 and above Ethnicity: Non-Hispanic White n=64 Non-Hispanic Black n=5 Other n=1 Educational Status: Obtained high school education or less n=24 Attended some college and beyond n=46 Marital Status: Married n=25 Lives alone n=34	Design: Mixed Methods Aims: To better understand older women’s experience with breast cancer treatment decisions. Data collection Techniques: Women were interviewed at the time of their breast biopsy, but before they knew their results, and 6 months later Method(s) of data analysis: 1. χ^2 tests were used to compare sociodemographic and tumour characteristics, treatments received and decision making by age. 2. For continuous variables two samples t-tests or the Wilcoxon Rank-Sum Test was used. 3. Progressive coding techniques were used to identify themes within participants’ qualitative data.	Mastectomy, Lumpectomy plus radiotherapy, Hormonal therapy, Chemotherapy	41% of women reported making their treatment decisions with their physicians and their family 34% reported sharing treatment decisions with their physician only 17% reported that they made their final decision on their own 8% reported that their physician or family made their final treatment choice.
8. Sinding, Wiernikowski and Aronson (2005), Canada	N=15 Study population: Women who were diagnosed with cancer at age 70 or older Women diagnosed with breast cancer n=10 Women diagnosed with gynaecologic cancer n=5 Age Range: Full age range of participants was not reported. However, participants were separated into several age groups. 1. Those aged between 70 and 74 years at the time they were diagnosed with cancer 2. Those aged between 75 and 79 years at the time they were diagnosed with cancer 3 Those aged 80 years or above at the time they were diagnosed with cancer Ethnicity: One third of participants self-identified as members of visible minority ethnic groups Educational Status: Grade 8 education or less n=2 Obtained high school education n=9 Attended post-secondary school n=0 Attended university n=1 Attended college n=3 Marital Status: No information recorded Household Status: Lived alone n=8 Lived with one other person n=6 Lived in a seniors’ residence facility n=1	Design: Qualitative Aims: To understand how older age affects cancer care, from the perspectives if older women Data collection Techniques: Semi-structured interviews Method(s) of data analysis: Grounded theory methods	Hysterectomy, chemotherapy,	Not recorded
9. Takase-Sanchez, Brooks, Hale and Heit (2015), USA	N=77 Study population: Women who underwent an obliterative surgery for pelvic organ prolapse Age Range: 72 to 86 years Mean age= 79 years	Design: Quantitative Aims: To identify patient-reported reasons for selecting obliterative surgery for the purpose of predicting decision regret and satisfaction Data collection Techniques: Telephone survey	Obliterative surgery for pelvic organ prolapse	Not recorded



Ethnicity:
Non-Hispanic White n=52
Non-Hispanic Black n=1
Not recorded n=24

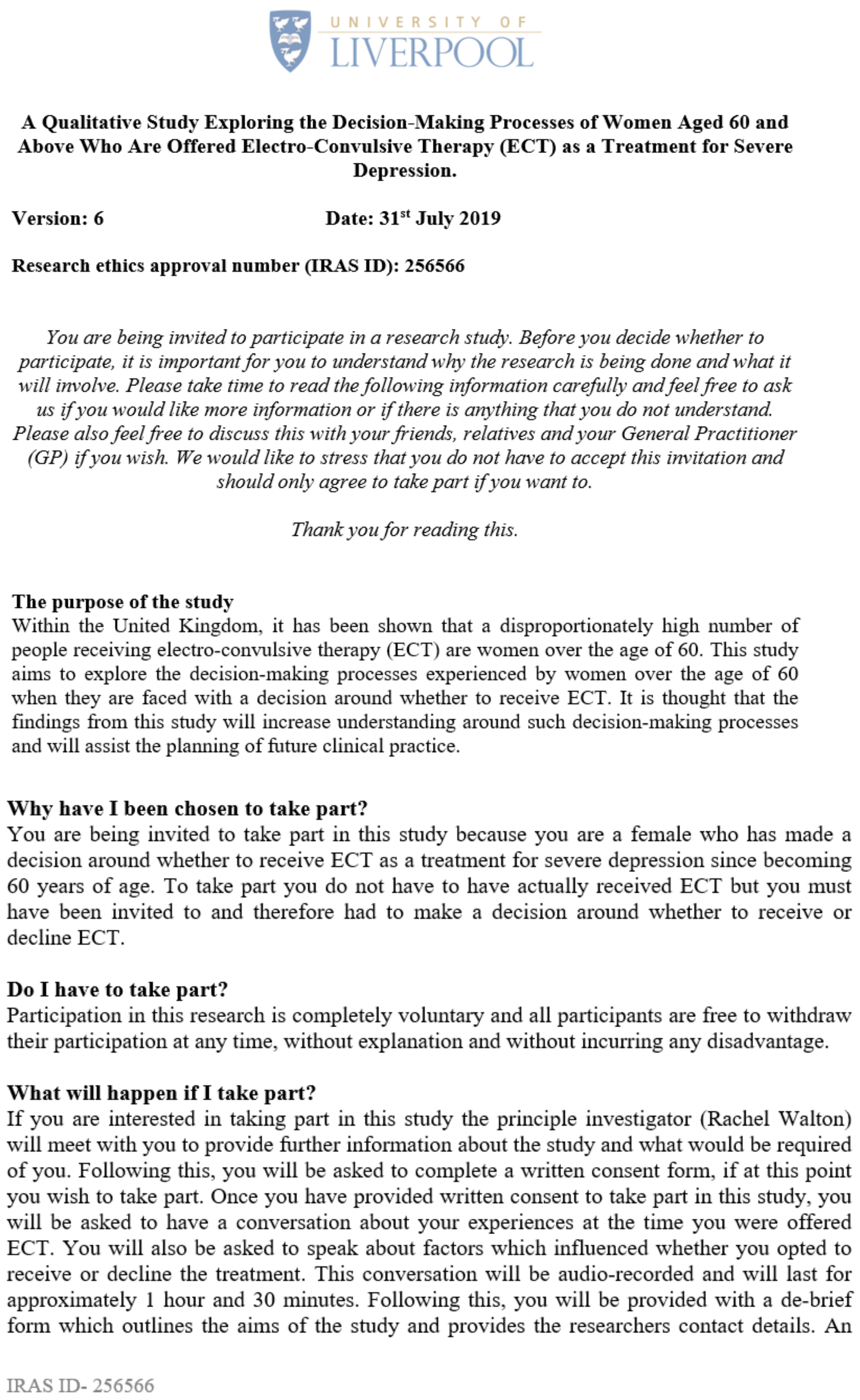
Educational Status:
No high school degree n=2
High school degree n=32
Associates degree n=9
Bachelor’s degree n=6
Graduate degree n=2

Marital Status:
Married n=31
Widowed n=36
Single n=7

Method(s) of data analysis:
1. Categorical sociodemographic, clinical and surgical outcome data for women who participated in the survey were comparted to similar data from women who declined participation using χ^2 tests.
2. Normal and non-normally distributed continuous sociodemographic, clinical and surgical outcome data for women who participated in the survey were compared to similar data from women who declined participation using t-tests and Mann-Whitney U tests.
3. Bi-variate analyses were performed to identify potential predictors of regret and satisfaction.
4. Mean regret and satisfaction scores were compared across the 6 patient-reported reasons for selecting obliterative surgery using spearman rank correlation coefficients.
5. Mean regret and satisfaction scores were compared across potential socio-demographic, clinical and surgical outcome predictors using t-tests and analysis of variance
6. Independent predictors of regret and satisfaction were identified with parsimonious multi-linear regression.

Appendix C

Participant Information Sheet



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A Qualitative Study Exploring the Decision-Making Processes of Women Aged 60 and Above Who Are Offered Electro-Convulsive Therapy (ECT) as a Treatment for Severe Depression.

