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DRUMBEAT© for arthritis “a shared purpose” rather than a “lonely struggle”

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DRUMBEAT® for arthritis
“a shared purpose” rather than a “lonely struggle”

By Jan Warhurst
Student Number

A thesis submitted in Partial Fulfilment of the Requirements for the
Master of Science (Medical Science)
School of Medical Health Sciences, Edith Cowan University.
Submitted 25th November 2020

Signature
I declare that this thesis is my own work and does not include:

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ABSTRACT

BACKGROUND:
Australia is regarded as a healthy nation, with life expectancy one of the highest in the world. Yet the latest National Health Survey tells a very different story. Almost 50% of Australians are now living with one or more chronic conditions, with arthritis and other musculoskeletal (MSK) conditions representing the most expensive chronic disease group in Australia. As the leading cause of chronic pain and second most common cause of disability and early retirement due to ill health in Australia, Arthritis is costing the economy over $7 billion a year, in addition to over $1.1 billion in extra welfare costs and lost tax revenue. Although personal, social and economic burdens of arthritis are immense they tend to be poorly recognised, with government investment considerably lower than for any other major disease group, with the exception of asthma.

While very common, arthritis is not well understood. Prevailing myths inaccurately portray arthritis as an old person's disease and an inevitable part of aging. More than 150 types of arthritis and related MSK conditions have been described; classified as either inflammatory, or non-inflammatory. Osteoarthritis (OA) is the most common type of non-inflammatory, characterised by progressive damage to cartilage and other joint tissues. Rheumatoid arthritis (RA) is the prototypical inflammatory arthritis, followed by gout, psoriatic arthritis (PsA), ankylosing spondylitis (AS), juvenile idiopathic arthritis (JIA) and systemic lupus erythematosus (lupus), among others. Classified as chronic autoimmune disorders, the symptoms of inflammatory arthritis (IA) are not localised to the damaged joint, and individuals may also experience fever, weakness, and organ damage, in addition to the stiffness and pain in the joints. As the sample size of this pilot study is small, it was decided to not recruit from the entire target population but rather to focus on those individuals living with IA.

The measure of prevalence of arthritis and other MSK conditions in Australia poses a challenge as there are wide variations in condition specific data. A snapshot from the Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of Statistics (ABS) indicates almost 4 million Australians, 1 in 6 people, live with some form of arthritis – this number has almost doubled since the 1950’s and is expected to significantly increase by 2030. Limited national
statistics and publications show an estimated 456,000 Australians (1.9% of the total population) with RA; JIA as affecting around 1 child in every 1,000 aged 0–15; PsA occurring in up to 30% of people who have psoriasis, a common skin disorder that affects approximately 2% of the population; and suggest AS affects one in 200 Australians. The limited data relating to incidence, treatment, costs and outcomes of the many types of arthritis is seen as a major barrier to recognition of the impact and potential severity of the disease group by the general public, clinicians and policymakers.

According to the NHS 2017–18, 1 in 5 Australians (22%) with arthritis experience high to very high levels of psychological distress, with depression and anxiety two of the most common mental illnesses experienced by individuals living with RA. Given the strong evidence supporting the benefits of music therapy as an adjunct therapy for chronic health conditions, the most recognised application being improvement in mental health, this pilot study explored the rationale for inclusion of a facilitated drumming intervention into the Arthritis and Osteoporosis WA (AOWA) disease specific education and self-management programs for individuals living with arthritis.

The study investigated whether individuals living with various forms of IA could improve levels of self-management by participating in a drumming intervention based on the Holyoake DRUMBEAT (Discovering Relationships Using Music – Beliefs, Emotions, Attitudes, & Thoughts) format, that uses hand drumming to allow participants to explore and engage connections between making music together as a group and development of emotional skills, such as self-regulation and self-confidence.

**AIM:**

The initial aim of the study was to help understand the unique experiences of those individuals living with IA, as expressed by research participants in this study. The subsequent and overarching aims of the research were to investigate what benefits persons living with IA might derive through their participation in innovative and novel hand-drumming programs such as DRUMBEAT.
DESIGN AND METHODS:

Seven participants with varied forms of IA were invited to take part in a 6-week hand-drumming intervention based on the Holyoake DRUMBEAT program. The 2.5-hour weekly sessions were held in 2019 at the headquarters of AOWA. Each session consisted of playing djembe drums and/or percussion, and discussions to facilitate effective interaction between participants. Additionally, the inclusion of breaks before, after and during the sessions was an important consideration to encourage social interaction with others possibly facing similar challenges in life. Ad hoc adaptations led to change in peripheral delivery components of the program so as to suit the participants’ abilities, rather than their disabilities. Modification was about flexibility and this is inherent in the way the sessions were delivered. The core content of the program remained the same. Exclusion criteria included presence of a major depressive disorder, or a previously diagnosed depressive disorder that had not been stabilised through treatment; or presence of any co-existing musculoskeletal conditions that prevented participation.

A sequential mixed-methods action research design was adopted for this exploratory health promotion intervention. The integration of mixed methods and action research allowed for various research tools to be used: researcher observations; weekly transcripts; one-on-one interviews; final focus group transcripts; and pre, interim, and post – program questionnaires. Depression, anxiety and quality of life (QoL) were assessed using the RAND 36-Item Health Survey 1.0 and the Hospital Anxiety and Depression scale (HADS). In analysing the results, each participant’s general self-efficacy was assessed using the Rheumatoid Arthritis Self-Efficacy (RASE) questionnaire and the Locus of Control of Behaviour Scale (LoCBS). The UCLA Loneliness Scale (Version 3) was utilised to measure loneliness and social support, together with a simple, four-item Session Rating Scale (SRS) administered, scored and discussed at the end of each session, to get real-time feedback from participants. The Visual Analogue Scale (VAS) was also completed at the end of each session to help capture any differences in pain intensity and/or severity, pre- and post-drumming.

RESULTS:

Quantitative results show depression was significantly lower from baseline to follow up. Depression had decreased from a mean (Median; SD; IQR) of 6.29 (7.0; 3.15; 5.0) to 4.42 (5.0; 2.82; 5.0) during the 6-week intervention. Anxiety reduced from a mean (Median; SD; IQR) of 7.86 (7.0; 4.98; 10.0) to 7.14 (7.0; 4.91; 9.0). Statistically significant improvements in QoL scores
were observed in physical functioning from a mean (Median; SD; IQR) of 55 (65; 20.41; 30) to 65 (75; 18.26; 25). Trends in improvement in role physical / role emotional scale was noted, together with reduced bodily pain. There were smaller non-significant improvements in energy / fatigue, emotional wellbeing and general health. All QoL measures appeared to improve, though all but physical did not reach statistical significance due to small sample size and inadequate exposure to the intervention for some participants. The study encountered poor participation rates, with fatigue and lack of confidence identified as the main reasons for non-attendance. Only 28.57% (n=2) of the participants completed the full 6-week DRUMBEAT program, with 57.14% (n=4) completing four, or more sessions. Social function and differences in loneliness, as measured by UCLA scale (version 3) were the only scales to remain unchanged. The degree of change was also not significant in self-report measures of locus of control. The majority of participants (n=6) indicated small non-significant improvements in self-efficacy. Qualitative analysis revealed a significant sense of community and by week two there was a noticeable sense of bonding within the group. In addition to community features the qualitative analysis revealed some positive signs of improvement in multiple domains of social-emotional behaviour.

CONCLUSION AND RECOMMENDATIONS:
We conclude that the drumming intervention may have a beneficial effect on both mental and physical self-reported health, in the short term, in an IA population. These findings add to the growing evidence on how engagement in a group drumming intervention, such as DRUMBEAT may influence participants to utilise experiences drawn from their own lives to find solutions to challenges, and promote healthy behaviour changes.

To support these results, further studies are needed to measure outcomes and the potential usefulness of incorporating DRUMBEAT into a successful management strategy of IA. This will allow for the opportunity to produce more evidence and determine the effects of outside factors.

While appreciating the role of medications to alleviate symptoms, clearly the current approach to the management of chronic conditions, such as IA, is not working and therein presents an opportunity for innovative interventions such as DRUMBEAT. Based upon the findings and recommendations of this study, DRUMBEAT appears to be an easily accessible, fun, sustainable
program that may help participants gain the social support and skills necessary for them to thrive, learn, work, earn and participate in community life.

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ACKNOWLEDGEMENTS

"What the doctor did not tell me - what no one could - is that these last ten years of coming to terms with my disease would turn out to be the best ten years of my life - not in spite of my illness, but because of it." Michael J. Fox

This quote resonated with me. I’ve had to make many adjustments to how I live my life with rheumatoid. This is not the life I imagined I would be living. My journey through uni began as part of an endless search for a cure. That proved fruitless! But studying turned out to be an inspirational endeavour that has helped me acquire some valuable skills needed to not just survive rheumatoid but to also thrive in spite of it. But it was not a solitary journey. I could not have done it without the support and love of so many people along the way. To all of you who have made this life-changing opportunity possible for me, I want to say a big thank you.

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It’s fair to say that anyone who has gone through this process knows the importance of support and good supervision. I would like to express special thanks to all of my supervisors for guiding me through the hitherto unknown world of research and for often having to steer me in the right direction! It was a privilege to work with you all.

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LIST OF ACRONYMS

AHHA  Australian Healthcare and Hospitals Association
A&OV  Arthritis and Osteoporosis Victoria
ABS   Australian Bureau of Statistics
AIHW  Australian Institute of Health & Welfare
AOWA  Arthritis and Osteoporosis West Australia
AS    Ankylosing spondylitis
BPS   Biopsychosocial
CAM   Complementary and Alternative Medicine
CBT   Cognitive Behavioural Therapy
IA    Chronic inflammatory arthritis
DoH   Department of Health
DRUMBEAT  Discovering Relationships Using Music, Beliefs, Emotions, Attitudes & Thoughts
ECU   Edith Cowan University
HRQoL Health related quality of life
JIA   Juvenile idiopathic arthritis
LUPUS Systemic lupus erythematosus
MSK   Musculoskeletal conditions
NCCAM The National Centre for Complementary and Alternative Medicine
NHMRC National Health & Medical Research Council
NHPA  National Health Priority Area
NRAS  National Rheumatoid Arthritis Society
OA    Osteoarthritis
PsA   Psoriatic arthritis
PTSD  Post-traumatic stress syndrome
QoL   Quality of life
RA    Rheumatoid arthritis
RACGP The Royal Australian College of General Practitioner
TAG   Young arthritis support group
UK    United Kingdom
CHAPTER 1: INTRODUCTION

1.1 Introduction

My personal experience with rheumatoid arthritis (RA) has been the main motivation for this research, whereby I was inspired to investigate whether a novel and innovative group drumming intervention could be adapted for chronic inflammatory arthritis (IA). Diagnosed with RA in my mid-30s, I have experienced first-hand the impact of living with a chronic health condition that is often inaccurately portrayed and generally misunderstood by the wider public (Arthritis Australia, 2017). I have drawn on these experiences of how RA affects my life to gain insight into what participants are describing, and experiencing, during this study (Corbin & Strauss, 2015). In acknowledgement of my active engagement within the study, I have chosen to intermittently use a first-person perspective in this thesis. This research helps identify aspects of health interventions that motivate others with arthritis to self-manage, and pinpoints opportunities for them to take control of their own health.

1.1.1 Holyoake’s DRUMBEAT program

This research marked the beginning of a new collaboration between Holyoake and Edith Cowan University. Established in 1975, West Australian based Holyoake is a not-for-profit enterprise that provides support programs to those affected directly, or indirectly, by alcohol, drugs, and other addictive behaviours (Beattie, 2018). Holyoake’s DRUMBEAT, an acronym for Discovering Relationships Using Music, Beliefs, Emotions, Attitudes, and Thoughts, is an evidence-based music therapy program that began primarily as a way to engage young individuals identified as being at risk and resistant to talk based approaches (Faulkner, 2011). DRUMBEAT is purported to be a fun drumming intervention and the first structured learning program to use music, psychology and neurobiology to explore themes at a deeper level, allowing participants to utilise experiences drawn from their own lives to find solutions to challenges, and promote healthy behaviour changes (Faulkner, 2016). While DRUMBEAT relies on experiential processes to establish social cohesion amongst participants, it was considered useful to also include, for the purpose of the current study, a closed Facebook group as an additional communication channel for participants to voice their opinions, support social connectedness and gain a sense of belonging (Wong, Merchant, & Moreno, 2014).
Since its initial success in engaging marginalised and at-risk youth (Wood, Ivery, Donovan, & Lambin, 2013) DRUMBEAT is demonstrated to be generalisable as an early intervention program in contexts beyond those for which it was initially designed, these include armed forces, post-traumatic stress disorder (PTSD), prisons, and the mental health and behaviour of disadvantaged and alienated youth, among others (Wood, Martin, Chapple, & Ford, 2019; Bensimon, Amir, & Wolf, 2008; Martin, Wood, Tasker, & Coletsis, 2014). One group for whom DRUMBEAT had not previously been evaluated was those with IA, or arthritis in general. The concept of the arthritis population as being a possible intervention group came about for two main reasons: (1) a gap was identified in existing literature for evaluating drumming interventions in the chronic disease population in general, and (2) the study represented a potential window of opportunity for the researcher to extend her own personal experiences of living with IA and to gain a deeper understanding of the arthritis community overall.

When considering an intervention for arthritis, drumming might not be the most obvious choice. However, as chronic health problems increase in an ageing population who are likely to experience high levels of physical inactivity, and social isolation, group drumming represents an innovative, non-medical intervention, that creates a space for social connection, with the objective of decreasing anxiety, while increasing wellbeing (Thomson, Camic, & Chatterjee, 2015; Fancourt et al, 2016). It may also represent a creative strategy to engage younger people. In addition, research provides evidence of the potential of group drumming to increase social resilience and alter the inflammatory immune responses that underlie other health conditions, such as anxiety and depression (Fancourt et al, 2016).

In light of growing scientific evidence that group drumming can effect positive changes in psychosocial functioning (Fancourt et al., 2016; Ascenso, Perkins, Atkins, Fancourt, & Williamson, 2018) the DRUMBEAT program was seen as a timely, adjunct intervention for individuals with arthritis, who face both increased risk of future mental health problems, and a reduced QoL (Fuller-Thomson, Ramzan, & Baird, 2016). Following discussions with the research team and both consulting rheumatologist, and manager of Health, Education and Research (AOWA), it was considered DRUMBEAT may fit well within models of self-management of chronic disease in general, given these models also promote a holistic approach to wellness. Furthermore, interventions such as this may also help reduce demands on mental health services, by
encouraging self-management and a focus on primary prevention, rather than secondary prevention, or treatment. Further details regarding the therapeutic value of drumming are discussed in the literature review.

1.1.2 Arthritis: why the confusion?

Arthritis, although very common, is generally not well understood by the public, and is often viewed as less serious than other chronic conditions (Hewitt, 2014). A report from the National Rheumatoid Arthritis Society (NRAS), UK (2013) which aimed to improve society’s overall awareness and understanding of RA, offers a real insight into public perceptions of the disease, and its impact and associated risk factors. The report established how, for the most part, understanding the nuances of arthritis is not easy, and how incorrect assumptions had led the majority to think of arthritis as a disease of the elderly and an inevitable consequence of aging. Whilst some forms of arthritis are associated with increased age, 50% of the Australian arthritis population are aged between 15-64 years (Ackerman, Bohensky, Pratt, Gorelik, & Liew, 2016). In the case of RA, a study by Crowson et al. (2011) indicates the likelihood of a young adult developing the condition in their 20s may be higher than originally thought, particularly in women; the lifetime risk being 1:714 for women and 1:2778 for men. The misconception that arthritis affects only the elderly undermines prevention and effective management of the condition, and creates a sense of futility among the general population (Department of Health [DoH], 2019). According to Arthritis Australia (2019) awareness, prevention and education are key priority areas which require attention, in order to reduce the health burden of arthritis both now, and into the future. Currently, individualised help and support is lacking from the existing health system, with limited services, inequity of access, delays in treatment, fragmentation of care, lack of psychosocial support and a heavy financial burden, being reported as common problems by individuals trying to cope with this devastating disease group (Arthritis Australia, 2019).