Version: 6 **Date: 31st July 2019**

Research ethics approval number (IRAS ID): 256566

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. Please also feel free to discuss this with your friends, relatives and your General Practitioner (GP) if you wish. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Thank you for reading this.

The purpose of the study

Within the United Kingdom, it has been shown that a disproportionately high number of people receiving electro-convulsive therapy (ECT) are women over the age of 60. This study aims to explore the decision-making processes experienced by women over the age of 60 when they are faced with a decision around whether to receive ECT. It is thought that the findings from this study will increase understanding around such decision-making processes and will assist the planning of future clinical practice.

Why have I been chosen to take part?

You are being invited to take part in this study because you are a female who has made a decision around whether to receive ECT as a treatment for severe depression since becoming 60 years of age. To take part you do not have to have actually received ECT but you must have been invited to and therefore had to make a decision around whether to receive or decline ECT.

Do I have to take part?

Participation in this research is completely voluntary and all participants are free to withdraw their participation at any time, without explanation and without incurring any disadvantage.

What will happen if I take part?

If you are interested in taking part in this study the principle investigator (Rachel Walton) will meet with you to provide further information about the study and what would be required of you. Following this, you will be asked to complete a written consent form, if at this point you wish to take part. Once you have provided written consent to take part in this study, you will be asked to have a conversation about your experiences at the time you were offered ECT. You will also be asked to speak about factors which influenced whether you opted to receive or decline the treatment. This conversation will be audio-recorded and will last for approximately 1 hour and 30 minutes. Following this, you will be provided with a de-brief form which outlines the aims of the study and provides the researchers contact details. An opportunity for you to review and provide feedback on the theory developed once the study has been completed will also be highlighted within the de-brief form. Finally, the principle investigator will contact you by telephone the day after you have met with her and taken part in the audio recorded conversation to see whether you have any questions or concerns in relation to your involvement in this study.

How will my data be used?

The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of 'advancing education, learning and research for the public benefit'.

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. Rachel Walton, Trainee Clinical Psychologist and Principle Investigator and Dr Sarah Butchard, Clinical Psychologist, Senior Lecturer and Chief Investigator act as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to Rachel.Walton@liverpool.ac.uk or Butchard@liverpool.ac.uk. Further information on how your data will be used can be found in the table below.

How will my data be collected?	Identifiable data will be collected through a telephone conversation with the principle investigator and through the completion of written consent forms. Data relating to the aims of the research will be collected via an audio-recorded semi-structured conversation with the principle investigator.
How will my data be stored?	All data will be stored in accordance with The University of Liverpool's Research Data Management Policy. Identifiable data will be stored in password protected files within the University's secure network and in locked filing cabinets which are stored within the chief investigators office at The University of Liverpool. All audio-recorded data and anonymously transcribed data will be stored in separate password protected files within the University's secure network.
How long will my data be stored for?	Audio-recorded data will be destroyed within two months of data collection. Anonymously transcribed data will be stored for a minimum of ten years. Identifiable data will be destroyed upon completion of this research project, it is estimated that the study will be complete in September 2020. Once the Primary Investigator completes the doctorate in clinical psychology the chief investigator, who acts as data custodian will be responsible for this data.
What measures are in place to protect the security and confidentiality of my data?	Data will be stored within secure and password protected University networks.
Will my data be anonymised?	Yes, all transcribed data will be anonymised and saved under a pseudonym. However, for audit purposes participant identifiable data and their allocated pseudonym will be saved in a database. This database will be password protected, stored within the University of Liverpool's secure network, stored separately to any audio recorded and transcribed data and destroyed upon the

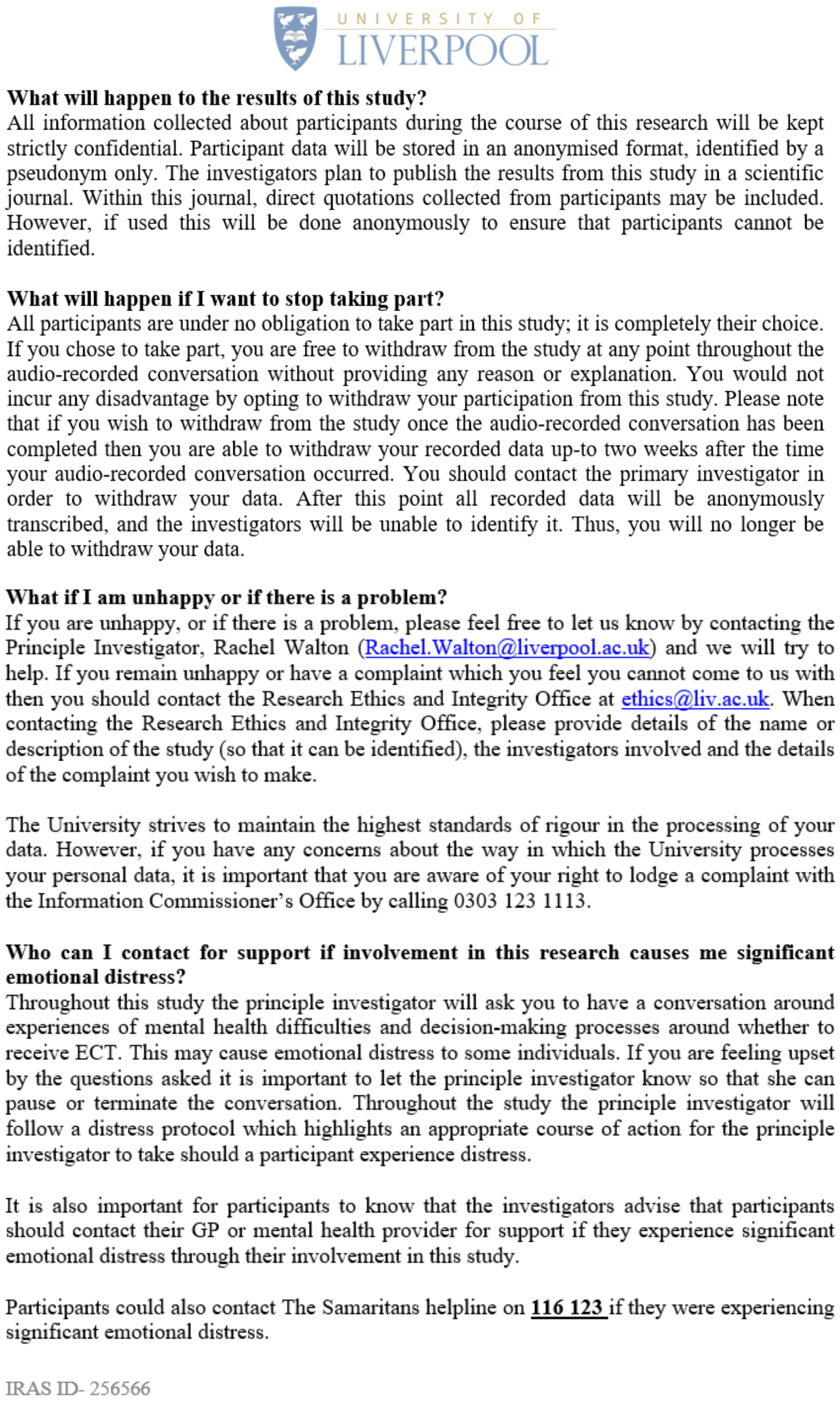
	completion of this study in September 2020.
How will my data be used?	For the completion of the primary investigators research thesis, a journal article and conference presentations.
Who will have access to my data?	The investigators of this research project. Transcription services may also have access to raw recorded data. However, they will not have access to any other personal details.
What are my rights with regards to my data?	Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. You can, however, withdraw your audio-recorded data up-to two weeks after the time your audio-recorded conversation took place. After this time all audio-recorded data will be transcribed and anonymised. The investigators will therefore be unable to identify it
Will my data be archived for use in other research projects in the future?	Anonymously transcribed data will be stored by The University of Liverpool for a minimum of 10 years. Other authorised researchers may request to use your anonymised data to support other future research projects.
How will my data be destroyed?	Data will be destroyed in accordance with The University of Liverpool’s Research and Data Management Policy
Who can I contact about the use of my data?	Any queries relating to the handling of your personal data can be sent to Rachel.Walton@liverpool.ac.uk or Butchard@liverpool.ac.uk. The University of Liverpool’s data protection policy can also be accessed through the following link https://www.liverpool.ac.uk/legal/data_protection/policy/

Expenses and or payments
All participants will be reimbursed of any reasonable travel expenses incurred through their involvement in this research study.

Are there any risks in taking part?
Throughout this study the principle investigator will ask you to have a conversation around experiences of mental health difficulties and decision-making processes around whether to receive ECT. This may cause emotional distress to some individuals. If you are feeling upset by the questions it is important to let the principle investigator know so she can pause or terminate the conversation. Throughout the study the principle investigator will follow a distress protocol which highlights an appropriate course of action for the principle investigator to take should a participant experience distress.

Should participants experience significant emotional distress, the investigators also advise participants to contact their GP or mental health care provider. In addition, participants could contact The Samaritans helpline on **116 123** if they were experiencing significant emotional distress.

Are there any benefits in taking part?
There are no direct benefits from participating in this study apart from the opportunity to contribute to psychology research which may guide future interventions and clinical practice.



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What will happen to the results of this study?

All information collected about participants during the course of this research will be kept strictly confidential. Participant data will be stored in an anonymised format, identified by a pseudonym only. The investigators plan to publish the results from this study in a scientific journal. Within this journal, direct quotations collected from participants may be included. However, if used this will be done anonymously to ensure that participants cannot be identified.

What will happen if I want to stop taking part?

All participants are under no obligation to take part in this study; it is completely their choice. If you chose to take part, you are free to withdraw from the study at any point throughout the audio-recorded conversation without providing any reason or explanation. You would not incur any disadvantage by opting to withdraw your participation from this study. Please note that if you wish to withdraw from the study once the audio-recorded conversation has been completed then you are able to withdraw your recorded data up-to two weeks after the time your audio-recorded conversation occurred. You should contact the primary investigator in order to withdraw your data. After this point all recorded data will be anonymously transcribed, and the investigators will be unable to identify it. Thus, you will no longer be able to withdraw your data.

What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting the Principle Investigator, Rachel Walton (Rachel.Walton@liverpool.ac.uk) and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Ethics and Integrity Office at ethics@liv.ac.uk. When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so that it can be identified), the investigators involved and the details of the complaint you wish to make.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner’s Office by calling 0303 123 1113.

Who can I contact for support if involvement in this research causes me significant emotional distress?

Throughout this study the principle investigator will ask you to have a conversation around experiences of mental health difficulties and decision-making processes around whether to receive ECT. This may cause emotional distress to some individuals. If you are feeling upset by the questions asked it is important to let the principle investigator know so that she can pause or terminate the conversation. Throughout the study the principle investigator will follow a distress protocol which highlights an appropriate course of action for the principle investigator to take should a participant experience distress.

It is also important for participants to know that the investigators advise that participants should contact their GP or mental health provider for support if they experience significant emotional distress through their involvement in this study.

Participants could also contact The Samaritans helpline on **116 123** if they were experiencing significant emotional distress.

IRAS ID- 256566

Who can I contact if I have any further questions?

Rachel Walton, Doctorate in Clinical Psychology Training Programme, Whelan Building, University of Liverpool, Liverpool, L69 3GB. Email: Rachel.Walton@liverpool.ac.uk Telephone: 0151 794 5530.

Contact details of the Investigatory Team

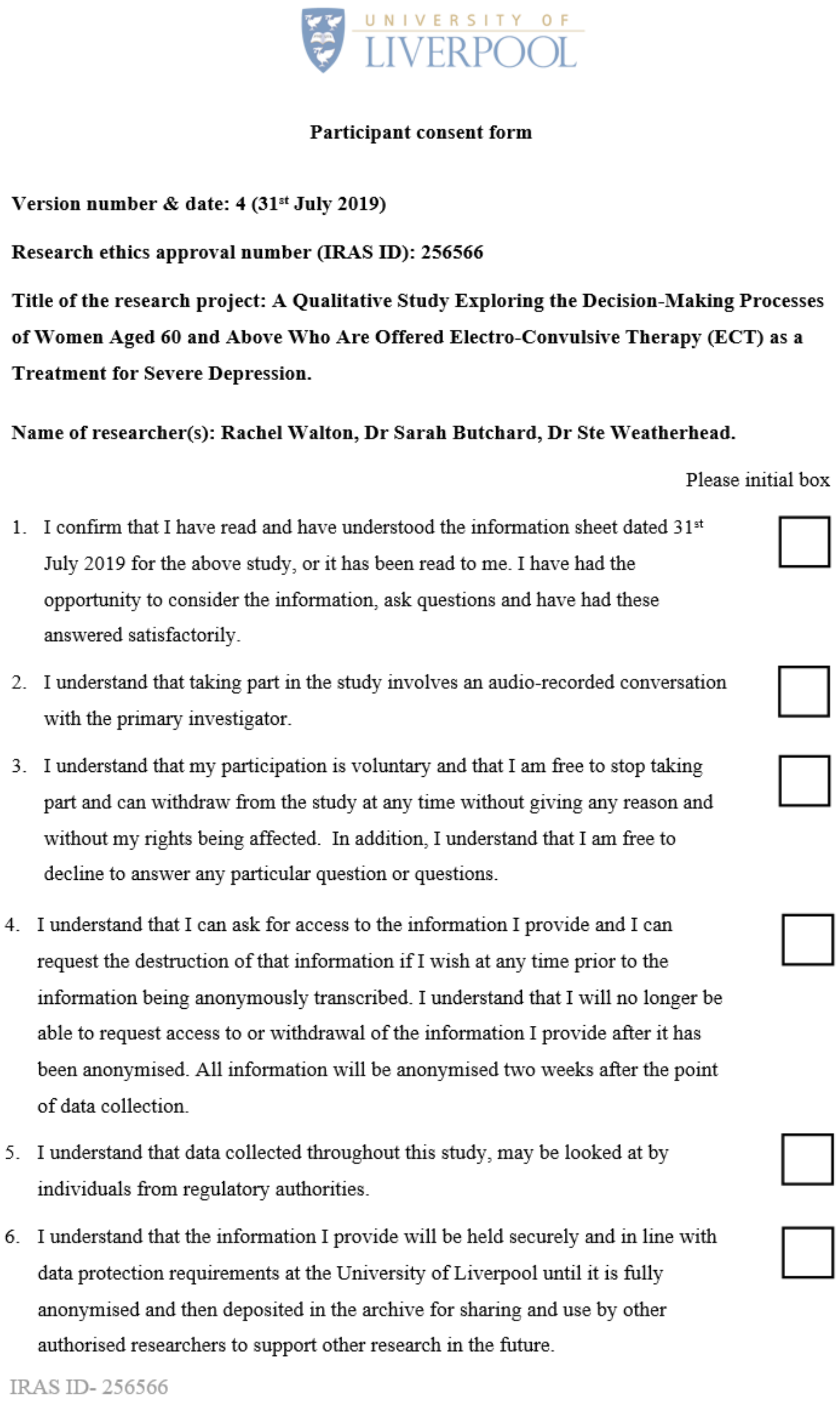
Rachel Walton, Doctorate in Clinical Psychology Training Programme, Whelan Building, University of Liverpool, Liverpool, L69 3GB. Email: Rachel.Walton@liverpool.ac.uk Telephone: 0151 794 5530.