Arthritis is not a disease on its own but rather a broad, generic term representing over 100 different types of arthritis and their related conditions (DoH, 2019). It is often referred to as an invisible condition, whereby an individual’s outer appearance can often belie the level of physical and psychological pain associated with this profoundly debilitating and disabling disease. The NRAS (2013) report revealed a great deal of confusion particularly between RA and osteoarthritis (OA), with routine misunderstandings about the disease symptoms. Most
surprisingly, the report indicated 27% of individuals with a personal association to the disease were also not fully aware of the distinct differences in types of arthritis.

Despite different pathogeneses, RA and OA, being the two most common forms of the condition, do present with phenotypic similarities and overlapping characteristics, such as pain and stiffness in the joints (Woetzel et al., 2014). Arthritis is further classified as either inflammatory, or non-inflammatory (DoH, 2019). OA is the most recognised non-inflammatory type, whereas the inflammatory group, which are generally systemic, include RA, psoriatic arthritis (PsA), ankylosing spondylitis (AS), juvenile idiopathic arthritis (JIA) and systemic lupus erythematosus (lupus), among others (DoH, 2019). The term autoimmune is also often used to describe many of the IA diseases, being conditions in which the body's immune system is thought to be involved in causing, or perpetuating the disease (Stolt et al., 2010; Nossent, 2017, p. 25).

![Figure 1: Environmental exposures associated with the development of autoimmune diseases (ADs). Anaya, Ramirez-Santana, Alzate, & Rojas-Villarraga. (2016)](https://doi.org/10.3389/fimmu.2016.00139)

The specific aetiology for autoimmune diseases remains unclear, with Figure 1 showing some of the suspected causes: bacterial, or viral infection, effects from certain drugs, chemical toxins and environmental pollutants, the Western diet, and genetics, among others (Anaya et al., 2016;
Stolt et al., 2010; Nossent, 2017, p. 25. A study by Tobón, Youinou and Saraux (2010) established links between an increased risk of RA and smoking, which is currently considered to be the foremost risk factor. While individual diseases, such as RA, can have their own unique symptoms, the underlying cause in all autoimmune diseases, is a failure of the underlying mechanisms of the immune system and it is hoped this commonality will help pave the way for a greater understanding of and potential treatments for autoimmune diseases (Anaya et al., 2016). Even with recent biomedical advances, a cure remains elusive and RA remains a QoL epidemic (Casey, 2015; National Rheumatoid Arthritis Society, 2013). To ensure optimal physical and psychosocial functioning and a quality of life, the focus of arthritis treatment is a multidisciplinary approach to slow progression of the disease and control symptoms, whilst minimising its intrusiveness as much as possible (Casey, 2015).

1.1.3 Arthritis and the growing demand for complementary and alternative therapies
An increasing number of individuals faced with lifelong medical conditions such as IA, for which there is no known cure and the possibility of considerable sequelae, are searching for complementary and alternative (CAM) strategies, in an attempt to improve the quality of their lives (Armstrong, Thiébaut, Brown, & Nepal, 2011). A systemic review by Reid, Steel, Wardle, Trubody, and Adams (2016) revealed Australian adults with arthritis, particularly women, as having a high prevalence of CAM use, alongside conventional treatments (Table 1).

Table 1: Prevalence of Australian adults who treat their chronic condition with CAM 2004-2005 (Armstrong et al., 2011)
According to the National Health and Medical Research Council (NHMRC, 2017), use of CAM is one of the most rapidly developing approaches to self-management for chronic disease in Australia and a well-established part of healthcare. These findings are not surprising, as although regular medications to manage IA have greatly improved, they do carry some notable and serious side effects such as organ damage, severe skin reactions, higher risk of lymphoma, weakened immune system, leading to higher risk of infections, and neurological complications (Rentsch, 2017, p. 101; Reid et al., 2016).

CAM is commonly divided into two divisions: complementary and alternative. Chiappelli, Prolo, and Cajulis (2005) stress the importance of distinguishing between the two as complementary medicine is used in conjunction with, or alongside, conventional medical treatments, whereas alternative interventions are there to replace traditional therapies (Chiappelli et al.). As a consequence, complementary strategies are more widely recognised and approved by many healthcare professionals, whereas alternative therapies are not so readily accepted (Chiappelli et al.). The broad range of CAM modalities are divided into five domains (Table 2) (National Centre for Complementary and Alternative Medicine [NCCAM], 2010). Whilst the DRUMBEAT program is not specifically defined as a CAM therapy it does reflect the modalities of a complementary mind-body intervention; the focus being on interactions of mind, body and behaviour, with intent to promote healthy behaviours through music therapy (NCCAM, 2010).

Table 2: Five domains of CAM modalities adapted from NCCAM (2010).
Despite the challenge presented by the increasing incidence of chronic disease and a growing awareness of the importance of preventive health that is driving the growth of the CAM industry in Australia, at the time this study commenced, the amount of evidence-based research on CAM therapies varied widely, depending on the classification. Music therapy is shown to be the most extensively researched intervention in the area of mental health, whereas group drumming is particularly under-represented (NHMRC, 2017; Wood et al., 2013).

1.2 Background and significance to the study

Currently Australia achieves excellent health outcomes, but in coming decades the health system will be defined by its capacity to manage, and respond to, the increasing prevalence of chronic conditions (Wilcox, 2014). Arthritis is a much bigger issue than many people realise. A 2019 report by the Australian Institute of Health and Welfare (AIHW) reveals that the cost to the health system of treating arthritis and other musculoskeletal (MSK) conditions more than doubled in less than a decade, from $5.7 billion in 2008-9 to $12.5 billion in 2015-16. In total, these conditions now represent the most expensive disease group in Australia (Table 3).

Table 3: Health system expenditure by disease group, 2015-16 (AIHW, 2019).

Arthritis is also a recognised National Health Priority Area (NHPA), yet there is major disparity between the burden and cost associated with this disease group on the one hand, and its prioritisation in policy and resourcing on the other (Arthritis Australia, 2016; Ackerman et al.,
2016). It remains the most chronically underfunded NHPA; as government investment is considerably lower than for any other major disease group, with the exception of asthma (Figure 2) (Arthritis Australia, 2017; DoH, 2019). As the leading cause of chronic pain and the second most common cause of disability and early retirement due to ill health in Australia, arthritis is costing the economy over $7 billion a year, in addition to over $1.1 billion per annum in extra welfare costs and lost tax revenue (Arthritis Australia, 2017; Schofield, Shrestha, & Cunich, 2016).

Figure 2: NHPA (2016) compared to burden of disease (2011) (Source NHMRC).

The impact of RA alone on employment figures is concerning, with unemployment, long-term absence from work and early retirement, all potential outcomes of the disease (Hansen et al.,
Figure 3 illustrates how individuals with RA are twice as likely as the rest of the population to not be in the labour force and, of those working, only 31% are employed full time, compared with 52% of the general populous (Ackerman et al., 2016; AIHW, 2015; Schofield et al., 2016).

In a long-term study Hansen et al explored the social limitations imposed by RA. By comparing the rates and risks of long-term sickness absence, unemployment and disability pension, and the chance of returning to work and the changes in these risks over time (1994-2011) the study identified 50% of individuals who worked before disease onset, stopped working within ten years of diagnosis, and between 20-30% were unable to work two to three years following diagnosis.

Australian data relating to RA incidence, treatment, costs and outcomes are limited, and Arthritis Australia (2014) view this as a major barrier to recognition of the impact and potential severity of RA by the public, clinicians and policymakers. Projected costs of arthritis to the health system are expected to increase across the board for all types of arthritis and MSK conditions, across all Australian states. When looking at the figures for RA in Western Australia (WA) alone (Table 4), estimated costs, based on population growth rates from 2015, are
forecast to rise by 50.0%, from $47.89 to $71.82 million by 2030, as prevalence and costs increase in line with national data (Arthritis Australia, 2016; Ackerman et al., 2016).

Table 4: Projected healthcare costs for RA to 2030, by State or territory (Arthritis Australia, 2019)

In addition to the economic impact, data consistently demonstrate the need to consider the profound effect of IA on individuals who live with this painful and disabling group of conditions (Wilcox, 2014; Arthritis Australia, 2016). Whilst not normally life-threatening at the onset, most of the personal burden of arthritis is due to a significant reduction in the QoL, beyond that of the more traditional measures of disease (Wilcox, 2014). The socioeconomic cost for instance, is not just restricted to medical costs (Arthritis Australia, 2017). Significant ongoing expenses are also needed for items such as physiotherapy and other allied health services, prescription and non-prescription medications, CAM therapies and medical equipment and devices (Edelman, 2017, p. 20).

Preventing and reducing the effects of arthritis is a complex public health concern, and the pressing need for a coordinated, and strategic, national response to the challenge, is addressed in the National Strategic Action Plan for Arthritis (2019). Implementation of the actions included in the Plan require collaboration of a wide range of partners-in-health including individuals, all levels of government, non-government organisations, public and private health sectors, together with industry and research. Hence, the current study focussed specifically at individual
level, with the aim of developing a new support program that would assist people with arthritis to proactively manage their condition and become participants in their own health care.

Lastly, although the benefits of individuals taking charge of their health are well documented, for many the costs of doing so can be prohibitive; with neither private health insurers, nor Medicare, offering refunds for a number of complimentary therapies (Bodenheimer, Lorig, Holman & Grumbach, 2002). DRUMBEAT represents a sustainable, low-cost intervention, that can be used alongside conventional treatment. Furthermore, interventions such as this may also help reduce demands on mental health services, by encouraging self-management and a focus on primary prevention rather than secondary prevention, or treatment and recovery.

1.3 Overview of thesis

The thesis has five chapters which allow the reader to gain insight into the unique challenges of adapting and contextualising the learning resources of an already established program, to the needs of individuals living with IA. The text guides the reader through the joys and pitfalls of development, the initial recruitment process and the evolving design issues. The chapters are set out accordingly:

Chapter 1 introduces the research problem, outlines the purpose of the study and provides an overview of this thesis. It begins by discussing the personal motivation behind the study, which originates from my experience of living with RA.

Chapter 2 justifies the specific theoretical frameworks chosen to underpin the approach to the study. This is followed by a structured review of current literature pertaining to the research question and sub-questions. The chapter concludes with the purpose of the study, the key research questions and expected outcomes.

Chapter 3 discusses the two stages of the research design, namely the intervention development and delivery. The difficulties and solutions surrounding participant recruitment are also discussed in this chapter. Issues arising in the development stage ultimately resulted in changes to recruitment strategies and the program content. In addition, the ethical issues are discussed.
Chapter 4 includes an explanation of the results for both quantitative and qualitative data. Some reflective diary excerpts are also included, detailing personal thoughts throughout the research process. From the onset it became apparent that my own experience with RA increased my personal investment in the project and that my active participation in all aspects of the group sessions was expected, and indeed actively encouraged, by the study participants. Capturing these observations and self-reflection is a central component of qualitative research in relation to increasing transparency (Ortlipp, 2008).

Chapter 5 discusses the findings and their significance. These findings provide a personal insight into the lived experiences of individuals with arthritis and their potential vulnerability. Contextual considerations and limitations in relation to this study are also discussed. A section on engagement and impact follows before concluding with recommendations for further research.
CHAPTER 2: LITERATURE REVIEW AND THEORETICAL FRAMEWORKS

2.1 Introduction

As a multifaceted and fluctuating condition, IA has the ability to negatively impact an individual’s life on a global scale, with the effect on not only physical and psychological functioning, but also self-image, loss of identity and the inability to participate in valued life events (Sanderson, Morris, Calnan, Richards, & Hewlett, 2010). Katz and Yelin (2001) suggest the combination of a chronic physical condition, diminished independence and, in particular, the inability to participate in social and recreational activities, can lead to the development of anxiety and depressive symptoms.

This literature review provides a snapshot of the challenges faced by individuals living with IA. Firstly, it outlines the reasons for adopting specific theoretical frameworks in the context of this thesis, in particular the biopsychosocial (BPS) framework used to guide the selection of variables to affect quality of life of a population group with arthritis. Next, in order to establish the significance of these health challenges, literature in relation to the vulnerability of adults with IA to anxiety / depression and suicide attempts and the connection between chronic pain and mental health will be discussed. The review goes on to detail additional factors relevant to this study. The review concludes with current evidence on the benefits of music therapy and more specifically, group drumming.

2.2 Theoretical Frameworks

A number of theories were selected to help guide this research: the BPS model (Engel, 1980), the self-efficacy theory (Bandura, 1978), the DRUMBEAT theoretical model (Faulkner, 2016), and the social cognitive theory (Bandura, 2004). A theoretical framework and research question matrix (Appendix 3) provide an overview of how the frameworks were applied.

2.2.1. The Biopsychosocial Model

Within a more traditional biomedical approach to healthcare the focus is on treatment, rather than prevention (Nolte & McKee, 2008, p. 65). The biomedical model has been defined as one that “excludes psychological and social factors and includes only biological factors” (Stedman, 2006). For more than a century this model has been the dominant force in Western medicine, but in recent years a paradigm shift marks a move away from this long-established model of
healthcare, to one that can more successfully address the challenges of chronic disease (Willcox, 2014). Without doubt, biomedicine still plays a crucial role in healthcare, but in light of emerging health trends, a new and more encompassing view is needed. By rejecting the conventional idea of individuals as passive recipients of care, the BPS model encourages personal management by empowering the individual to take charge of their own health, and commit to long-term behavioural change (Wutzke, Morice, Benton, & Wilson, 2017).

The BPS model illustrates the importance of psychological and social factors of a disease and promotes an integrated approach to treatment (Engel, 1981; Covic, Adamson, Spencer, & Howe, 2003). Put simply, this model, which has met with both acclaim and criticism, is known as the mind-body connection (Willcox, 2014). Figure 4 (adapted from Keefe, et al., 2002) demonstrates how the biopsychosocial perspective, in which health is understood, as being a product of biological, psychological and social processes. These factors link to several of the measurable outcomes of the current study: anxiety / depression; pain; the need for self-efficacy in the management of IA and the role of social support.

*Figure 4 The biopsychosocial model of arthritis pain and disability. Adapted from Keefe et al., 2002.*
According to Covic et al (2003) numerous studies have shown that adoption of a BPS framework is particularly relevant to chronic disease, which can impact on multiple functional domains. To minimise both the physical and psychological effects of chronic disease effectively it is important to understand why, and how, individuals adopt, or reject, certain health behaviours (Ryan & Carr, 2016). As an example, when biomechanical and/or physical issues are present, the source of the acute pain is generally identifiable and treatable, as seen in joint degeneration (Covic et al., 2003). However, chronic pain is an ongoing experience associated with a plethora of additional symptoms that help demonstrate the bi-directional relationship between pain, fatigue and psychological stress. This relationship can significantly change the course and prescriptive management of conditions such as arthritis (Sturgeon, Finan, and Zautra, 2016).

Consequently, the BPS model recognises how the biological, psychological and social factors, unique to each individual, must all be simultaneously addressed (Sturgeon et al; Nicassio, 2016; Ryan & Carr, 2016). Yet, establishing how these factors affect health is only the first step. Ryan and Carr emphasise the main strength of the model as being a framework for individuals to actively self-manage. Evidence suggests that effective self-management support strategies, such as cognitive behaviour therapy (CBT), that encourage the individual’s capacity to change themselves (their thoughts, feelings and behaviours) can have a positive impact on clinical outcomes (Nicassio, 2016; Ryan & Carr, 2016). Based on this rationale, the current study includes measures for self-efficacy, and enhanced coping strategies, as critical components of QoL.

2.2.2. Self-efficacy Theory

Bandura (1978) posits that self-efficacy reflects an individual’s confidence in their ability to perform and achieve a desired outcome; namely, how to exert control over one's own motivation, behaviour, and social environment. Self-efficacy is considered to exert its influence through four major processes (Figure 5); performance accomplishment, vicarious experience, verbal persuasion and physiological states (Bandura, 1978).

Coping with IA requires a substantial level of self-management, and research implies that enhancing an individual’s self-efficacy to encourage positive health behaviours is an essential feature of any successful self-management intervention (Brady, 2011). Thus, the measurement
of change in self-efficacy was a key component of this study and discussed further in the literature review (see section 2.3.5).

2.2.3. The Social Cognitive (Social Learning) Theory

The Social Cognitive (social learning) Theory (Figure 6) recognises past experiences, social context and environmental factors, as key influences on behaviour change (Bandura, 2004). The theory provides opportunities for social support through instilling expectations, self-efficacy, and using observational learning and other reinforcements through a shared sense of purpose (Nabavi, 2012). It is frequently used to guide behaviour change interventions, such as the current DRUMBEAT study, and is useful in understanding the influence of the social determinants of health and a person’s past experiences of behaviour change (Bandura, 2004).
2.2.4. The DRUMBEAT Theoretical Model

The conceptual framework used to develop, plan and deliver the study sessions and group discussions was guided by DRUMBEAT’s underpinning theoretical model (Figure 7). Holyoake (2017) describes how the Drumbeat program focusses strongly on reducing social isolation by increasing both the social skills and self-efficacy of participants (Holyoake, 2017). This strategy derives primarily from the Social Learning Theory (Bandura, 2004) that places the social context as a primary influence on behaviour. This model offers a range of easy, non-threatening engagement strategies that do not require previous exposure to drumming (Holyoake, 2017).

DRUMBEAT is based on five Core Elements; core rhythms, discussion and storytelling, games, improvisation and performance (discussed in more detail in Chapter 4 - intervention development) (Faulkner, 2006).
This particular selection of known theories, although used to frame the pilot study, also allowed freedom of outcomes and themes to emerge naturally from the participants involved in this study.

Figure 7: DRUMBEAT Theoretical model. Image courtesy of Holyoake (2017).
2.3 Literature Review

From a biopsychosocial perspective, the main components of this study centred around the possible impact of a group drumming program, such as DRUMBEAT, to help manage the pain associated with IA and the psychological factors that significantly contribute to the experience of that pain, such as life stressors, social support, or isolation.

2.3.1 Stressors related to arthritis

Like countless communities that manage chronic health, the arthritis population has complex health needs (Keefe et al., 2002). As the clinical outcome for most types of arthritis is variable and difficult to predict, the disease management of inflammatory conditions is particularly challenging for both the individual, and clinician alike (Bagchi, 2011; Arthritis Australia, 2017). When considering RA, part of the difficulty is the nature of the disease itself. Being a multifaceted and fluctuating condition, with no universal pattern of symptoms, the level of variability between individuals can differ greatly from severe, to almost invisible (Bagchi, 2011). RA, in how it presents, is predictable only in its unpredictability, and often no two people share the same experience (Katz & Morris, 2007; Kvien & Uhlig, 2005). This unpredictable deterioration in health status and loss of independence has been shown to negatively impact an individual’s emotional state, leaving them vulnerable to bouts of anxiety, depression and feelings of helplessness; with the possibility of much poorer health outcomes, and treatment response (Bagchi, 2011; Casey, 2015; Keefe, Smith, Buffington, & Gibson, 2002).

While the physical impact of IA is generally well documented and widely researched, less is known about the significant psychosocial factors and their negative affect (Backman, 2016). Living with chronic arthritis can threaten an individual’s ability to participate in many of the normal life activities, freely and without pain (Backman, 2016; Versus Arthritis, 2018). IA can negatively impinge on independence, employment, financial resources, relationships with family and friends, and the ability to engage in everyday social situations; all the activities needed to live a quality life (Backman, 2016; Versus Arthritis, 2018). Family difficulties are far-reaching and can extend from the inability to perform physical parenting duties, to possible fertility issues, or the inability to continue with intimate relationships (Evans, Shipton, & Keenan, 2005). According to Backman (2016) many individuals with IA, women in particular, commonly suffer from sleep
disturbances, fatigue, sexual dysfunction, poor self-image and, not surprisingly, depression and mood / behavioural changes.

People living with any chronic disease confront similar kinds of stress as everyone else, with stress being an unavoidable part of life (Eustice, 2019). However, whilst stress and anxiety are a common response to pressure situations, when added to the additional medley of complications created by living with IA, they are shown to increase the possibly of developing poor mental health (Eustice, 2019; Matcham, Rayner, Steer, & Hotopf, 2013). In summary, Eustice states that living with an invisible illness that does not necessarily affect appearance but does significantly affect the ability to do normal daily activities, can impact considerably on a person’s psychological wellbeing.

Despite the increased attention on psychiatric conditions comorbid with IA, several studies and reports suggest healthcare providers may not readily recognise mental health problems, and tend to prioritise physical health concerns instead (Machin, Hider, Dale, & Chew-Graham, 2017; Australian Healthcare and Hospitals Association [AHHA], 2017; Arthritis Australia, 2017). A key problem with this negative experience of care is that individuals may feel unable to raise mental health issues for discussion during future consultations, possibly through fear of social stigma and discrimination (Machin et al., 2017). The findings of Machin and colleagues (2017) emphasise the importance of effective patient-doctor communication, as individuals can have very different perceptions of the relationship between their condition and poor mental health. Some may recognise their IA as being related to mood problems, whereas others may fail to see the connection, unless highlighted by their medical specialist. Overcoming potential barriers to the discussion of mental health issues is important as it fosters an individual’s ability to better manage the psychological burden associated with their IA (Arthritis Australia, 2017).

Unfortunately, a relatively recent survey indicates the problem as still ongoing— with only 30% of individuals who received treatment for IA are satisfied with the support they received for emotional and mental wellbeing (AHHA, 2017).

2.3.2 Prevalence of anxiety and depression with inflammatory arthritis

There is a complex relationship between anxiety and depression that makes it difficult to differentiate between the two (Davidson, 2000). Davidson states that while the two share commonalities, they are separate conditions and the causes of each generally determine if the
individual affected will go on to develop anxiety, depression, or both. Knowing the difference between anxiety and stress is critical to health. Stress is generally regarded as a response to a specific external cause, whereas the origin of anxiety is more internal (Eustice, 2019). Unlike stress, anxiety persists even after the cause has passed and is typically characterised by a ‘persistent feeling of apprehension, or dread in non-threatening situations’ (Moss, 2016). What makes depression different is the severity of symptoms (National Institute of Mental Health [NIMH], 2018). The symptoms of major depression, such as persistent low mood, profound sadness, or a sense of despair, are defined as lasting at least two weeks but usually last much longer — months or even years (Davidson, 2000).

In the first Australian report to quantify how chronic physical health contributes to a wide range of mental health conditions, including anxiety and depression, the Australian Mental and Physical Health Tracker reveals over a quarter of Australians living with arthritis experience some mental health concerns (Harris et al., 2018; AIHW, 2018). The report shows almost 46% of women and a high percentage of men aged ≤ 44 years, living with arthritis-related conditions, were more likely to have a mental health condition than the general population (Table 5) (Harris et al., 2018; AIHW, 2018).

Table 5: Arthritis and mental health risk indicator (Harris et al., 2018)
Although the numbers reported demonstrate, arthritis-related conditions are associated with major psychiatric morbidity, to what extent is debatable (Covic et al., 2012). To demonstrate the inconsistency in prevalence rates, a systematic review and meta-analysis conducted by Matcham and colleagues (2013) established the rate of depression in RA at around 17%. A later study by Jacob, Rockel, and Kostev (2017) reported a significantly higher rate of (30%). A further study from the same year, by Machin et al (2017) reported 39%. Murphy, Sacks, Brady, Hootman, and Chapman (2012) established anxiety as being even more common than depression, among adults with RA. According to Covic et al. disparity in these prevalence rates may depend on various factors: the population, the type of arthritis, the size of the study and the variation in measurement tools used. These data, however, show that the rates of anxiety and depression can be between two- and ten-times greater than the rates of the general population, depending on the type of arthritis (Covic et al., 2012).

A recent systematic review by Kamalaraj, Hay, and Pile (2019) examining the relationship between Psoriatic Arthritis (PsA) and depression, identified an even higher propensity for psychiatric comorbidity than that seen in other arthritis conditions, with suggestions that the differing role of inflammatory responses in PsA, when compared with RA, may play a part.

### 2.3.3 Risk of suicide

An important finding of a 2016 Canadian study shows that having arthritis doubles an individuals’ risk of suicide attempts (Fuller-Thomson, Ramzan, & Baird, 2016). The two main objectives of the study were to determine the odds of suicide attempts among those with IA, and to identify the factors associated with suicide attempts in this population group. To further understand how arthritis and suicide are linked, their study included a large nationally representative sample of 21,744 individuals, including 10,032 men and 11,712 women, 4,885 of whom had IA. Fuller-Thomson et al went on to report 1 in 26 men with IA had attempted suicide at least once, compared to a much lower rate of 1 in 50 among men without IA. Similarly, the prevalence of suicide attempts in women with IA was higher than in those without the condition (5.3% vs 3.2%, respectively). After adjustment for mental health status, age, income and chronic pain levels, results still showed those with IA as having a 46% higher risk of attempted suicide than those without the condition. Although no causable link was established and further research on the topic is needed, the findings of Fuller-Thomson et al do help highlight how
suicide attempts can correlate to not only mental health but also to having a chronic condition, such as IA.

In summary, studies repeatedly demonstrate an association between IA and anxiety / depression. Having reviewed the dearth of literature in regard to how physical and mental health are fundamentally linked, it would appear the frequency with which the two are connected is less understood. Experiencing firsthand the psychological toll of living with IA, I am able to appreciate how integrated support for mental and physical health is fundamental in fostering resilience, self-awareness, and overall wellbeing.

2.3.4 The Chronic Pain / Mental Health connection

Much remains to be learned about the mechanisms and effects of inflammation related to IA, but the intimate relationship between physical pain and mental health, in regard to overall functioning and QoL, is now indisputable (Harris et al., 2018). Sturgeon et al (2016) demonstrated how the bi-directional relationship between pain, fatigue and psychological stress can change the course and management of arthritis. Of concern, is that when depression co-exists with IA, the effects exerted on functional disability and QoL are not merely additive, but rather multiplicative, with each amplifying the effect of the other (Sturgeon et al, 2016) (Figure 8).

One review by Sharpe (2016), examined numerous publications, meta-analyses, and individual randomized clinical trials on psychosocial interventions for pain management in arthritis. Sharpe concluded that for individuals with RA, especially early in the disease course, cognitive behavioural therapies (CBT) were the most effective strategies, that showed the strongest evidence-base. These findings had implications for the current study, as CBT interventions are integrated into the DRUMBEAT program, including some of the more frequently used techniques such as mindfulness, stress management, problem solving, goal setting, assertiveness, managing relapse and coping strategies (Beattie, 2018). Sharpe reasoned that CBT helps individuals develop a more optimistic, yet realistic, attitude toward their health condition, whilst also helping them manage other life stressors.
2.3.5 Self-efficacy

A considerable amount of literature has been published on the importance of self-efficacy in understanding arthritis management and interventions. Self-efficacy, in the context of arthritis, is described as an individual’s belief in their own ability to make the necessary behaviour changes to control pain and, where possible, prevent deterioration of their condition over time (Keefe & Somers, 2010). It has been conclusively shown that due to the strong relationship with health behaviours, self-efficacy is one of the most important psychosocial factors to influence outcomes in arthritis self-management interventions (Brady, 2011; Primdahl, Wagner, & Hørslev-Petersen, 2011). A literature review of 74 studies reported that those with IA experience a growing association between lower self-efficacy and higher levels of pain, poorer physical functioning, increase in fatigue and heightened anxiety and depressive symptoms (Primdahl et al., 2011; Keefe et al., 2002; Keefe & Somers, 2010). Individuals with low self-efficacy are also likely to be less proactive with their self-management (Primdahl et al., 2011; Keefe et al., 2002). Therefore self-efficacy was a relevant measure to use in this study of an intervention to encourage self-management.

Figure 8: Poor mental health can negatively impact physical symptoms of RA (adapted from Sturgeon et al., 2016).
As previously discussed in section 2.2.2 self-efficacy is considered to exert its influence through four major processes of performance accomplishment, vicarious experience, verbal persuasion and physiological states (Bandura, 1978). Participation in the DRUMBEAT program allows the opportunity to feature a combination of all four processes, within this study:

1) Mastery Experiences are the result of self-efficacy firsthand. For those who performed a certain task in the past are more likely to have a strong belief they can accomplish that task again in the future. To help increase this source of self-efficacy DRUMBEAT encourages participants to master the art of drumming by setting small weekly goals. Participants are reminded throughout the process that having some setbacks along the way is normal and that their goals should have an element of challenge but also be realistic and attainable.

2) Vicarious learning is derived from indirect sources such as hearing, or observation, rather than direct, hands-on, instruction. In observational learning, participants are influenced by listening to and watching others in the group. Seeing others, specifically role models, succeed and reach their goals despite adversity, raises the observers’ belief in their own ability to succeed.

3) Verbal Persuasion is often dependent on finding the right supportive network. While vicarious learning refers to the observation of a role model, verbal persuasion is having others directly influence one’s self-efficacy.

4) Emotional and Physiological factors. Emotions, moods and physical states all influence our interpretation of self-efficacy. Hence, positive moods increase feelings of self-efficacy, whilst negative moods can reduce it. As an illustration, everyone can become nervous when attempting something new, such as drumming. What is important is how they interpret that nervousness; as excitement at the prospect of stepping outside of their comfort zone, or as anxiety and fear.

2.3.6 Social support / Social media

Given that the current study included a closed Facebook group, some literature is reviewed briefly to understand the implications of social factors in the psychological reactions to IA disease activity. Lanza and Revenson (1993, p. 97) define social support as the “processes by which interpersonal relationships promote well-being and protect people from health declines,
particularly when they are facing stressful life circumstances.” Humans are reliant on connection with others for survival and any social exclusion has the capacity to influence a variety of biological responses (DeWall, & Bushman, 2011). The brain does not process emotional pain and physical pain identically but there are underlying commonalities (Sturgeon & Zautra, 2016). It is suggested by Sturgeon and Zautra that exposure to socially painful conditions, such as exclusion and isolation, a common occurrence when living with IA, can result in poor sleep quality and a compromised immune system. An earlier study by Benka et al. (2014) found that engaging with supportive people, whether family, friends, or support groups, was associated with less depression and helped improve outlook and coping skills, something that research has linked to less pain and fatigue in IA. The effect is shown to be bi-directional, in that individuals with a low level of social support, experience higher levels of pain and more functional problems (Benka et al., 2014).

Accumulating evidence reveals that building stronger social connections through participation in social groups, or networks, can help relieve the damaging psychological, behavioural, and physiological effects of isolation, or rejection (Sturgeon & Zautra, 2016). Sturgeon and Zautra propose that psychological interventions which build supportive social relationships could have a profound impact on the overall health outcomes of IA. Hence the collaborative concept of a group drumming program could address this and enhance the idea of self-management.

### 2.3.7 Arthritis and Quality of Life

QoL is seldom clearly defined within the health arena (Barcaccia et al., 2013). Due to the unpredictability of disease progression in chronic arthritis, any measure of QoL is highly subjective and multidimensional, and how and what to measure continues to be debated (Garip, Eser, & Bodur, 2011). Nonetheless, QoL remains a major area of health research and an important patient-reported outcome of arthritis (Garip et al., 2011).

A 2011 study reported the health-related quality of life (HRQoL) for U.S. adults with arthritis as much worse than for the general populous (Furner et al., 2011). Based on data collected over three years, from a nationally representative sample of more than one million adults, the five HRQoL indicators measured overall health, number of both physically / mentally unhealthy days in the study period, number of days in which daily activities were restricted by overall poor health, and total of both physical and mental unhealthy days. Results showed HRQoL for those
with arthritis as being 2-3 times worse than for those not living with the condition. Those with arthritis reported more physically unhealthy days (7:3); more mentally unhealthy days (5:3), twice the number of unhealthy days (10:5), and significantly more days in which daily activities were restricted by overall poor health (4:1) than those without arthritis.