Dr Sarah Butchard, Doctorate in Clinical Psychology Training Programme, Whelan Building, University of Liverpool, Liverpool, L69 3GB. Email: Butchard@liverpool.ac.uk Telephone: 0151 794 5530.

Dr Ste Weatherhead, Doctorate in Clinical Psychology Training Programme, Whelan Building, University of Liverpool, Liverpool, L69 3GB. Email: Ste@liverpool.ac.uk Telephone: 0151 794 5530.

Appendix D

Participant Consent Form



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Participant consent form

Version number & date: 4 (31st July 2019)

Research ethics approval number (IRAS ID): 256566

Title of the research project: A Qualitative Study Exploring the Decision-Making Processes of Women Aged 60 and Above Who Are Offered Electro-Convulsive Therapy (ECT) as a Treatment for Severe Depression.

Name of researcher(s): Rachel Walton, Dr Sarah Butchard, Dr Ste Weatherhead.

Please initial box

1. I confirm that I have read and have understood the information sheet dated 31st July 2019 for the above study, or it has been read to me. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that taking part in the study involves an audio-recorded conversation with the primary investigator. ☐
3. I understand that my participation is voluntary and that I am free to stop taking part and can withdraw from the study at any time without giving any reason and without my rights being affected. In addition, I understand that I am free to decline to answer any particular question or questions. ☐
4. I understand that I can ask for access to the information I provide and I can request the destruction of that information if I wish at any time prior to the information being anonymously transcribed. I understand that I will no longer be able to request access to or withdrawal of the information I provide after it has been anonymised. All information will be anonymised two weeks after the point of data collection. ☐
5. I understand that data collected throughout this study, may be looked at by individuals from regulatory authorities. ☐
6. I understand that the information I provide will be held securely and in line with data protection requirements at the University of Liverpool until it is fully anonymised and then deposited in the archive for sharing and use by other authorised researchers to support other research in the future. ☐

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7. I understand that copies of signed consent forms will be retained on the University of Liverpool's secure network and the investigators of this project will have access to these until September 2020. ☐

8. I understand that original audio recordings will be retained on the University of Liverpool's secure network up to 2 months after the point of data collection ☐

9. I understand that other authorised researchers may use my words in publications, reports, webpages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form. ☐

10. I agree to take part in the above study. ☐

______________________	__________	____________________
Participant name	Date	Signature
______________________	__________	____________________
Name of person taking consent	Date	Signature

Principal Investigator

Rachel Walton, Doctorate in Clinical Psychology Training Programme, Whelan Building, University of Liverpool, Liverpool, L69 3GB. Email: Rachel.Walton@liverpool.ac.uk Telephone: 0151 794 5530.

Chief Investigator

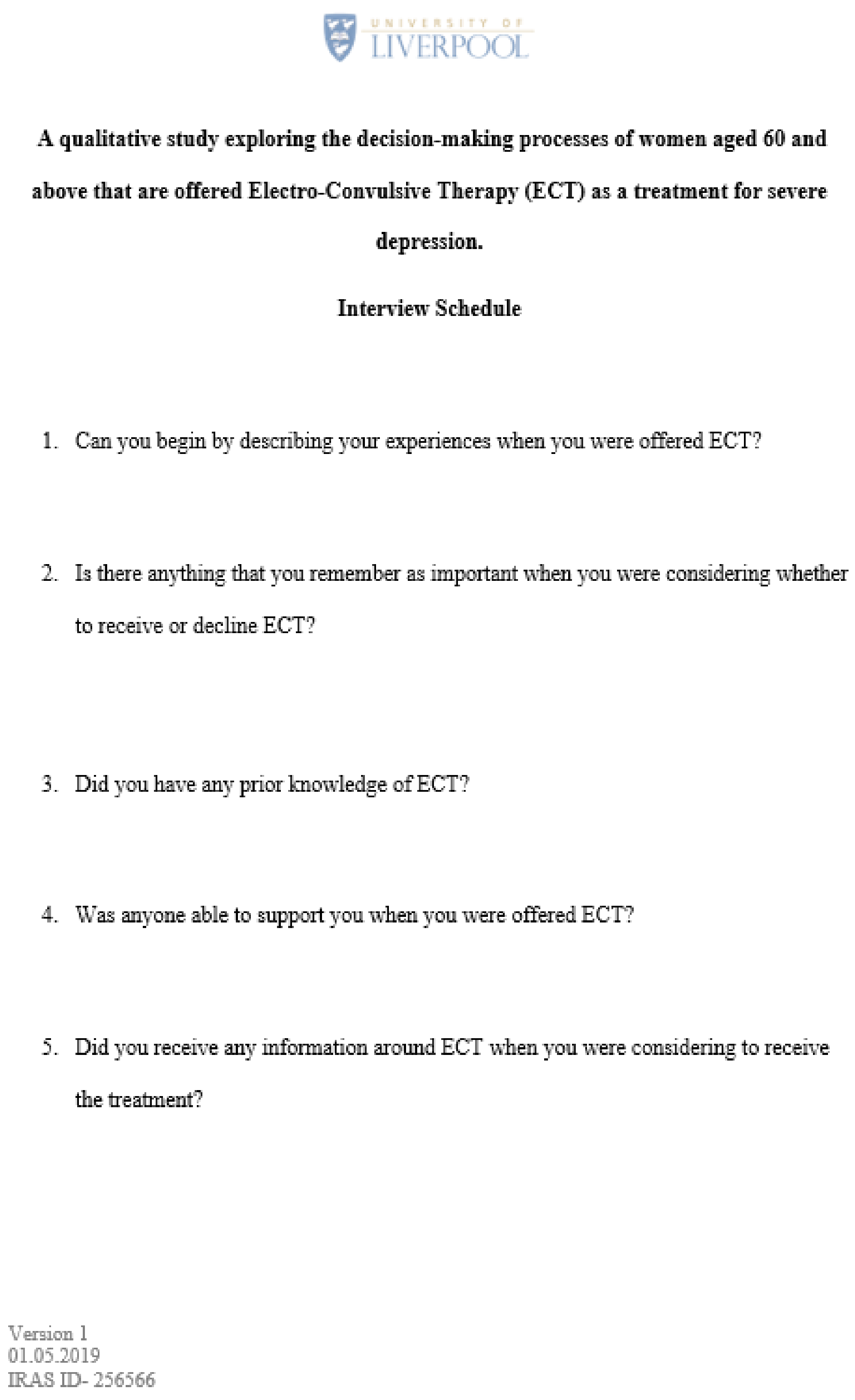
Dr Sarah Butchard, Doctorate in Clinical Psychology Training Programme, Whelan Building, University of Liverpool, Liverpool, L69 3GB. Email: Butchard@liverpool.ac.uk Telephone: 0151 794 5530.

Secondary Supervisor

Dr Ste Weatherhead, Doctorate in Clinical Psychology Training Programme, Whelan Building, University of Liverpool, Liverpool, L69 3GB. Email: Ste@liverpool.ac.uk Telephone: 0151 794 5530.

Appendix E

Interview Guide



A qualitative study exploring the decision-making processes of women aged 60 and above that are offered Electro-Convulsive Therapy (ECT) as a treatment for severe depression.