QoL measures are useful in interventions that target behaviour changes, such as DRUMBEAT, as they help shed light on aspects of life that are important to the specific participant group, many of which often extend beyond supportive health interventions (Palmer & Miedany, 2016). For this reason, the numerous biological and psychosocial benefits that are inherent to group drumming are gaining recognition across social, physical and psychological healthcare domains (Kalani Music, 2002; Yap, Kwan, & Ang, 2017).

2.4 Drumming as a therapeutic tool

2.4.1 The power of music: how it can benefit health

The belief that music can regulate mood and promote physical and psychological health and well-being, dates as far back as Palaeolithic times (Macdonald, 2013). More recently, this universal potential of music has led to significant and growing academic, media and public attention; exemplifying the vibrant diversity of interests both within the traditional biomedical arena, and non-clinical settings (Macdonald, 2013; Bittman, Berk, Felten, & Westengard, 2001). Although the traditional research-based music therapy, performed within the confines of medical, or educational environments, generally remains more acceptable to health professionals, the 21st century has brought about a significant change in conventional therapy, one that continues to challenge traditional boundaries and definitions; namely that of community music (Macdonald, 2013).

In a large-scale review of research into the neurochemistry of music, Chanda and Levitin (2013) were able to clearly demonstrate the benefits of playing and listening to music on both mental, and physical health. According to Chanda and Levitin, in one study, music was shown to help reduce pain and anxiety for children at the Great Ormond Street Hospital. Music is shown to help alleviate stress, independent of social factors, whilst also improving immune system function via both its effect on pulse, heart rate, blood pressure and body temperature,
and by reduction in cortisol levels, the stress hormone within the body (Chanda & Levitin, 2013). The review was able to verify that any relationship between music and health is not, as some consider, solely a “feel-good” treatment, or passive exercise of listening, or playing music, but more a way of addressing a variety of health issues, in a non-clinical setting (Chanda & Levitin, 2013; Hallam, 2005; Wood et al., 2013). The findings of the review allowed Chanda and Levitin to detail the main neurochemical mechanisms by which music exerts its positive effects on health outcomes: mood management, stress, immunity and as a support to social connectedness.

The major health challenges of today’s complex, chronic conditions often require a combination of medical interventions and wider psychological, social and behavioural support (Fancourt, 2019). According to Fancourt (2019) music could provide that support in several ways, be it a recollection session for those with dementia, or a drumming session for mental health support. Scientific data into the neurochemical effects of music is still in its infancy but based on the research to date, there is certainly evidence that music is much more than just an emotional connection. Whilst there remains much debate amongst health professionals as to what constitutes music therapy, the one area of exploration that continues to grow in popularity is drumming; with studies showing a range of positive and measurable effects on overall health (Bittman, Berk, Felten, & Westengard, 2001).

2.4.2 The benefits of group drumming

One of the first studies to investigate the therapeutic potential of drumming, published in 1970 by Jorgenson and Parnell, indicated a strong positive correlation between drumming and improved social and emotional behaviours and self-esteem in children with special needs. In 2001, Bittman, a clinical psychologist specialising in neurobiofeedback for stress management, co-authored the paper Composite Effects of Group Drumming Music Therapy on Modulation of Neuroendocrine-Immune Parameters in Normal Subjects. This foundational study was the first known research using group drumming to create biological changes in patients. Findings from this study indicated a unique collective effect that occurred when basic cognitive behavioural techniques were combined with the physical act of drumming (Bittman, Berk, Felten, & Westengard, 2001). Being the first study of physiological effects of drumming on human biology, drumming was shown to boost immune system ability, with an increase in natural killer (NK) cell activity (Bittman et al., 2001). The following measures were taken before and after the
drumming session: plasma cortisol, plasma DHEA, plasma DHEA-to-cortisol ratio, NK cell activity, LAK cell activity, plasma interleukin-2, and plasma interferon-gamma. According to Bittman (2001) DHEA-to-cortisol ratios suggested a shift in adrenal steroids in an immune-enhancing direction, and LAK and NK cell activity confirmed immune system enhancement. Done regularly, a drumming activity may produce lasting, sustained immunological effects for individuals facing long-term conditions for which an increase in killer cells is beneficial (Bittman et al., 2001).

Building on previous research, Bittman, Dickson, and Coddington (2009) customised a group drumming program as part of a court-referred rehabilitation technique for at-risk inner-city youth. The study was the first of its kind to test a drumming protocol as a catalyst for non-verbal and verbal disclosure to empower success with at-risk youth (Bittman et al., 2009). This ground-breaking research demonstrated statistically significant improvements in the level of instrumental anger in addition to improvements in school/work performance and behaviour toward others (Bittman et al., 2009). Less depression, less reactive anger and less interpersonal problems were reported in participants, than in the control group who did not participate in the music activities (Bittman et al., 2009). In addition, extended impact (experimental vs control) was characterised by statistically significant improvements continuing 6 weeks after completion of the protocol.

Earlier studies by Bittman and colleagues (Bittman, Bruhn, Stevens, Westengard, & Umbach, 2003; Bittman et al., 2004) demonstrated how group drumming can be used outside of the healthcare arena. The findings of Bittman et al (2003) suggested participation in group drumming as a cost-effective means of reducing staff turnover. As staff turnover rate in long-term care facilities is shown to be high, mainly due to emotional factors, such as burnout, 112 employees at a retirement community were asked to participate in group drumming sessions for one hour per week, for six weeks (Bittman et al., 2003). Before and after each session participants completed questionnaires designed to assess their mood. Participants included nurses, dietary workers, accountants, administrators and housekeepers. Immediately following the sessions, a 46% improvement in total mood disturbance was noted and a 62% improvement 6 weeks post intervention, suggesting that emotional boost can continue long after the music has ended. Moreover, during in the year following the study, 49 fewer employees resigned than in the previous year. Based on the 18.3% reduction in employee turnover, the projected economic implications for the long-term care industry as a whole are significant, with total
annual savings estimated at US$1.46 billion (Bittman et al.). In a more recent study Bittman et al hypothesised that participation in a 6-session drumming program, focusing on group support and stress reduction would improve the mood states in first year nursing students and help reduce burnout rates (POMS-Profile of Mood States & MBI-Maslach Burnout Inventory) including: tension/anxiety, depression/dejection, anger/hostility, vigour/activity, fatigue/inertia and confusion / bewilderment. A 28.1% improvement was recorded in total mood disturbance. Analysts concluded that use of drum circles in this population group could help improve retention rates for nurses and result in cost savings of more than USD1.5 billion for the US healthcare industry, as a whole.

Drumming is proving to be an effective therapy for returning war veterans and others recovering from PTSD. In 2008 Bensimon, Amir, and Wolf published a study titled Drumming Through Trauma: Music Therapy with Post-Traumatic Soldiers. It identified drumming as having the capacity to reduce PTSD symptoms, by allowing individuals to regain a sense of self-control and relieve emotions that may otherwise remain unexpressed. The group drumming was shown to be a holistic, non-intimidating strategy that facilitated access to traumatic memories, and a means of coping with the difficulties of loneliness, latent anger and loss of control (Bensimon, Amir, & Wolf, 2008).

Application to other chronic health conditions have used drumming as an adjunct to therapy. A 2014 study by Smith, Viljoen, and McGeachie found that drumming may improve cardiovascular health due to the physical nature of playing the instrument, whilst decreasing stress and anxiety levels. Smith et al (2014) closely observed two groups of djembe drummers - middle aged experienced and a young beginner’s group - participate in 40-minute sessions, with heart rate monitored at 5-second intervals throughout each session. Blood pressure levels, blood lactate and stress and anxiety levels were also recorded pre- and post-sessions (Figure 9). Smith et al also suggested African drumming as an alternative holistic approach to healthcare for those individuals with other chronic conditions associated with high-stress lifestyles, providing them with a sustainable strategy for physical exercise. Some individuals are physically unable to participate in traditional forms of exercise and drumming could offer a way to sustain a long-term exercise program, without posing any of the possible risks of more intense forms of exercise (Smith et al., 2014).
Additionally, Fancourt et al. (2016) investigated the effects of group drumming on mental health and social resilience, alongside inflammatory immune response, in adults with access to mental health services. Compared to the control group, the drumming group displayed a marked decrease in depression and increase in social resilience, followed by significant improvement in anxiety and mental wellbeing (Fancourt et al., 2016). All psychological improvements were maintained at three months follow-up, as was a shift away from a pro-inflammatory towards an anti-inflammatory immune profile (which correlates with mood improvement) (Fancourt et al., 2016).

There is limited scientific data documenting additional physiological benefits of drumming such as improved pain management and elevated pain levels (Kostas, Ian, & Vinnie, 2012); retraining the brain after a stroke, or other neurological impairment, as with Parkinson’s and Huntington’s (Metzler-Baddeley et al., 2014); even in late-stage Alzheimer’s the physical act of drumming allows individuals to copy simple rhythms (Yap et al., 2017). This form of interaction in Alzheimer’s, no matter how transient, takes on great significance when considering that all other forms of communication have diminished (Yap et al., 2017). These findings are consistent with the knowledge that music engages areas of the brain concerned with motivation, emotion, cognition and motor function (Yap et al., 2017). In their systematic review Yap et al (2017) go one step further and recommend that drumming should become an accepted part of integrated...
medicine; the blending of conventional and evidence-based natural and complementary medicines and/or therapies with lifestyle interventions to treat the whole person, rather than just the disease.

2.5 Conclusion

The health of adults with IA is not just important in terms of individual wellbeing but also as a major determinant of economic, and social development. Investment in research to improve the health of the arthritis population as a whole is a key strategy for preserving Australia’s economic future.

The literature review has helped gain a better understanding of the therapeutic value of drumming as an effective intervention for the arthritis population. Numerous studies (Bittman et al., 2001; Bittman et al., 2003; Bittman et al., 2004; Bittman et al., 2009) suggest drumming as an excellent vehicle for building resilience and for practising patterns of thinking and behaviours using rhythmic analogies that enhance overall wellbeing, and mental health. Drumming is shown to reduce stress, improve mood, reduce anxiety and depression, reduce burn out and fatigue, and improve immune functioning (Bittman et al., 2003; Fancourt et al., 2016). When combined with basic CBT components, a unique collective effect occurs that can further enhance mood levels and increase self-esteem (Bittman et al., 2001). Drumming has the potential to reduce cognitive problems associated with brain injury, other disabilities or disorders (Metzler-Baddeley et al., 2014). Drumming may improve cardiovascular health due to the physical nature of playing the instrument and also be considered as a long-term exercise program for those individuals unable to participate in more intense forms of exercise (Smith et al., 2014). Group drumming has the capacity to enhance self-efficacy through the experience of mastery, improvisation and social persuasion; all core elements within the DRUMBEAT program (Faulkner, 2016). By inducing a stable mood state in cases of PTSD, it allows individuals to regain a sense of self-control and relieve emotions that may otherwise remain unexpressed (Bensimon, Amir, & Wolf, 2008). Group drumming brings people together in a way that fosters social inclusion and positive social and emotional well-being (Wood et al., 2013). The facilitation of social connection through participation in a drumming group, can relieve the damaging psychological, behavioural, and physiological effects of isolation, or rejection (Sturgeon & Zautra, 2016).
The body of research and quantifiable data on the benefits of drumming is mounting but no studies have been identified at the time of this literature review, that investigate the effects of drumming with arthritis. With evidence that group drumming can help in building emotional resilience and coping skills, this study was a timely and well-targeted intervention for those individuals who face an increased risk of future mental health problems. The results enable a greater understanding of the diversity of self-managed interventions used outside the clinical domain, whilst also helping to raise the awareness and confidence of health professionals to support such interventions. Equally important is the possibility of further research on DRUMBEAT, tailored to other chronic health conditions.

In summary, group drumming may have the ability to be a non-intimidating, holistic strategy to promote positive and significant enhancement of physical, psychological, emotional and cognitive functioning, one through which people of all ages and ability levels can achieve a sense of success, and a connection with others.

2.6 Purpose of the study

The initial aim of the study was to:

Understand the unique experiences of those individuals living with IA, as expressed by the research participants in this study. This is considered an essential first step in public health research because it enables the reader to empathise with the challenges of this diagnosis. Having this perspective as a starting point, means that the reader can gain an insight into the worlds of IA patients before the main objectives of the research are addressed and the results presented.

The subsequent and overarching aims of the research were to:

1) extend the DRUMBEAT program to meet the needs of an arthritis population and tailor resources and facilitation accordingly;

2) evaluate each individual participant’s experience of the intervention, and;

3) establish if a DRUMBEAT intervention could provide an enabling environment for people with arthritis, one that facilitates a sense of belonging and offers an opportunity to improve
individual self-management skills, through participant support of those in a similar situation to themselves.

Therefore, the approach of this thesis is to help understand what is important to adults with arthritis living with their condition, and how to avoid the things that make their arthritis worse. Hence, the primary impetus for conducting this research was not to determine if the adapted DRUMBEAT program was feasible or sustainable for IA patients, but to determine whether innovative and novel programs like this, might offer benefit in terms of QoL, improved coping, self-efficacy. As such, the research is driven by the following key questions:

2.7 Research questions

Specifically, does participation in a 6-week DRUMBEAT program influence:

- The needs of a group of individuals with chronic inflammatory arthritis?
- Quality of life?
- Self-efficacy?
- Ability to cope with arthritis signs and symptoms?
- Social support through the group?
  - Can social support be successfully augmented through a closed Facebook group to provide a health promoting environment?

2.8 Expected outcomes

DRUMBEAT, through its holistic approach, aims to create social inclusion through engaging in a community-based music therapy group. Cognitive behavioural therapy interventions are also integrated into the program that further increase self-efficacy, which in turn has been shown to increase social and emotional wellbeing among high priority population groups (Beattie, 2018).

Although DRUMBEAT had not already been trialled is chronic disease communities, it was intuitive that the program would fit well within models of self-management of chronic diseases given these models also promote a holistic approach to wellness. Based on the evidence that a number of components included in the DRUMBEAT program make it a useful addition as a treatment modality for emotional health and wellbeing, it was expected that:
• Participation in the DRUMBEAT program would have a positive impact on emotions and emotional regulation.
• Participants would build self-confidence and self-esteem.
• A sense of community would be experienced by participants, particularly through an enhanced sense of support and a common connection with other group members.
CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

Chapter three describes the rationale for a mixed method approach used in this study. The methodology and the methods employed are also put forward in this chapter. Each step taken in designing and conducting the study is documented to outline the approach, design, data collection and analysis methods employed. Furthermore, the issues of validity, reliability and ethical considerations adhered to throughout the study, are discussed. The considerable formative work undertaken prior to commencing this study is explained. The recruitment strategies and the difficulties and solutions, are also reported in this chapter.

A pragmatic mixed method approach: of the four common paradigms (post-positivism, constructivist, participatory and pragmatism), all of which provide a different perspective pragmatism, or worldview, was chosen to guide the present study (Creswell, 2013). According to Creswell, a pragmatic approach gives rise to the use of mixed methods, and allows a researcher to address questions that do not sit comfortably within a wholly quantitative, or qualitative approach, to design and methodology. Adopting a “what works” tactic to best address the research question grants the freedom to use any method typically associated with quantitative, or qualitative research, whilst appreciating that every method has its limitations, and that different approaches can be complementary (Creswell, 2014). In this study, the methods are integrated during data collection and analysis, with more emphasis placed on qualitative interpretation of the data, in terms of the dominant aim of the research (Lingard, Albert, & Levinson, 2008). The clear and considered relationship of mixed methods helps ensure triangulation of data, to produce greater insight than use of a singular method (Lingard, 2008).

3.2 Research Design

Figure 10 illustrates the major steps of the research: (Stage 1) a reference group to inform study design; (Stage 2) formative phase specifying who will participate in the study; the content of the program; how, when, and where the program will be implemented and how data will be
collected and pre-intervention measures; (Stage 3) intervention phase (Stage 4) post-intervention analysis and reporting of relevant data and findings.

Figure 10: Diagrammatical representation of research design for proposed study
3.3 Stage 1: Focus group

A consultative group was established in March 2018 to guide the pilot study design. The group included representatives of key stakeholder organisations, health professionals, service providers, and one representative of the population group of interest (≥18-30 years). A rheumatologist and chairman of Arthritis and Osteoporosis WA (AOWA) and an ophthalmologist with an interest in inflammatory conditions both agreed to act as external advisors, if required. A list of attendees is provided in Appendix 1. The group met face-to-face to identify key areas for the adaptation of DRUMBEAT for use in a young arthritis population group. A summary of the key points discussed are shown in Appendix 2. Although the focus group was a useful place to start to share ideas and ask questions, there was limited relevant discussion. At this early stage in study development the motivations of those who participated were quite varied and there were conflicting opinions and views as regards the usefulness of such a program as DRUMBEAT, particularly with the younger arthritis population. In short, group dynamics prevented any in-depth discussion. Other approaches were necessary in order to foster more productive discussions. Following an introduction to the Consumer and Community Health Research Network, members of the TAG young arthritis support group, who operate out of AOWA, were approached. These individuals, being a true representation of the younger population group that was originally of interest, played an integral part in the research design. Initial collaboration with the Holyoake project planner, responsible for contextualising DRUMBEAT for groups outside school environments, was also advantageous following the focus group stage. The outcome of the initial meeting with TAG committee members was 1) an offer to help with identifying key issues and potential solutions relating to the recruitment process, and 2) permission to post on the TAG private Facebook group page and 3) inviting members to a series of three 1-hour introductory DRUMBEAT “taster” sessions.

3.4 Stage 2: Formative Phase

3.4.1 Facebook group development

A public Facebook group, RA1830-DRUMBEAT, was created to raise the profile of the upcoming study through social media, and to assist with recruitment. This was an open group to facilitate access to a cross-section of people using a range of platforms for the sharing of information
about the study. Advertising opportunities were also sought on sites that potential research participants were likely to frequent, but not specifically sites based on IA diagnosis. Contact was made with a number of public health-related and community focused social networking sites with different targets, purposes and functions. In total, 21 public and private groups in WA with a link to arthritis agreed to help with advertising the study online, as did a range of community groups covering mainly the northern suburbs and city locations. RA1830-DRUMBEAT group also partnered with organisations that have built their own communities, such as AOWA, Holyoake, Movewell Physiotherapy and St John Medical Centre based at Edgewater WA. This approach allowed the value of the study to reach a diverse group of organisations and for engagement with a wider audience.

In February 2019, ethics approval by the Edith Cowan University (ECU) Human Research Ethics Committee (#19513) was received and recruitment commenced. At this stage the difficulty of engaging young adults in the research became apparent and the Facebook group was renamed DRUMBEAT & ARTHRITIS. Online advertisements (a small selection is shown in Figure 1) were developed and the use of jargon, or technical information, was avoided to keep the messages simple, fun and easy to understand.

In consideration of the anonymity of users, the group privacy status was changed to ‘closed’ in April 2019 once all participants were recruited. Participants were to register on the page using their allocated I.D. number and continue to use this as their sign-in identification throughout the study period. However, at the first week’s discussion all study participants concurred that they preferred to use their own name for the purpose of communicating online. The closed group is ongoing at the time of writing this thesis, as participants requested they be kept in touch as regards the possibility of any follow up drumming sessions. All group members have remained in touch and are keen to impart information regarding their continuing progress. Some of their difficulties and uplifting stories will be outlined in chapter four.
3.4.2 Introductory DRUMBEAT ‘taster’ sessions

In March 2019 a Facebook event was created in collaboration with several co-hosts, including Holyoake, TAG and AOWA, for the series of taster sessions. The overall response was encouraging but unfortunately many enquiries were from people with non-inflammatory OA.
This did highlight the misconception held by many that IA is the same as OA, and the need to create a better understanding of arthritis in general. Despite significant interest and the regular updating of event pages as a reminder to invitees, the impersonal nature of the Facebook platform meant no commitment could be gained from interested parties and the event posts were not a great success.

The free to all “have-a-go” drumming sessions were a suggestion of Holyoake, having been successfully employed in a previous DRUMBEAT study, where recruitment was also an issue. Three ‘taster’ sessions were conducted at AOWA, on the same day and time each week, commencing in March 2019 (See Appendix 4 for minutes from Meetings 1-2). Only two people attended the first session, with several cancelling at the last minute. Unfortunately, this pattern of last-minute cancellations continued for the next two sessions, with only one attendee both weeks. Although none of the sessions were well attended, the socialising opportunities afforded by the meetings allowed for positive connections to be formed with the TAG group organisers, the Holyoake Facilitator and ABC radio, who had requested to come along to the final session.

Taking the time to get to know the TAG group and their experiences was essential formative and some key issues came to light at the meetings, that informed on how recruitment would proceed. In reply to the question:

“There is a perception this age group (18-30 years) is difficult to reach and even more challenging to engage—what can we do to get your group interested in this study?” The following responses were received:

• We (TAG members) don’t like to be specifically targeted. You need to open the study out to everyone and anyone—all ages—not just 18-30.

• Remember most of us [TAG] have lived our whole lives with arthritis and we look at things very differently to someone who has just been diagnosed. We take a different approach to self-management. The newly diagnosed (≤ 2 years) would more likely benefit from this [study] as they might well be older and searching for answers. This is not the case for most of us.

• Our lives/families/jobs/travel/study all take priority and we are generally very “anti” arthritis courses. Rightly, or wrongly, the majority prefer to only think about it [arthritis] when specialist appointments are due, or we are having a flare-up.
• Most prefer to hide the fact they have a disease. They prefer to be very private about their condition, as many have found in the past it affected their chances of gaining employment/making friendships/finding a partner. That’s why our Fb group is tightly regulated. We don’t like just anyone seeing our private lives.

• Incentives don’t work either!

• Even if you could recruit the numbers, we won’t commit to ten weeks, or twice a week over 5 weeks. You need to look at a shorter time frame and run it out of AOWA if you must—one a week. Most of us try to avoid going to Shenton Park [AOWA]

• There is no right platform, or right message for us—it’s just what works on the day – sorry I know we are a difficult lot!
3.4.3 Industry collaboration

Pre-study, a collaborative relationship was developed with AOWA, mainly through communication with the Health, Education & Research Programs Manager. To raise awareness of the study, a drumming session was undertaken at Camp Freedom; a camp held annually for 7-17-year-olds with Juvenile IA. The camp organiser expressed an interest in continuing this association with Holyoake and the DRUMBEAT program at future camps. In order to maximise recruitment through AOWA it was important to have the AOWA staff on board. To address this, a short introductory session to DRUMBEAT was organised, which gave AOWA staff an opportunity to experience group drumming and to voice any concerns and / or questions they...
had about the program. Interest has also been shown by the fibromyalgia and AS support groups, in future group drumming sessions.

By working closely with Holyoake’s program Facilitator and Counsellor and DRUMBEAT Coordinator, the research team were able to tailor the drumming sessions to the issues being addressed, and to the participants involved. This meant the time allocated to the group drumming sessions was used as effectively as possible. Further collaboration determined the program content prior to commencement, to support the research process.

3.4.4 Grant application

Once the study commenced potential funding opportunities were identified to support the cost of drums for future adaptations of the DRUMBEAT program for people with arthritis. Financial support was also requested for the development of the Facilitator’s Manual and 2-day facilitator training course. These resources will be used to assist with ongoing delivery beyond the period of this study and dissemination of the IA-adaptation of DRUMBEAT. It is envisaged that it will be possible to scale-up the program to include additional CD management. Having successfully addressed grant application requirements a Heathway’s Health Promotion Project grant was awarded #33334 and provided six drums for future use.

3.5 Stage 3: Intervention Development Phase

The original proposal was to contextualise the DRUMBEAT program prior to the start of the study, on the assumption it would make the session content more meaningful for the research participants. However, following discussions with Holyoake Senior Project Officer – Social Enterprise, whose responsibility it is to contextualise DRUMBEAT for groups outside the school environment, it was deemed that any suggested adaptations at the pre-study stage need only serve as a road map for the process, not the program content, with specific focus on the how, when and where. Changing the program content beforehand would be to assume that a standard DRUMBEAT program needs to be adapted for arthritis. The question “how can we know before the start if the program content needs to be re-worked, or whether it is just the process that needs changing?” was asked of the research team. As a result, it was decided participants would be taken through a standard DRUMBEAT program, with very little change to
the core content. The few changes to process that did occur before commencement of the study included:

- **Timeline:** DRUMBEAT is designed to run over ten sessions, with one session per week. On the recommendation of TAG members, the decision was made to run the study over six weeks, with one session per week.

- **Session length:** DRUMBEAT sessions are generally of 1-hour duration but a longer session of 2.5 hours was deemed appropriate for the study, to allow for more in-depth discussions.

- **At the end of each weekly session all participants completed a simple, four-item scale session rating score (Appendix 16).** Designed to get real-time feedback on the program, it enabled any problems to be identified and addressed before the following week (Duncan et al., 2004). Participants were also asked to complete, after each session, a Visual Analogue Scale (VAS), to capture a comparison of pain intensity / severity before, and after the drumming.

- **Program integrity:** DRUMBEAT is a learning program using the medium of music and hand drumming to engage participants. This is achieved using a combination of five core elements, as outlined in Figure 13: core rhythm, core rhythm games, discussions, improvisation and a public performance on completion. Although structured, the program is adaptable and flexible around research timelines. As Holyoake recommend half of each session be spent planning and rehearsing for the final concert, a decision was taken to exclude the performance element, due to time restraints. Consequently, only four of the core elements shown below were incorporated into the program to achieve the study objectives.
Figure 13: Core elements of the DRUMBEAT program.
3.5.1 Ethics

ECU Human Research Ethics Committee gave approval for this study to be undertaken (Project 19513). Informed consent was gained from all participants (Appendix 6). The letter of introduction (Appendix 7) clearly outlined the purpose of the research, the way in which recipients would be involved in the study, the use of recording devices in all group discussions, how the data collected would be securely stored, and the confidentiality of information provided.

Participant confidentiality was maintained throughout this study by adhering to ECU Human Research Ethics guidelines. The study required that participants be identified at the application stage only. Once the initial screening process was complete, for the purpose of data collection, each participant was identified solely by use of a unique code number, and this was used for the duration of the study. Participant request to join the study Facebook group was using their own Facebook account. However, any information collected via Facebook e.g., comments and insights were kept de-identified and private and confidential for the purpose of this study and did not identify participants in any way. In regards to the images used throughout the study, participants were made aware that it is common practice for Holyoake to take videos and photographs of DRUMBEAT sessions for use on their website and / or social media accounts. Each participant gave their consent and authorised the use of any and all photography / video / voice taken, by Edith Cowan University (WA) and HOLYOAKE (WA), for the purpose of the research project identified. All participants gave their permission to distribute any videos, photos or voice recordings for presentations, publications, educational purposes, or through any other medium, provided their name was not used.

Ethical obligations to ensure anonymity were further upheld by separating informed consent forms and data collection responses; using participant number codes, not names, on all transcriptions of focus group discussions; and ensuring that all electronic data was password protected and accessed by the researcher and the supervisory team only. For the purpose of reporting qualitative data within this thesis, pseudonyms were created for each participant, to replace the previously allocated code numbers (Bryman, 2012).
3.6 Stage 4: Intervention Phase

3.6.1 Selection criteria

The original objective of the study was to improve health outcomes for young adults 18-30 years living with IA. However, in response to feedback from TAG members and, on advice of the rheumatologist, the study was eventually opened out to all ages $\geq 18$ years living with IA. According to the rheumatologist, if the underlying condition is not evident at the time of initial consultation, the specialist will often refer to it as IA, a generic term to describe how it differs from OA. The rheumatologist considered inclusion of all adults with IA would be a better representation for the study. OA remained an exclusion.

The exclusion of those with pre-existing, or current clinically diagnosed depression, was discussed in some detail at the preliminary focus group meeting, where it was decided the exclusion would remain. The rheumatologist initially concurred with this recommendation, commenting that although depression is common with RA, it is not necessarily diagnosed. Later, the rheumatologist considered that, in an attempt to make the study more inclusive, it would be prudent to only exclude those with a *non-stabilised* major depressive disorder.

**Inclusion criteria included:**

- confirmed clinical diagnosis of a chronic inflammatory arthritis (excludes OA);
- age $\geq 18$ years;
- the ability to speak and understand English; and
- a letter of support from GP/Specialist (Appendix 9)—the GP/Specialist would be informed of the intention to enroll in the study and to participate in the activity of drumming.

**Exclusion criteria included:**

- disclosed presence of a major depressive disorder recently, or previously diagnosed (i.e. by medical practitioners) that has not been stabilised through treatment; and
- perceived presence of any co-existing musculoskeletal conditions that may prevent participation in the program.
3.6.2 Recruitment process

Recruiting younger participants into the study was a more challenging task than anticipated. The roadblocks encountered in recruitment for the study were representative of some of the issues related to 18-30-year-olds and despite expressing significant interest in the study, their lack of commitment to participate was frustrating.

Flyers and brochures (Appendices 10 and 11) were distributed to rheumatologists operating out of public and private clinics at AOWA, Sir Charles Gairdner Hospital and Hollywood Specialist Centre. RA nurses and clinic staff offered to distribute posters into all other relevant clinics in the metropolitan area. AOWA also promoted the research in-house, as did Holyoake, via websites and through e-newsletters. In addition, the flyer was posted on numerous other websites, Facebook pages, and at various locations, as outlined in Figure 14.

Due to the involvement of AOWA in the formative stage of this study, two participants from AOWA were recruited through a purposive, convenience recruitment technique (Bowling, 2009). Of the remaining five participants, two responded to the researcher’s radio interview on 89.7Fm; two made contact via the ECU student intranet and one joined through a clinician referral. The recruitment strategies were divided into four main themes:

In response to the recruitment campaign, potential research candidates wishing to participate, or interested in learning more about the study, were asked to forward their contact details via Facebook Messenger, or ECU email. They were then contacted by telephone and asked to complete a brief screening survey to confirm eligibility (see section 3.6). Screening candidates by telephone was considered more appropriate than completing a questionnaire, and proved to be very time effective. The information gathered was used to collect standard demographic (self-reported) data including age, gender, marital status, ethnicity, type of IA, date of diagnosis, school / work / employment status and individual use of complementary and alternative therapies (Table 4). Provided selection criteria were met, an information sheet and consent letter, with a RAND Health survey was emailed to each potential participant detailing the purpose of the study, expectations of participants and issues of confidentiality. This informed participants that their identification would remain anonymous through the use of I.D numbers and pseudonyms in the thesis write-up, to ensure confidentiality throughout the program.
Implementation of the DRUMBEAT and arthritis intervention: setting the scene

The setting for the study was the AOWA headquarters in Shenton Park, WA. A total of six group drumming sessions ran once a week for six weeks and lasted for approximately 2.5 hours, including time for discussions and refreshments. Each session was delivered in consultation with an experienced DRUMBEAT Facilitator, and myself acting as co-facilitator. Before the arrival of study participants, each week the room was set up with drums and a whiteboard for discussion notes (Figure 15). It was important to create a suitable space to run the program—a carpeted room to dampen sound and to minimise noise levels; a room with limited distractions; and of a size that allowed participants to sit in a circle formation, with facilitator and co-facilitator sitting
opposite each other within the circle (Figure 16). Everyone in the room formed a part of a drumming circle, with no observers. In further consideration of AOWA staff members, all sessions were conducted during the evening.

All participants were provided with a traditional African djembe drum. The name djembe (pronounced JEM-bay) comes from the Bambara saying, “everyone gathers in peace,” and everyone played a drum of a similar size to emphasise equality (Holyoake, 2017). Holyoake describe the djembe as being one of the most versatile and widespread percussion instruments, that requires no previous drumming experience. The group primarily played the drums but also had access to a variety of different percussion instruments as / when needed. The choice of instruments was left entirely to the individual, allowing autonomy for improvisation.
Figure 15: Setting the scene. Session 1, April 2019. Used with permission.