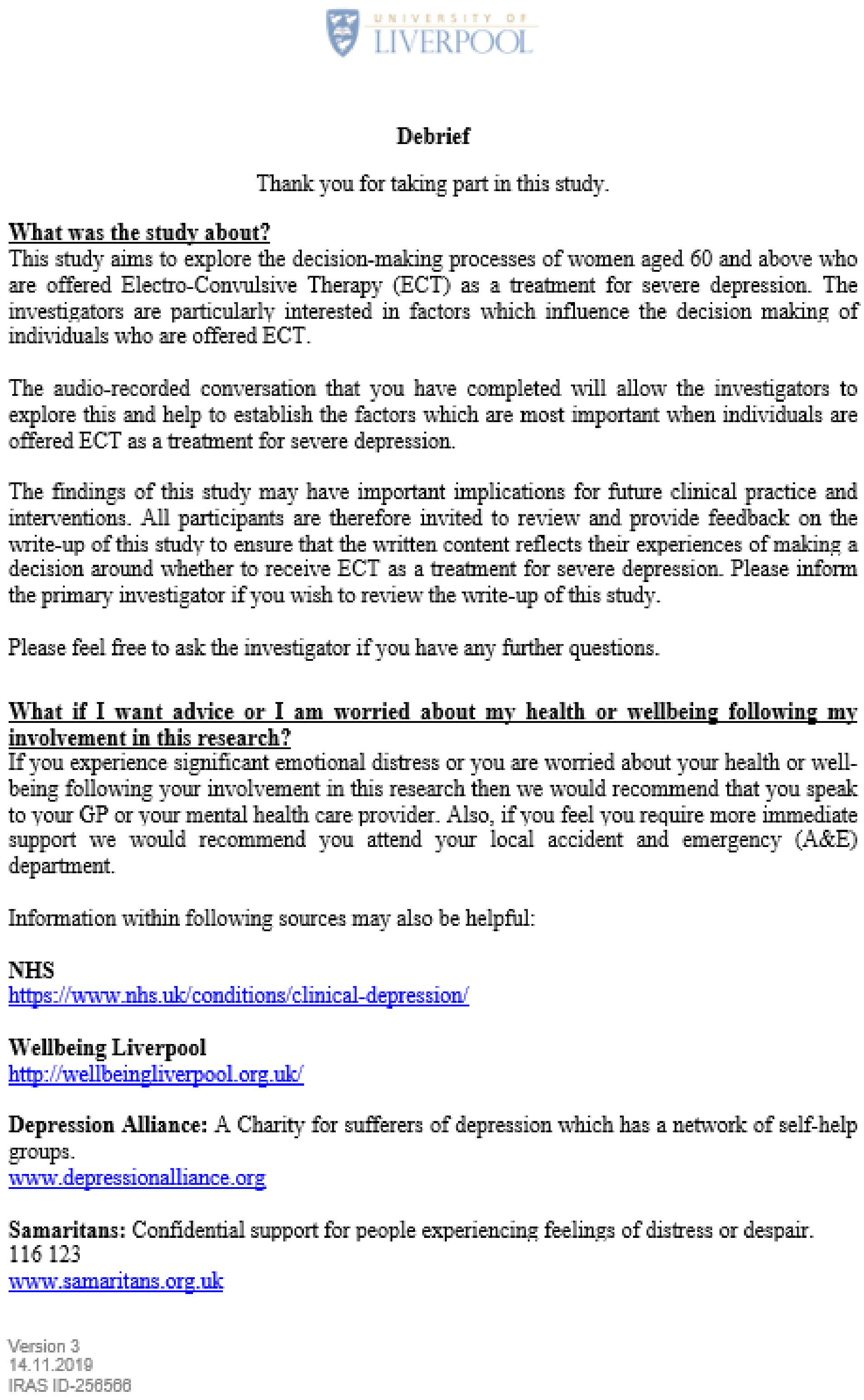
Interview Schedule

1. Can you begin by describing your experiences when you were offered ECT?
2. Is there anything that you remember as important when you were considering whether to receive or decline ECT?
3. Did you have any prior knowledge of ECT?
4. Was anyone able to support you when you were offered ECT?
5. Did you receive any information around ECT when you were considering to receive the treatment?

Version 1
01.05.2019
IRAS ID- 256566

Appendix F

Participant Debrief Form



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Debrief

Thank you for taking part in this study.

What was the study about?
This study aims to explore the decision-making processes of women aged 60 and above who are offered Electro-Convulsive Therapy (ECT) as a treatment for severe depression. The investigators are particularly interested in factors which influence the decision making of individuals who are offered ECT.

The audio-recorded conversation that you have completed will allow the investigators to explore this and help to establish the factors which are most important when individuals are offered ECT as a treatment for severe depression.

The findings of this study may have important implications for future clinical practice and interventions. All participants are therefore invited to review and provide feedback on the write-up of this study to ensure that the written content reflects their experiences of making a decision around whether to receive ECT as a treatment for severe depression. Please inform the primary investigator if you wish to review the write-up of this study.

Please feel free to ask the investigator if you have any further questions.

What if I want advice or I am worried about my health or wellbeing following my involvement in this research?
If you experience significant emotional distress or you are worried about your health or well-being following your involvement in this research then we would recommend that you speak to your GP or your mental health care provider. Also, if you feel you require more immediate support we would recommend you attend your local accident and emergency (A&E) department.

Information within following sources may also be helpful:

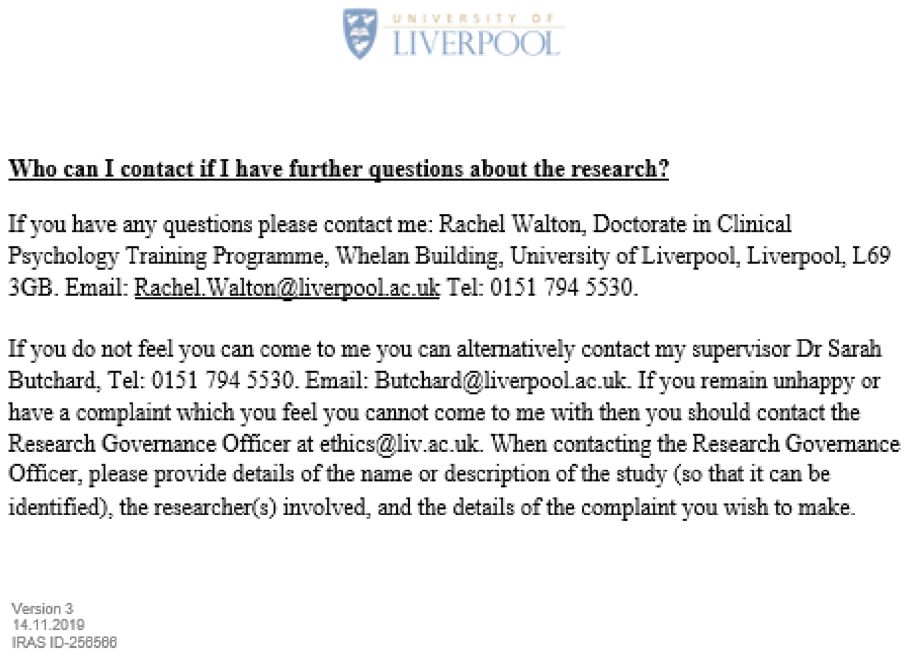
NHS
https://www.nhs.uk/conditions/clinical-depression/

Wellbeing Liverpool
http://wellbeingliverpool.org.uk/

Depression Alliance: A Charity for sufferers of depression which has a network of self-help groups.
www.depressionalliance.org

Samaritans: Confidential support for people experiencing feelings of distress or despair.
116 123
www.samaritans.org.uk

Version 3
14.11.2019
IRAS ID-256566



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Who can I contact if I have further questions about the research?