Figure 16: Session 1, April 2019. Used with permission.
The health and safety of group members was of paramount importance and as playing the djembe requires a certain level of physically (Smith et al, 2014) it was emphasised that overuse, and over-exertion was to be avoided. The risks were addressed by making the participants aware of a few minor safety issues (Figure 18) and the need to warm up and stretch on a regular basis, so as to avoid any injury that may lead to the exacerbation of existing health problems.

Although some drum techniques were taught, the participants were aware of the main focus of the study and that identification and expression of feelings would occur both verbally and through drumming. A typical workshop would consist of playing the djembe drum, playing games with call-and-response exercises and talking about central themes and issues that were important to them for their wellbeing.
Before each weekly session there was consultation among the research team regarding facilitation techniques, objectives, individual participant issues and any interpersonal dynamics that needed to be addressed. A debrief session was conducted each week in readiness for the next week. Sessions were semi-structured but there was flexibility within the program that allowed for modification of content to meet the needs of the participants on the night. The team aimed to foster a relaxed and light-hearted atmosphere.

Prompts and guiding questions were used in the weekly workshops and any themes that emerged informed future program content (Appendix 5 for original program design). The positioning of the prompts within the parameters of the DRUMBEAT program was determined in consultation with the Holyoake facilitator. The discussion elements required participants to reflect on their own lives, particularly their feelings and behaviours. The group were guided into drawing analogies between drumming and aspects of living with arthritis. As an example, participants were asked:

Finding out that you have a chronic condition can change things. Sometimes this can affect your outlook and mood. How did you feel when you first got your diagnosis? Tell us about your journey so far?

Each session was audio recorded and captured all interactions and comments. Each weekly record was transcribed as soon as possible so nuances were not lost over time. Audio and video recordings were also paired with other relevant data points, including how many people attended each session and their personal characteristics (Chapter 4).

### 3.6.4 Program content

Designed with a holistic approach, the DRUMBEAT program was developed to help participants increase resilience and support healthy outcomes. Through the medium of group drumming the program teaches key life skills that translate into behavioural change. For the purpose of the study the learning was extended through discussions that promoted self-reflection and awareness on how feelings, thoughts and actions impact on overall health and well-being. The discussions were linked to real life experiences to personalise the learning experience, and to promote group problem solving. The drumming activities added the fun element and acted as a catalyst for personal discussion and sharing of information. Figure 18 summarises the 6-week program content:
Figure 18: Program content (Warhurst, 2019)
3.6.5 Data Collection and instruments

Data collection done in association with the drumming sessions included; pre- and post-workshop questionnaires, group transcripts and end of session rating scores. Observations were also made throughout the six sessions and noted after workshops. An overview of data collection points is outlined in Figure 19. Although both qualitative and quantitative research methods were used, more emphasis was placed on qualitative interpretation of the data through the use of thematic analysis.

Data collection also formed part of the group sessions. Hard copies of the pre- and post-program questionnaires were completed by all participants at the first session and again at week 6. Participants absent on the final week completed the post-program questionnaires at their individual face-to-face interviews, conducted by myself, within 2 weeks of the program completion. Participants were also asked to complete a simple session-rating score at the end of each weekly session. This allowed collection of real time feedback, so that any problems, or suggestions, could be quickly identified and addressed before the next meeting. The Visual Analogue Scale was also completed at the end of each session and helped capture any difference in pain intensity or severity pre- and post-drumming.

<table>
<thead>
<tr>
<th>Pre Drumbeat workshop questionnaires</th>
<th>Quantitative data collected at week 1 (Appendices 12,13,14,15,18) Participants physical functioning, anxiety/depression scores, QoL, self-efficacy and locus of control were measured.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post Drumbeat Workshop questionnaires</td>
<td>Quantitative data was repeated on the final week and collected from questionnaires (includes final DRUMBEAT evaluation) (Appendices 12,13,14,15,17,18).</td>
</tr>
<tr>
<td>Sessional throughout weeks 1-6</td>
<td>Qualitative and quantitative data collected at end of each workshop using both Session Rating Scale combined Visual Analogue Scale (VAS) for pain (Appendix 16) and observations from the group</td>
</tr>
<tr>
<td>Facebook Insights</td>
<td>Qualitative and quantitative data was collected from closed FB group. Likes, shares, comments, posts and interactions between members were reported</td>
</tr>
<tr>
<td>Final Focus group meeting &amp; one-on-one interviews</td>
<td>Qualitative data was collected at the final focus group meeting and one-on-one interviews. Information collected included project feedback. (Appendix 19).</td>
</tr>
</tbody>
</table>

Figure 19: Data collection points.
A final focus group meeting with four participants took place in the week following completion of the program. The feedback gained was complemented by face-to-face interviews with two of the remaining participants at a later date. Both face-to-face discussions and weekly workshops were audio-recorded with permission and transcribed verbatim. The remaining participant was not available for final feedback due to illness but did complete the post study questionnaires.

Data collection tools and methods of collection are now discussed in more detail below:

- **Quality of Life (QoL):** The RAND 36-Item Health Survey 1.0 has been shown to be a valid, reliable and responsive measure of the health aspects relevant to patients with RA (Rand Health, 2018) (Appendix 12). It contains eight subscales that represent physical and social functioning, bodily pain, and role limitations due to both emotional and physical health problems, emotional wellbeing (mental health), energy/fatigue (vitality) and general health perceptions. Cronbach’s α has been found to range between 0.81 to 0.95 and item discriminant validity tests to range between 96.9%-100.0% (Krops et al., 2017; Kosinski, 1999).

- **The Hospital Anxiety and Depression Scale (HADS)** is a 14-item self-rating scale used extensively to measure anxiety and depression in both hospital and community settings (Covic et al., 2012) (Appendix 13). It provides a clear cut-off score to indicate the severity of the disorder and has been shown to be both valid and reliable (Cronbach’s alpha 0.68 – 0.93), with a sensitivity and specificity of approximately 0.80 (Bjelland, Dahl, Haug, & Necklemann, 2002). The HADS performs well in assessing the symptom severity in primary care patients and the general population (Vermaak, Briffa, McQuade, Langlands & Inderjeeth, 2015; Bjelland et al., 2002).

- **Self-efficacy and the Rheumatoid Arthritis Self-Efficacy (RASE) questionnaire:** The RASE (Appendix 14) is a measurement of an individual’s belief in their capabilities to perform a certain task, or behaviour (Brady, 2011). The RASE is shown to have good internal reliability (Cronbach's alpha 0.89) and test-retest reliability (0.90) (Brady, 2011). In terms of construct validity, the RASE has been found to correlate with corresponding self-management behaviours, with studies identifying a significant, although small, ability to detect change in self-efficacy following self-management education programs (mean change 5.2 points on scale scoring 28–140) (Brady, 2011).
• **Locus of Control of Behaviour Scale (LoCBS):** Locus of control can be either internal, if people believe that they have control over what occurs to them, or external, whereby they perceive that they have no control over their destiny. The LoCBS is a 17 item self-report scale developed by Craig, Franklin, and Andrews (1984) as a specific measure of locus of control (Appendix 18). They proposed locus of control was a single construct, and not multidimensional as had been previously suggested by Levenson (1974). Levenson proposed that locus of control consists of three orthogonal factors: internal, powerful others and chance. Craig et al. (1984) found test-retest correlations to range between 0.72 and 0.90. Exploratory factor analysis was used to establish construct validity, with Craig et al. finding two factors, however, they determined that the second factor was not meaningful and hence this analysis was proposed as evidence that the LoCBS measures a single construct. Bright, Kane, Marsh, and Bishop (2013) sought to further investigate the construct validity of the LoCBS by conducting confirmatory factor analyses comparing unidimensional models to various multidimensional models. A four-factor solution that included a single internal factor and three types of external control provided the best fit, though it was described as “reasonable” rather than “good.” Subsequent exploratory factor analysis found that the items measuring internal locus of control were robust and cohesive, while the externality dimension appears to fragment into smaller components, suggesting these items are measuring a single construct. Therefore, only these items of the LoCBS (1, 4, 5, 7, 8, 13, 15,16) are used in this analysis.

• **Social Support and the UCLA Loneliness Scale (Version 3):** Results indicate this measure of loneliness (Appendix 15) is highly reliable both in terms of internal consistency (coefficient a ranging from 0.89 to 0.94) and test-retest reliability over a 1-year period (r = 0.73) (Russell, 1996). Convergent validity for the scale was indicated by significant correlations with other measures of loneliness (Russell, 1996).

• **Session Rating Scale (SRS):** SRS is a simple, four-item scale (Appendix 16) designed to assess key dimensions of effective therapeutic relationships (Duncan, Miller, Sparks, & Claud, 2004). The SRS was administered, scored and discussed at the end of each session to get real-time feedback from participants, so that problems could be identified and addressed (Duncan et al., 2004). Research on the SRS has demonstrated good reliability (Cronbach’s alpha 0.88) and adequate test re-test reliability (0.64) (Campbell & Hemsley, 2009; Duncan
Campbell and Hemsley (2009) compared the SRS with the Health Assessment Questionnaire. Correlation between the two measures was 0.48 ($p < 0.01$), providing evidence of concurrent validity for the SRS (Campbell & Hemsley, 2009).

- **Visual Analogue Scale (VAS):** These were also completed at the end of each session to capture a comparison of pain intensity / severity before and after drumming. This scale (Appendix 16) has been widely used in diverse adult populations and adolescents (Hawker, Mian, Kendzerska & French, 2011). In terms of construct validity, the pain determined through VAS shows a high correlation with a numeric rating scale (with response options from 0 [no pain] to 10 [unbearable pain], with correlations ranging from 0.71–0.78 and 0.62–0.91, respectively (Hawker et al., 2011).

- **DRUMBEAT Week 6 Feedback Questionnaire:** This questionnaire (Appendix 17) captured the participant’s overall enjoyment of the program using a five-point response scale from strongly agree to strongly disagree (Holyoake, 2017).

- **Group Transcripts:** As a sole researcher with no prior knowledge of transcription, the task of transcribing the drumming sessions was not an easy one. The original intention was to have a colleague help with note taking but unfortunately this did not occur. The use of an iPhone was the only option available but problematic for recording a drumming group. It was difficult to capture all of the voices above the noise, especially interjections and overlapping conversations but due to the closeness of the group I was able to distinguish most of the speakers.

### 3.6.6 Final focus group

The final focus group was implemented (Appendix 19) to gain in-depth qualitative information from the participants through their opinions, perceptions and feelings about, and attitudes towards, the DRUMBEAT program, in an interactive group setting. It was also an opportunity to identify any areas of the program that required further customisation to meet the specific health needs of an arthritis group. The focus group session was also recorded for transcription. In-depth, one-on-one interviews (Appendix 19) were conducted in person with two group members who were unable to attend the focus group. The semi-structured interview plan was based on the same questions and prompts used for the focus group meeting. The one-on-one
interviews (audio-recorded) were particularly effective as they captured feedback of a more personal, sensitive nature.

3.6.7 Facebook insights
The Facebook group was a platform to provide a social connection and a space for sharing ideas, rather than a source of support. It also allowed for continued connection between participants following completion of the study. Both qualitative and quantitative data were collected in the form of photos, comments and “likes.”

3.6.8 Researcher field notes
The researcher field notes were of a personal nature and included private thoughts and ideas only (non-coded). They were not intended to be part of the qualitative data for this study but are made mention of here as they did assist with the development of the Facilitator’s Manual. Details of all informal conversations with participants after audio recordings were imported into QSR International Pty Ltd. (2018) NVivo (Version 12), and coded and were separate to the field notes.

3.7 Data analysis
As discussed in section 2.5, the adoption of a pragmatist view for this study allowed for the application of a diverse range of data analysis strategies to answer the research questions (Creswell, 2013). Collected at different times, the quantitative and qualitative data have been used to measure changes in the physical and psychological functioning of participants; deliver metadata on Facebook use; identify areas of the DRUMBEAT program that require further customisation to meet the specific health needs of an arthritis group; and provide contextual data for triangulation of findings.

3.7.1 Quantitative data analysis
Prior to and on completion of the 6-week program, quantitative data was collected using the questionnaires. Participant demographic variables were tabulated and questionnaire construct scores were calculated. Due to a range of factors, including time constraints, the parameters of the DRUMBEAT intervention, the nature of arthritis and this being a feasibility study, a within subject study design was chosen. Due to the small sample size, minimal
adjustments were made to the analyses and non-parametric analyses were used to compare mean rank scores. More specifically, a Wilcoxon Signed Rank test was conducted on pre- and post- scores and comparisons taken, in order to gauge the reported impact of the group drumming. The DRUMBEAT closed Facebook Group provided mainly descriptive, qualitative data via posts, views, likes, and comments. These elements assisted in quantifying the total Facebook interactions.

3.7.2 Qualitative data analysis

Once the program was completed, qualitative data was gathered from observation, group and one-on-one discussions, session recordings, the final focus group meeting, and Facebook comments. Direct interpretation and naturalistic generalisations were used in this study to interpret the data (Creswell, 2013).

All transcripts were analysed using the software N-Vivo 12, for interpretation through inductive thematic analysis (Braun & Clarke, 2006). All selected documents, where possible, were imported into N-Vivo and coded to allow for development of themes and sub-themes that might otherwise have been obscured when using alternative methods (Creswell, 2014). Emerging themes were discussed in some detail at supervisory conferences, using line-by-line coding. As the study was investigating an under-researched phenomenon, the line-by-line approach enabled the researcher and supervisor to effectively discover the various components, whilst also controlling her own assumptions about it. This, together with triangulation, were strategies put in place to help assist with credibility of the study results.

3.7.3 Triangulation

When using multiple sources of data and research methods, triangulation is a common form of data analysis (Figure 20) (Bowling, 2009). The triangulation is important since it increases trustworthiness through the cross-verification of the different data sources (Golafshani, 2003). In this study data and findings from multiple sources allowed a more insightful interpretation of quantitative data from the small sample to support conclusions (Golafshani, 2003).
Integration and Interpretation

Findings

Quantitative Data
- Pre and Post Questionnaire
- Session Rating scores
- Facebook Insights

Qualitative Data
- Group discussions
- Focus Group
- Facebook Insights
- Observations

Figure 20: Data analysis - Triangulation.
CHAPTER 4: RESULTS

Both quantitative and qualitative findings of the study will now be presented and discussed in this chapter. While mixed methods were adopted, the qualitative paradigm dominated the research design (section 4.2).

4.1 Quantitative Results

4.1.1 Participants
Thirty-six participants were screened for eligibility, with a final eight recruited into the DRUMBEAT study. All participants completed the pre- and post-workshop questionnaires. The recommended group size for DRUMBEAT is between 6-10 participants. Of those deemed ineligible, four were under 18 years of age; six were unable to access public transport to and from the venue; and the remainder had a diagnosis of OA. Only seven went on to complete the study as unfortunately, one young man (age 28 years), was struggling with a recent diagnosis of PsA, and made the decision to not take part:

Sorry-feel an idiot [...] too afraid to come [...] don’t want to let you down, even though I know it would do me good [...] just not in a good place (crying) [...] don’t know how to get over this mental block [...] feeling pretty low (anon)

Attendance rate was an issue in this study but did reflect the unpredictable and fluctuating nature of IA. Fatigue and lack of confidence were identified as the main reasons for non-attendance. Only two participants completed the full 6-week DRUMBEAT program, with four completing four, or more sessions (Figure 21). One individual struggled emotionally at the start of the study, with lack of confidence in his ability to complete the full six sessions. He did, however, maintain contact throughout the study period via the Facebook group, or private messaging and was able to attend both the first and last session and participate in a final one-on-one interview.
➢ Type of inflammatory arthritis / duration:
Of the seven participants, four had RA; this being the most common type of IA. Followed by AS (n = 2), PsA (n = 1); with some participants having more than one condition (n = 3). Duration of disease differed considerably between participants, ranging from 4 to 25 years ($M = 10.4$ years; $SD = 8.04$) (Table 6).

➢ Gender / age
Consistent with epidemiological data, the majority of participants were female (71.4%). Females were aged between 36 and 67 years ($M = 56$ years; $SD = 12.84$); males were aged between 45 and 84 years ($M = 64.5$ years; $SD = 27.57$). Four presented with RA, one with PsA, two with AS and three with a combination of arthritic conditions (Table 6).

➢ Education:
All participants had completed secondary education, with the majority (85.7%) achieving university level (Table 6).
<table>
<thead>
<tr>
<th>Table 6: Demographic Information of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>n = 7</strong></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td><strong>Age</strong></td>
</tr>
<tr>
<td>18-30</td>
</tr>
<tr>
<td>31-40</td>
</tr>
<tr>
<td>41-50</td>
</tr>
<tr>
<td>51 and over</td>
</tr>
<tr>
<td><strong>Nationality</strong></td>
</tr>
<tr>
<td>Australian/Caucasian</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td><strong>Age at time of diagnosis</strong></td>
</tr>
<tr>
<td>18-30</td>
</tr>
<tr>
<td>31-40</td>
</tr>
<tr>
<td>41-50</td>
</tr>
<tr>
<td>51 and over</td>
</tr>
<tr>
<td><strong>Education</strong></td>
</tr>
<tr>
<td>High School</td>
</tr>
<tr>
<td>TAFE</td>
</tr>
<tr>
<td>University</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
</tr>
<tr>
<td>Employed</td>
</tr>
<tr>
<td>Full-time</td>
</tr>
<tr>
<td>Part-time</td>
</tr>
<tr>
<td>Retired</td>
</tr>
<tr>
<td>Voluntary</td>
</tr>
<tr>
<td>Student</td>
</tr>
<tr>
<td>Part-time</td>
</tr>
<tr>
<td><strong>Presence of physical limitations that may affect drumming</strong></td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Unsure</td>
</tr>
<tr>
<td><strong>Type of Inflammatory Arthritis</strong></td>
</tr>
<tr>
<td>RA</td>
</tr>
<tr>
<td>PSA</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Combination</td>
</tr>
<tr>
<td><strong>History of major depressive disorder</strong></td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>unsure</td>
</tr>
<tr>
<td><strong>Use of CAM therapies</strong></td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
</tbody>
</table>
➢ **Employment:**

Arthritis can impact a person’s career and professional life. Survey demographic data identified one third of participants as being of working age (≤ 67 years) and employed full time. Additional information provided through discussion identified three of the participants found working conditions difficult because of arthritis, and had felt forced to make a change in career, choosing to work part-time from home. One individual was unable to work because of the pain and joint immobility associated with their condition and is currently studying health and nutrition online. Trying to maintain a normal working life was identified in group discussions as a common problem (for more detail see section 4.2).

➢ **Level of social support:**

One aim of the study was to establish the level of social support gained through participation in the DRUMBEAT program. Keefe et al (2002) identify higher levels of social support as a key component of psychological health, playing a critical role in how a person with arthritis functions in day-to-day life. The majority of the group (n=5) indicated a good level of support at home, generally from their spouse, or partner. Two participants had been ostracised from their family network. One now received most support from friends and church community, and the other considered his local doctor to be the “only” person he can confide in. Less than half of participants viewed their doctor / specialist as a source of support. The main sources of self-reported social support each participant received outside of the study is shown in Figure 22.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Spouse/Partner</th>
<th>Extended Family</th>
<th>Friends</th>
<th>GP/Specialist</th>
<th>Support group</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>⭐</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>02</td>
<td>⭐</td>
<td>⭐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>03</td>
<td>⭐</td>
<td>⭐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>04</td>
<td>⭐</td>
<td>⭐</td>
<td>⭐</td>
<td></td>
<td></td>
<td>⭐</td>
</tr>
<tr>
<td>05</td>
<td>⭐</td>
<td>⭐</td>
<td>⭐</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>06</td>
<td></td>
<td></td>
<td>⭐</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>07</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>⭐</td>
</tr>
</tbody>
</table>

**Figure 22:** Participant self-reported levels of social support
Anxiety and depression:
Using the optimal cut off $\geq 8$ (sensitivity and specificity of approximately 0.80) for both the HADS anxiety and depression scores, three participants were not experiencing either anxiety, or depression, pre-intervention. The remaining four reported as having anxiety, depression, or both.

Due to the small sample size of this pilot study, minimal adjustments were made to the analyses and non-parametric analyses were used to compare mean rank scores. More specifically, a Wilcoxon Signed Rank test was conducted on pre- and post- scores and comparisons taken, in order to gauge the reported impact of the group drumming. Depression was significantly lower from baseline to follow up (Figure 23). The measure of depressive symptoms had decreased from a mean (Median; SD; IQR) of 6.29 (7.0; 3.15; 5.0) to 4.42 (5.0; 2.82; 5.0) ($Z = 1.94313$, $p = 0.03$) during the 6-week intervention. Anxiety did not change.

Quality of life:
A statistically significant improvement in QoL scores was observed in physical functioning, increasing from a mean (Median; SD; IQR) of 55 (65; 20.41; 30) to 65 (55; 18.26; 25), $Z = 1.8663$, $p = 0.03$. 

Figure 23: Psychological effect of participation in the DRUMBEAT program. Post difference from corresponding pre-value $P < 0.05$. ★ significant difference in depression ($n=7$) before and after the intervention.
➢ **Pain levels:**

Due to varying levels of non-attendance, the collection of pain intensity data taken at the end of each session using the Visual Analogue Scale (VAS) values to help capture any differences in pain intensity and / or severity, pre- and post-drumming, resulted in the presence of missing scores at one, or more time points, over the study period. Each participant established their own baseline and served as their own control. As there was minimal drumming in session one, pain intensity levels were only measured weeks 2 – 6. Immediately following each drumming session participants graded their level of pain showing range from 0 (no pain) to 10 (unbearable pain).

One participant experienced an increase in pain level at the end of every session and a second participant experienced increased pain from week three. This was later determined to be due to previously undiagnosed cervical spondylitis. Overall pain scores for the group did however, show a decelerating trend as the intervention progressed. This is considered to be attributable to the use of a combination of alternative instruments, rather than the djembe drum only and also to the participants themselves, who were observed as beginning to exhibit self-regulation in order to bring the right level of intensity to their own drum playing, as from week three.

**4.1.2 DRUMBEAT & ARTHRITIS Facebook Group**

All participants agreed to join the Facebook group. Being a closed group, it was never the intention to expand the community outside of the original seven participants. Despite significant effort on my part and the Holyoake facilitator, to engage participants into the online community, it was a key challenge and the low response rates and Facebook interactions reflected this. In an attempt to meet this challenge, weekly summaries were posted of each session online to allow participants to share comments before the next meeting. Postings mainly related to interesting facts about group drumming and relevant videos and adverts.

Some members were highly motivated to join the Facebook group and continued to make positive contributions throughout the study period. Figure 24 shows three participants as having contributed most to the Facebook group during the overall period of the study, being responsible for over 90% of the post / likes / comments / shared links. Two participants chose not to contribute any posts but did read all others weekly posts and notifications. The facilitator posts accounted for 17 of the totals of 20 posts throughout the study. Most participants preferred to respond with likes, comments, or shared links, rather than to post comments themselves.
Figure 25 shows an increased response rate to Facebook posts following week 3 and again post-study. This was not unexpected as week 3 activities were dominated by drumming, including the introduction of playing along to the contemporary music chosen by the participants. Although numbers were lower in week 3 it appeared an atmosphere of trust was developing between the participants, as supported by qualitative data (section 4.2). This developing change in group dynamics encouraged participants to talk quite openly about their feelings and to talk directly to one another about their personal problems. The added emotional connection filtered across into the Facebook group page, where two participants shared links to drumming videos as ideas to play along to in the following week. The overall session rating score for week 3 also reflected the satisfaction of the group, recording a total of 9.95, out of a possible score of 10. Figure 25 also indicates a significant increase in Facebook activity after the study finished. All the group made mention of being disappointed at the study coming to an end and would have liked to continue on. As Facebook is an easy communication tool, the page remains open at the specific request of the group members.
Some example participant posts from the Facebook page are shown in Figure 26.
some of the images in Figure 26 are not available in this version of the thesis

Figure 26: Examples of participant Facebook posts/videos (names are blocked out for confidentiality)
4.1.3 DRUMBEAT program feedback

Understanding how the study participants interacted with DRUMBEAT was crucial for the effective contextualisation of the program in arthritis. Whilst involvement in the study was still fresh in participant’s minds, they were asked to complete a Holyoake feedback questionnaire at the end of week 6. The questionnaire consisted of 15 closed questions, with participants requested to choose from a fixed number of options. The questions centred around the fun element of DRUMBEAT, the acquisition of new skills and the ability to recognise and reconfigure skills, so as to be able to do things differently. The questions also helped identify participant expectations and perceptions of the impact of the program beyond the 6-week study timeframe. Response rate was 100%. A quantitative overview is presented in Table 7.

Participation in DRUMBEAT received significant, positive feedback, with all seven participants shown to have enjoyed the experience. The success of the program depended on the contributions of every member of the group and all participants agreed, or strongly agreed, that their input was encouraged in group sessions, allowing for successful team collaboration. The majority expressed a sense of personal ownership in the group and overall, participants indicated they would pass on what they had learnt, with the majority happy to recommend DRUMBEAT to others.

On an individual level, feedback scores identify that more than half of participants considered being a part of DRUMBEAT had helped them to feel good about themselves; allowed them to work through problems easier; and provided them with a better understanding of the required skills needed to identify with their own feelings and beliefs. In summary, six participants considered DRUMBEAT had helped forge a deeper connection and understanding of themselves, with five viewing themselves as now being more responsible for their own behaviour.

A valuable part of the experience was the possibility of participants to connect with others and have the opportunity to make new friendships and expand social networks. Questions directed at communication and relationships showed that participation in the program had helped assist three participants to feel more comfortable in talking with others. Moreover, the majority of participants considered their relationships with those outside of family, had improved.
The structured questionnaire concluded with two general open-ended questions. These gave participants an opportunity to express, in their own words how DRUMBEAT had helped them personally, and to offer suggestions, or possibly to add valuable insight, into areas of the research previously overlooked. The responses form part of the qualitative data analysis (section 4.2).

Table 7: DRUMBEAT post - program feedback from all seven participants

<table>
<thead>
<tr>
<th>Question 1 - 15</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>(n=7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 I enjoyed being part of the DRUMBEAT program</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>2 My input was encouraged</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>3 I felt part of a team</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>4 The drumming skills I learnt helped me to feel good about myself</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>5 I find some problems easier to work through since doing DRUMBEAT</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>6 DRUMBEAT has helped me learn how to talk to others</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>7 I find it easier to work out what I am feeling since doing DRUMBEAT</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>8 I feel more responsible for my behaviour since doing DRUMBEAT</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>9 DRUMBEAT has assisted with improving my relationships with other people</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>10 DRUMBEAT has assisted with improving my relationships within my family</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>11 Since doing DRUMBEAT I aim for more harmony in my relationships</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>12 DRUMBEAT has helped me identify my main beliefs and a ‘safe’ place</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>13 DRUMBEAT has helped me learn about myself</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>14 I will pass on some of what I have learnt through DRUMBEAT to other friends or family</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>15 I would recommend the DRUMBEAT program to others</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>5</td>
</tr>
</tbody>
</table>
4.2 Qualitative data results: introduction

Although, the main objective of this study was to explore the benefits that IA participants might experience through DRUMBEAT, understanding their lived experience (and challenges) was a necessary first step in this research. The very nature of this intervention, the way the sessions were set up, in that participants were being asked to reflect – to cast their minds back to when they were first diagnosed – made it important to not only capture the unique experiences of living with IA but also to ensure that any benefits derived from participation in the DRUMBEAT program itself, were clearly differentiated.

For the current study, while mixed methods were adopted, the qualitative paradigm dominated the research design. This section of the thesis presents the thematic analysis of qualitative data extracted through inductive coding, from all data sources utilised throughout the study. The nature of the intervention allowed for a diverse range of qualitative data to be generated, from numerous sources. These are symbolised throughout the rest of the thesis by use of the icons depicted in Table 8: audio recordings and transcripts of weekly drumming sessions and accompanying group discussions (إقامة); focus group transcripts (مراسيم); one-on-one interview transcripts, (پاسخ); personal research field notes, mainly derived from observations of the weekly drumming sessions (لقطات); and finally, Facebook posts and comments (جواهر). As an additional note, gender will not be differentiated by markers. Pseudonyms were assigned to give anonymity to each participant which conveys their gender.

Table 8: Key of data collection sources

<table>
<thead>
<tr>
<th>Key icon</th>
<th>Source of data entry</th>
</tr>
</thead>
<tbody>
<tr>
<td>🎬</td>
<td>Workshop drumming / discussions audio recordings and transcripts</td>
</tr>
<tr>
<td>💡</td>
<td>Focus group transcripts</td>
</tr>
<tr>
<td>☁️</td>
<td>One-on-one interviews</td>
</tr>
<tr>
<td>⚫️</td>
<td>Research field notes</td>
</tr>
<tr>
<td>🌐</td>
<td>Facebook posts and comments</td>
</tr>
</tbody>
</table>
To that effect, the overarching themes and supporting sub-themes that identify with, and bring to life, some of the realities of living with arthritis, will be discussed first (section 4.3), followed by the themes and sub-themes, which reflect the perceived benefits of participating in the DRUMBEAT program (section 4.4). Each of the sub-themes within section 4.4 identify issues directly relating to the significance of the research. Specifically, does participation in a 6-week DRUMBEAT program influence:

- The needs of a group of individuals with chronic inflammatory arthritis?
- Quality of life?
- Self-efficacy
- Ability to cope with arthritis signs and symptoms?
- Social support networks and if a closed Facebook group has a role?

### 4.3 Lived experience – The Roller Coaster of living with inflammatory arthritis

This theme concerns some of the negative aspects of ‘being’ an individual living with IA. Describing some of the emotional, physical and accompanying social challenges brought on by living with this disease, helps capture some of the complexity of IA. It also allows the reader, who may be unfamiliar with the every-day challenges of this chronic condition, to appreciate IA as a serious, complex, systemic disease that has had a profound effect on the lives of the participants.

Remembering that participants were of differing ages and at different stages of diagnosis; having been diagnosed 4 to 25 years prior to involvement in the study, provided an opportunity for diverse personal narratives to be recorded across different life stages, with particular focus on the impact of arthritis-related symptoms on QoL, daily activities, emotional well-being and social / leisure activities. While each participant was unique in their experience of living with arthritis, the DRUMBEAT program was designed to allow individuals to reflect and reveal their own set of challenges, regardless of personal differences within the group. What emerged was the identification of five key themes and a number of sub-themes, which demonstrates the lived experiences of participants; summarised in Figure 27. Each theme is discussed and supported with direct extracts of participants; they are discussed in the following sequence:
1) **Emotional trauma** - which centres around the most common emotional responses of the group to living with arthritis: anger, or irritability at what has happened, often asking “Why me?”; the anxiety, or fear of losing control and of never really knowing what your day will bring; and the overriding sadness and grief of knowing “you can never go back to how things were before arthritis [...] won’t ever go away [...] you are never the same” (Jenny, 🌐);

2) **No-one understands** - which broadly relates to the general lack of understanding from others about the condition, from friends and family, from work colleagues, through to the perceived anachronistic views of the medical profession;

3) **Loss of identity** - which refers to the loss of self-worth and negative effect of IA on self-image;

4) **Hard to accept** - which concerns the resistance to change and the fear experienced by not being able to adapt to new ways. Primarily, how fear and uncertainty can fuel resistance to moving forward beyond mere coping strategies and learn to live successfully with a chronic condition, in a healthier, more effective way - a way that reduces the unnecessary emotional distress and brings about more happiness and fulfillment - and finally;

5) **Social isolation** - which refers to the withdrawal from others, and how the negative downsides of living with IA can contribute to loneliness and social isolation.
The themes are often interrelated. That is, participants rarely described their experiences in discrete, or independent ways. Instead, there was a complexity in their stories, where one theme was highly related to another. One member of the group demonstrated this interconnection quite aptly, with the summing up of his current situation:

RA? – just another thing to add to life’s many challenges and problems. Have struggled mentally – feel a sense of hopelessness [...] you know what it’s like, even when you have a recipe [...] things just don’t turn out [...] that’s my life - desperate to get out [...] not sure if I can even finish this [referring to the current study] – haven’t got it in me! (Tom, 😞)

Tom’s quote is charged with emotion, almost in a defeatist mentality. His comments demonstrate the complexity of his experiences, such as how he felt challenged by the perceived never-ending tsunami of life’s demands and how self-limiting beliefs, made him question his ability to move forward. As such, the theme of emotional trauma is discussed next.
4.3.1. THEME 1: Emotional trauma

As discussed in the literature review, many negative emotions can stem from the uncertainty of living with chronic disease and receiving a diagnosis of IA can exact a heavy mental burden. Insights from participants which informed this theme revealed that living with IA can be an unpredictable emotional and psychological process; one that individuals adjust to in their own way, and in their own time.