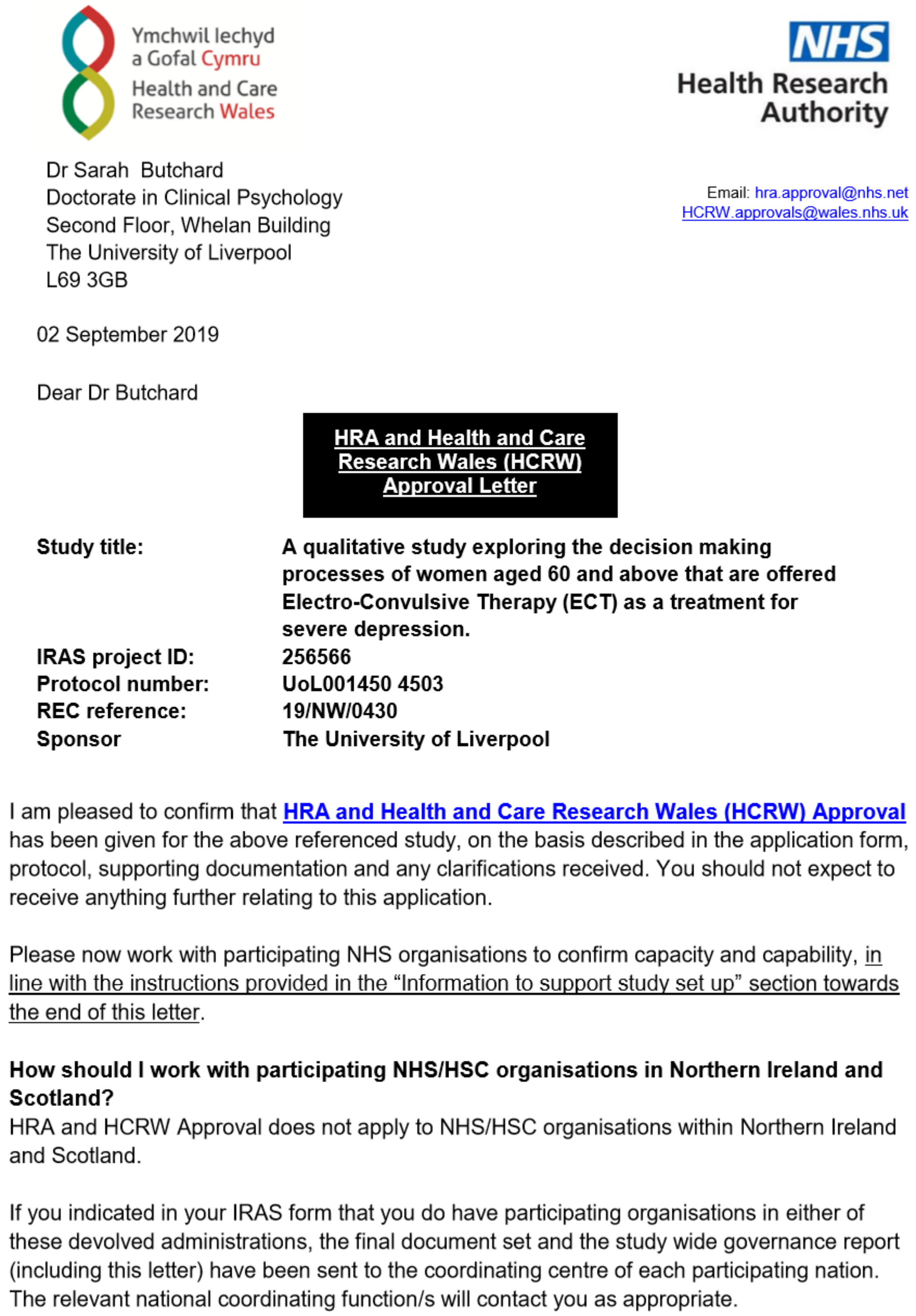
If you have any questions please contact me: Rachel Walton, Doctorate in Clinical Psychology Training Programme, Whelan Building, University of Liverpool, Liverpool, L69 3GB. Email: Rachel.Walton@liverpool.ac.uk Tel: 0151 794 5530.

If you do not feel you can come to me you can alternatively contact my supervisor Dr Sarah Butchard, Tel: 0151 794 5530. Email: Butchard@liverpool.ac.uk. If you remain unhappy or have a complaint which you feel you cannot come to me with then you should contact the Research Governance Officer at ethics@liv.ac.uk. When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

Version 3
14.11.2019
IRAS ID-258566

Appendix G

A Letter from the Research Ethics Committee Confirming HRA Approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Dr Sarah Butchard
Doctorate in Clinical Psychology
Second Floor, Whelan Building
The University of Liverpool
L69 3GB

Email: hra.approval@nhs.net
HCRW.approvals@wales.nhs.uk

02 September 2019

Dear Dr Butchard

HRA and Health and Care Research Wales (HCRW) Approval Letter

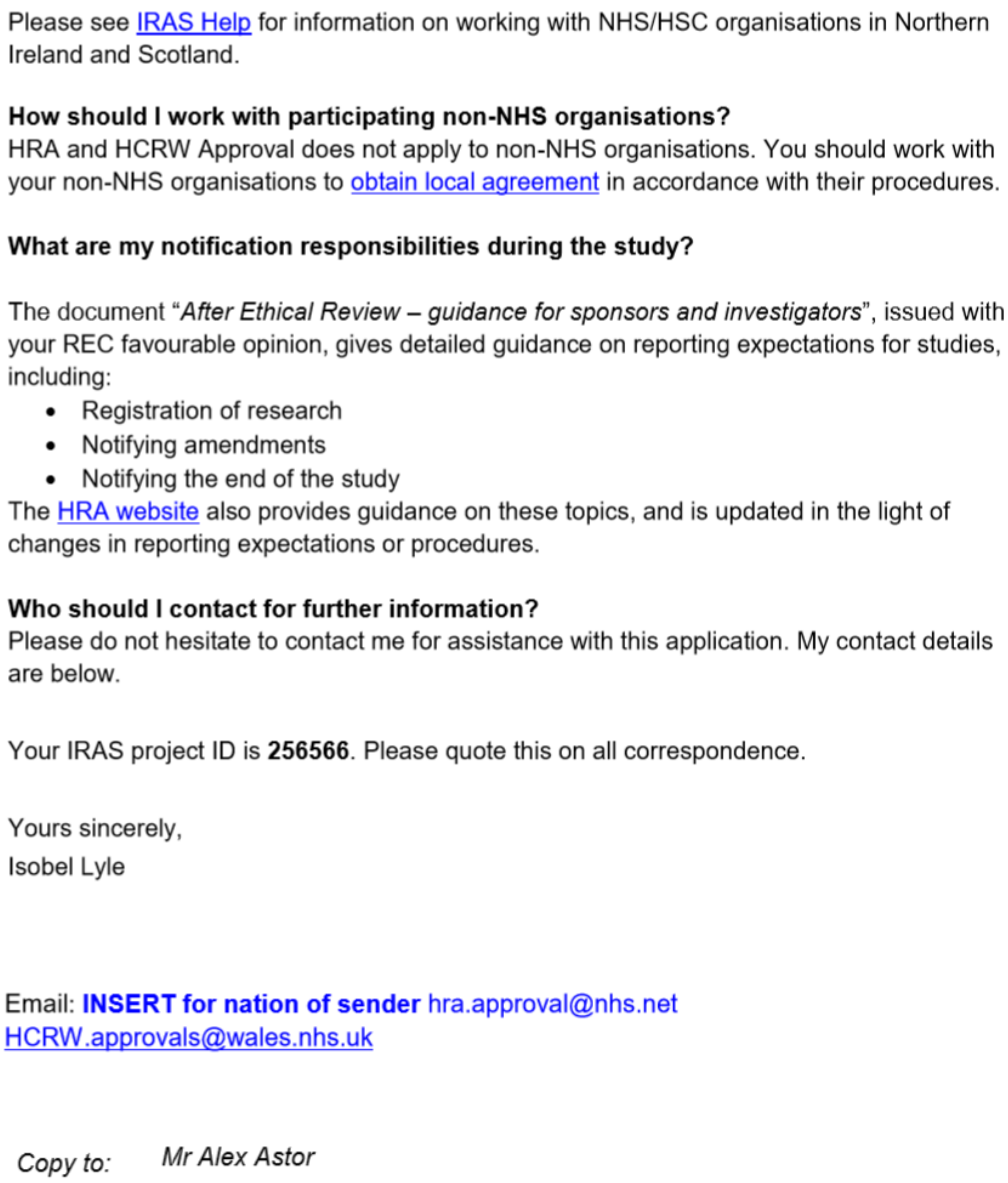
Study title:	**A qualitative study exploring the decision making processes of women aged 60 and above that are offered Electro-Convulsive Therapy (ECT) as a treatment for severe depression.**
IRAS project ID:	**256566**
Protocol number:	**UoL001450 4503**
REC reference:	**19/NW/0430**
Sponsor	**The University of Liverpool**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.



Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

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

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **256566**. Please quote this on all correspondence.

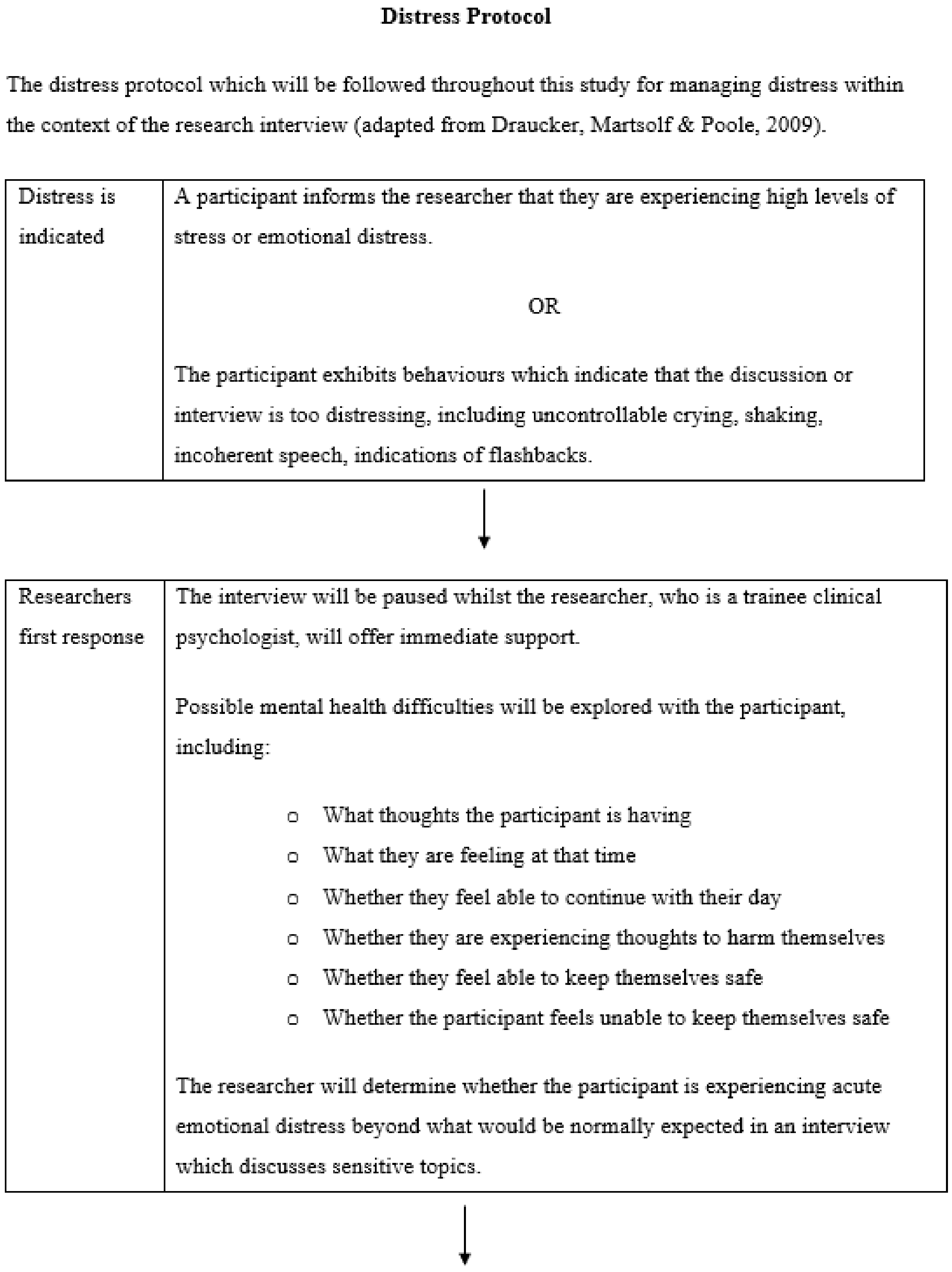
Yours sincerely,
Isobel Lyle

Email: **INSERT for nation of sender** hra.approval@nhs.net
HCRW.approvals@wales.nhs.uk

Copy to: *Mr Alex Astor*

Appendix H

Distress Protocol



Distress Protocol

The distress protocol which will be followed throughout this study for managing distress within the context of the research interview (adapted from Draucker, Martsolf & Poole, 2009).

Distress is indicated	A participant informs the researcher that they are experiencing high levels of stress or emotional distress. OR The participant exhibits behaviours which indicate that the discussion or interview is too distressing, including uncontrollable crying, shaking, incoherent speech, indications of flashbacks.

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Researchers first response	The interview will be paused whilst the researcher, who is a trainee clinical psychologist, will offer immediate support. Possible mental health difficulties will be explored with the participant, including: o What thoughts the participant is having o What they are feeling at that time o Whether they feel able to continue with their day o Whether they are experiencing thoughts to harm themselves o Whether they feel able to keep themselves safe o Whether the participant feels unable to keep themselves safe The researcher will determine whether the participant is experiencing acute emotional distress beyond what would be normally expected in an interview which discusses sensitive topics.

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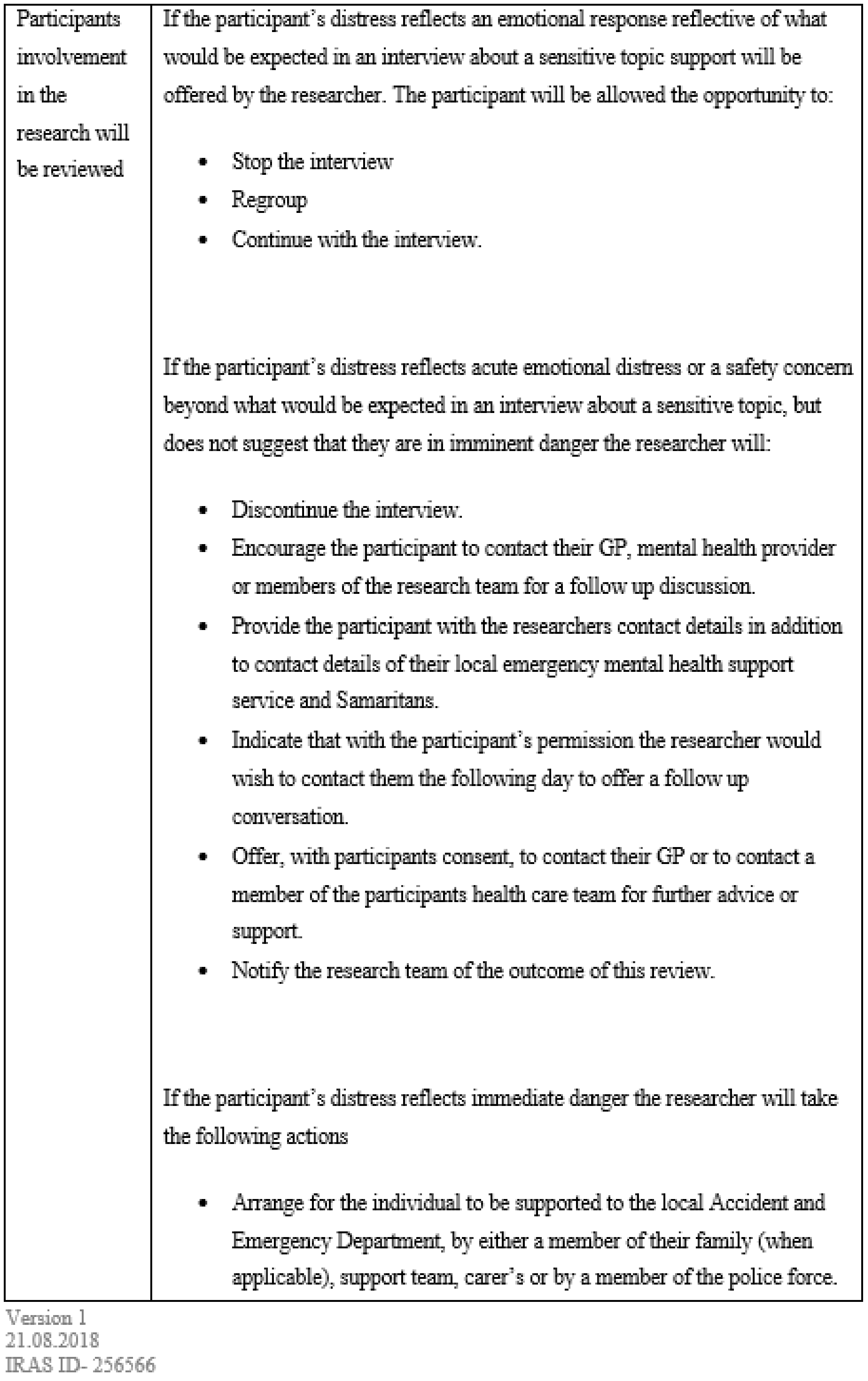

Participants involvement in the research will be reviewed	If the participant's distress reflects an emotional response reflective of what would be expected in an interview about a sensitive topic support will be offered by the researcher. The participant will be allowed the opportunity to: • Stop the interview • Regroup • Continue with the interview. If the participant's distress reflects acute emotional distress or a safety concern beyond what would be expected in an interview about a sensitive topic, but does not suggest that they are in imminent danger the researcher will: • Discontinue the interview. • Encourage the participant to contact their GP, mental health provider or members of the research team for a follow up discussion. • Provide the participant with the researchers contact details in addition to contact details of their local emergency mental health support service and Samaritans. • Indicate that with the participant's permission the researcher would wish to contact them the following day to offer a follow up conversation. • Offer, with participants consent, to contact their GP or to contact a member of the participants health care team for further advice or support. • Notify the research team of the outcome of this review. If the participant's distress reflects immediate danger the researcher will take the following actions • Arrange for the individual to be supported to the local Accident and Emergency Department, by either a member of their family (when applicable), support team, carer's or by a member of the police force.

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	• Indicate that, with the participant's permission, the researcher will contact them the following day. • Notify the research supervisors of the actions taken as soon as possible

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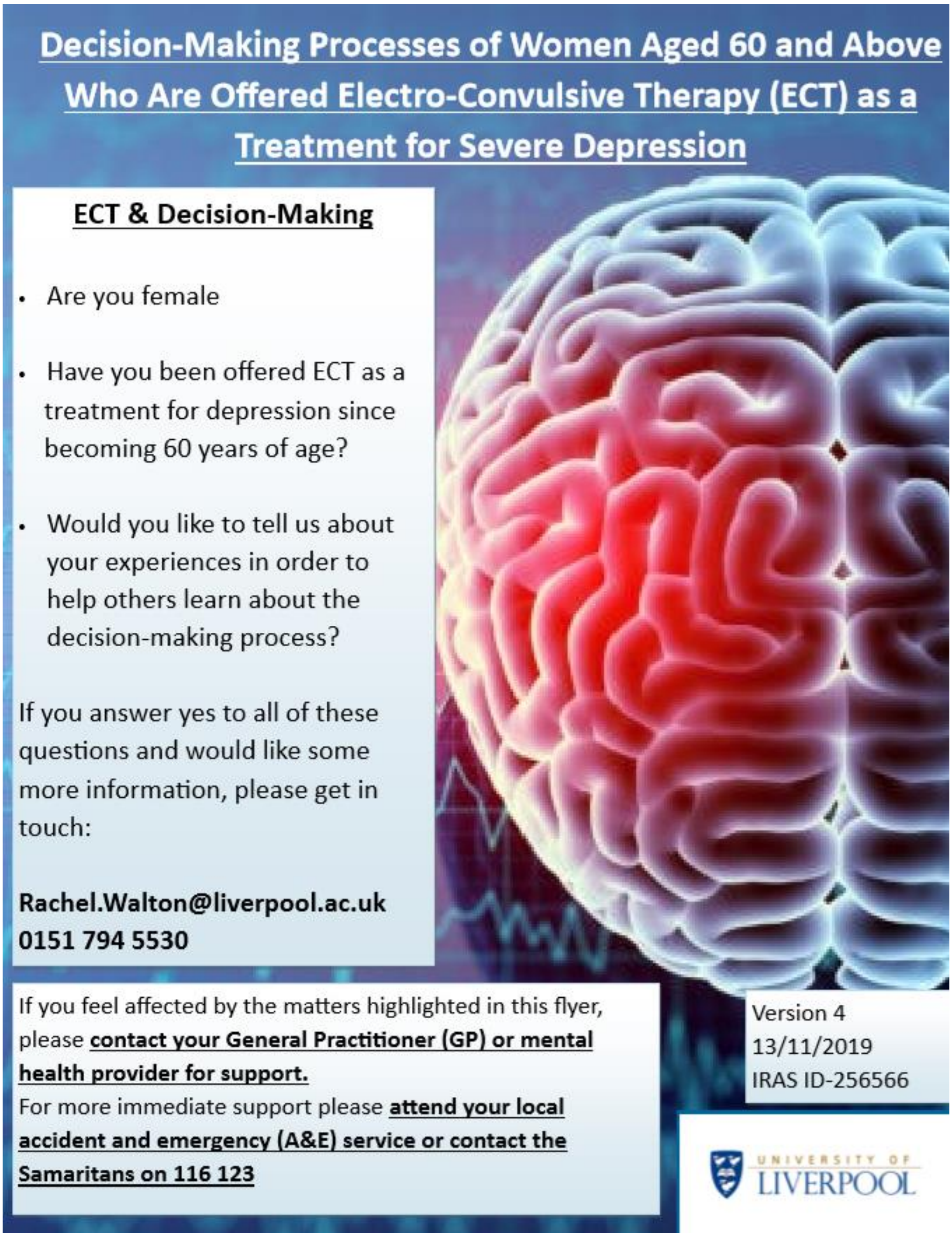
Following the research interview	Following the research interview the researcher will: • Provide a follow up telephone call to each participant the day after the research interview took place, provided the participant has given consent to this. • Encourage each participant to contact the research team if they experience distress in days following the research interview. • Encourage each participant to contact their GP, Samaritans or their emergency mental health team should they experience significant emotional distress or have concerns in relation to their safety following their involvement in this research. • Attend regular supervision with the research supervisors.

Appendix I

Recruitment Poster



Decision-Making Processes of Women Aged 60 and Above Who Are Offered Electro-Convulsive Therapy (ECT) as a Treatment for Severe Depression

ECT & Decision-Making

- Are you female
- Have you been offered ECT as a treatment for depression since becoming 60 years of age?
- Would you like to tell us about your experiences in order to help others learn about the decision-making process?

If you answer yes to all of these questions and would like some more information, please get in touch:

Rachel.Walton@liverpool.ac.uk
0151 794 5530

If you feel affected by the matters highlighted in this flyer, please **contact your General Practitioner (GP) or mental health provider for support.**
For more immediate support please **attend your local accident and emergency (A&E) service or contact the Samaritans on 116 123**

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