A number of emotional responses emerged from the group discussions, as regards the changes arthritis had exacted on participants lives. Some of the responses from the group included statements around feelings of guilt for the additional stress placed on relationships and families; the recurrent sense of hopelessness and disappointment; loneliness; and an underlying fear of their condition getting worse and becoming a significant burden to loved ones. The most commonly voiced emotions being anger, sadness and grief, and the fear of an uncertain future. To provide participants with an opportunity to share their own personal emotional journeys with the group, the following question formed part of a group activity in the Drumbeat program:

Finding out you have a chronic condition can change things.
How did you feel when you were first diagnosed? Did it affect your outlook, or mood?

When diagnosed with RA in her late 30’s Elsie described being totally overwhelmed by a wave of emotions, the likes of which she “had never felt before”. She described her diagnosis as if she was grieving “[the] death of a loved one” and the inflection in her tone revealed that she had difficulty processing how “dramatic” that really sounded when she spoke of it out loud. She could not bring herself to talk to anyone about the “terribly upsetting thoughts” that pervaded her daily life at that time, and described how she would often sit alone in the bathroom crying. Her sense of shame and embarrassment at what she described as “going mental” - was the barrier to her seeking help early on:

[…] decision to go for counselling wasn’t easy […] felt like giving in, throwing the towel in, not carrying on. I needed help so I could get back to normal […] still an emotional roller coaster, even now [14 years post-diagnosis] can sometimes feel like [I’m still] living with a lifetime of worry (Elsie,.

Jenny had worked for almost ten years as a beauty therapist when a rose thorn injury
triggered psoriatic arthritis in her fingers and hands. She continues to blame herself for not seeking medical treatment sooner. In her opinion, the latent anger she expressed towards herself is what holds her back from accepting what cannot be changed about living with a chronic illness and from actively seeking more satisfaction and meaning in the things she is able to do. Having been diagnosed four years ago, Jenny still remembers the exact moment that separated her former life from her new. Visibly struggling to hold back tears, she recalled the despair she felt at the time:

As soon as he [doctor] told me I had PsA [...] don’t remember feeling anything [...] scared, afraid, angry, sad, they were all there. Psychologically I was falling apart and he didn’t care [...] never been so scared in my life (Jenny, 📌).

Her account understandably, elicited outpourings of sympathy from other members of the group, but there was also observed admiration: “you should be very proud of yourself for telling us that” (Sarah, 📌). By sharing her story, Jenny prompted others in the group to reveal their own ‘present day’ anxieties and fears for the future.

For example, Sarah contributed to this discussion by describing herself as a naturally confident person, not someone “prone to panic attacks.” Yet, the knowledge that RA could have additional “unexpected side effects” [mental health problems] came as a “big shock” to her; one she still finds hard to come to terms with. Having never talked openly before about mental health - “mine or anyone else’s” - she expressed genuine surprise at how comfortable she felt discussing her need for anti-depressants, within the privacy of this particular group.

But not everyone in the group felt as open, or as comfortable as Jenny and Sarah, when it came to sharing their innermost feelings. The two men in particular, found it difficult to articulate their emotions. William, the eldest in the group, had a preconceived notion that most individuals who are sad, or anxious, for whatever reason, are in need of “a good whack behind the ear” and, in his opinion, should “stop self-doubting – enjoy it [life] whilst you can.” Not a great advocate of “fluffy self-belief stuff”, he admitted his embarrassment at the thought of opening up to anyone regarding any anxiety he had experienced “occasionally” about his health, never having done so before, even to his wife.

William’s revelation about this seemed to spark some emotional responses from others in the
group; at times, in ways that may, on paper at least, seem somewhat controversial. For example, Julie exclaimed that William’s comment was not a “fair one”. What she meant by her follow-up, was that there was no right, or wrong way, to talk about mental health: “it is inherent we all have different opinions and ideas but equally important to remain open-minded and respectful to the fact that not everyone shares our views and beliefs of this world”.

Ironically, despite her acknowledgment of the need for others to talk about personal mental health difficulties, Julie opened up to the group on how she felt vulnerable expressing her own feelings; worried that it would drive people away:

I try to stay positive, you need that positive attitude cos’ no one likes to be around negative people. It’s best to save that [negativity] for someone who will appreciate it and understand – and that’s not most people […] not even they [doctors] have the answers to make these feelings go away […] our lives as we know it have ended, so don’t tell me not to be scared! (Julie, 🌻)

The sentiments expressed in this section represent only a small example of a wider group of emotions shared by the participants in response to life disruptions and changes due to living with arthritis. Another common theme which was also discussed in an emotional way in the group, reflected the feelings participants expressed of frustration, or disappointment, in relation to a lack of understanding about arthritis, by others they encountered during their daily lives. This is discussed next.

4.3.2: THEME 2: No-one understands – “It’s just arthritis, you’ll be fine” (Jenny, 🌻).

Despite efforts to raise awareness of IA conditions, it became clear throughout all the group discussions, that a general lack of understanding and compassion from others, including family, friends and work colleagues existed and was a great source of frustration for some. More surprisingly, the personal challenges of dealing with lack of empathy from the medical profession was also a much-discussed topic. The confusion and common misunderstanding that surrounds the term ‘arthritis’ also extended to the participants themselves; they all admitted to having little, or no knowledge of the disease before diagnosis; or that it could be experienced so differently among those who are diagnosed. Sarah, for instance, was unaware that RA can affect individuals differently, at different times, and in different ways. It was clear, once having heard the trials and tribulations of some of the other group members and the difficulties they faced, she experienced a moderate feeling of embarrassment. Deeming herself
a “fraud”, she considered her arthritis was “possibly not bad enough” to have been actively seeking support at such an early stage of her journey with arthritis:

I confess to being as ignorant as everyone else [...] thought I had a DVT – was relieved when told only [emphasis] had arthritis! I thought should I be here? [...] feel a bit of an idiot - do I have to show people I have something wrong with me [...] maybe I should get a cane! (Sarah, 🙁).

To reassure Sarah that she had made the right decision in coming along, and to lighten the mood, William came back with a quick quip: [chuckling] “good point but why do you think I came? I’m only here for the company and free sandwiches!”

For Sarah, receiving clinical validation of her symptoms through diagnosis was a relief, but that was not the case for everyone in the group. Overall, the members had experienced positive encounters with medical specialists but for Jenny, her experience was the complete opposite. Feeling totally “manipulated” by doctors, she explained how she felt like she was not allowed to have an opinion and was “made to feel dehumanised, dismissed like an object, a nobody” (Jenny, 🙁). Her unhappiness was palpable at the failure of the specialist to care for her as “a human being, a person with worth:”

[...] trying for a third child at time of diagnosis [...] told by the time this [medication] was out of my system I’d be too old anyway and to be glad I already had two children. Was told - your choice, hands that work, or a baby - probably be unable to look after it, or able to pick it up anyway [...] and to assume I would lose 50% hand function by the time I’m 40! (Jenny, 🙁).

Her comments encapsulated what Jenny described as the medical profession’s dismissive attitude and this was a view echoed by Elsie. She wanted to shout “What the hell does that mean!” when told she had a degenerative disease, but instead remained silent. Desperate to talk about her fears with the doctor, she was told they were “imaginary” and to stop worrying and be grateful that she was not the “worst case” he had seen. Julie regarded her initial specialist as “arrogant” and “openly hostile” to discussing any worries and health concerns she had. She added the following comments to the discussion:

Diagnosis is not a ‘one fix’ box – [arthritis] effects everyone differently – and clearly, we don’t fit into the same boxes. So why don’t they [doctors] admit they don’t know how we are going to get on – we are all different [...] most of these chronic conditions are as unpredictable to them as they are to us. (Julie, 🙁).
The fact that a number of participants expressed similar sentiments is of particular interest here. It begs the question, what type of support would they like to see in place at the early diagnosis stage? For Elsie, this meant “harnessing the support of others” who were already going through, or had gone through, similar experiences and survived “intact”. This suggestion was met with an overwhelmingly positive response from the group.

As is often the case with an “invisible” illness such as IA, it can be difficult for others, including family, friends and co-workers, to appreciate why an individual is no longer able to perform certain tasks they could previously. For that reason, as discussion continued on the topic of ‘no-one understands’, the group were prompted to recall incidents where others, beyond the immediate medical arena, may have failed to understand, or relate, to their needs.

For the most part, Elsie’s family and friends were very understanding and supportive. However, like a number of others in the group, loss of friends because of her arthritis was noted. She went on to explain: “it’s so difficult to plan anything, as even I don’t know how I’m going to feel on the night.” She described a feeling of guilt at having to change plans at the last minute and mentioned how, over the years, she had lost a number of friendships due to the limitations of her condition: “even close friends left me, they [either] didn’t understand, or didn’t want to.” Julie also lamented her loss of friendships, describing that she “just had to let go [of] friends that expected too much. They had no idea what it takes some days to even get out of the house.”

Over the years Elsie’s main problems have stemmed from a perceived resentment from work colleagues: “they thought I was getting privileges I didn’t deserve.” A diagnosis of arthritis gave her the opportunity to achieve a long-time goal of working from home. Unfortunately, relationships at work made it awkward to continue and subsequently experienced a sense of pressure to resign. She described how she has only recently regained sufficient confidence to return to the workforce, after a two-year absence.

Jenny also felt she had experienced discrimination in the workplace, due to the “ignorance” of both management and work colleagues of her condition. Experiencing visible skin manifestations with psoriatic arthritis, meant Jenny had a realistic expectation that the condition would eventually impact her work as a beauty therapist. She did not however, expect
to feel “humiliated and shamed” by her employer, and to be unemployable within 2 months of diagnosis:

I’d go to work and they’d put me in the back-folding towels, like a hobbit because I was unpresentable [tearful]. Even my tremors, I said to a client one day don’t mind my shaking I have arthritis and she said ‘sure- looks more like day after a big night out to me!’ Why should I have to make excuses for it! (Jenny, 😢).

Sadly, not all participants had the benefit of a supportive family network either. Both Julie and Tom viewed their families as being unsympathetic to their struggles with ill-health and discussed how certain family members tended to minimise and invalidate the complexity of IA. For Julie and Tom, the impact of not having an understanding family for support was pervasive. As a consequence, their experiences differed fundamentally to those of other group members.

While Julie opened up to the group about how the indifferent attitude of her doctor had been difficult enough to deal with, the lack of understanding, and eventual rejection of her long-time partner, had been much worse. She had hoped, following diagnosis, he would be someone to share the arthritis journey with but unfortunately, this was not the case. That experience left her feeling “diminished” as a woman:

[he] didn’t understand what I was going through [he] expected me to function like a normal person – so they treat you normal as regards their own expectations and when you can’t cope with that there’s other things that come in play. At the start I was crashing and burning trying to be what he wanted me to be - made me feel even more different, no longer running with the pack – an outcast (Julie, 😢).

... it [IA] was impacting sexually, he wanted what I couldn’t give [...] it’s [IA] a total mood killer, does nothing for romance! I just went really? If that’s all that’s important to you then off you go – and there’s that isolation again and everything else that comes with that - avoidance of situations which may be difficult, or embarrassing, such as parties, dances, weddings, etc. You realise HEY! You have a chronic illness and no-one loves you (Julie, 😢).

She went on to explain that alongside the rejection from her partner being “branded” by her eldest brother as a “lazy, idle, welfare cheat was an additional pain that “no-one could see.” She told the group, how coming from a culture that values the importance of family and community, the “withdrawal of both love and family support” was extremely hurtful and difficult for her to cope with. Julie confided that she no longer regrets “cutting the ties” with her family. She
considered that her brother’s actions, as a ‘figure-head in her family, contributed to her escalating feelings of anxiety and fear. As such, family no longer play any significant part in her life. Although she now professed to being happy most of the time, she admitted the “scars never leave me.” Ostracised from what was then her only source of care, it has taken many years for her to find that level of support again. She eventually achieved this through her local church community, where they “embraced” her like a family should and helped her to stop feeling like a “burden.”

Tom described how the perceived “abandonment” of his family impaired his ability to trust others and negatively affected his past and present relationships, whether they be societal, or intimate:

> I struggle more because I don’t have a good support system [...] not close with family – they can be very negative. I regret that [...] something to be said, having positive people around you, helping get that internal world at peace so to speak [...] when really acute I don’t want to talk to anyone - want the cat but don’t want human company. I know my socialising abilities are very self-limited – notice I said self! (Tom, 📝).

As Tom’s comments indicated, his difficulty with socialising was perhaps, in part, due to his own internal limitations. Convinced he is “inherently undesirable” and unable to form friendships, even with his own family, he considered that for him to build a social support network would only add to his stress level, not reduce it:

> “Just getting here [the first meeting] was stressful, as pulling out on the day is a common theme for me. I could make a career out of it!” (Tom, 📝).

Tom recognised that a successful social relationship had to be a two-way street, one that required active participation. Nonetheless, he continued to avoid social events, preferring “self-imposed isolation.”

These themes help demonstrate how the participants’ sense of identity were impacted by social relationships and the reactions of others they encountered in their daily lives. As such, the participants’ loss of identity is discussed next.
4.3.3: THEME 3: Loss of identity

For some, the changes to identity, or diminished self-identity due to IA, was difficult to reconcile. This proved to be a sensitive topic for the group and I was asked to set the stage for discussion by putting forward my own thoughts, so as to help the group link concepts to their own lives:

IA can sometimes be painful. But as someone who lives with RA [...] physical pain is not always the worst thing [...] not being the person I was [pre-arthritis], and not being able to do the things I used to do [...] like being independent [...] tying my own shoe laces for one thing [...] dressing nice [...] and being my old “thinner self” of course! [...] (Researcher notes, E)

Body image was discussed repeatedly throughout the study, and demonstrated how unwanted changes in appearance was a significant aspect of identity for many of the participants. Unsurprisingly, this was a particularly relevant topic for the women in the group. Jenny shared her “shame” at how much “value” she placed on body image and the “ridiculous” efforts she had gone to in order to “conform to society standards”. For both Jenny and Julie, their comments centred mostly around self-consciousness and a desire to be viewed as normal:

[...] don’t feel attractive anymore [...] gave myself conjunctivitis for months, stabbing myself in the eye trying to put mascara on [tearful] [...] had real problems with my hair - doctors don’t appreciate how important this is, especially for women. Couldn’t hold a brush and then my hair started falling out [...] got so annoyed shaved it off. So unfair I should lose my hair to regain my health. These weren’t the terms I signed up for (Jenny, 🙁).

Socially, there is an element of rejection that’s probably felt and not heard [...] a certain look for women – whereas we dress for comfort and warmth – not fashion and pain - we struggle worse [than men] with what outward appearances are expected of us (Julie, 🙁).

For Sarah and Elsie, however, their stories centred around the changes heralded by their medications. Sarah was unaware that a side-effect of her medication included hair loss, and considered this a cruel side effect to endure, at a time when she was already feeling “at rock-bottom.” Hair loss was a severe psychological hurdle and she described it as a “huge blow” to her self-esteem, as hair forms “such a big part of who you are.” Elsie’s struggle, however, was with weight gain due to medication, which she believed her doctor had not warned her sufficiently about:
[...] doctors are guilty of missing the point about medicines causing more problems than they cure – never had trouble with weight before [...] bottom line is that doctors need to offer up all the facts before writing that scrip - it’s still our decision to make, if your self-confidence takes a huge hit are you just trading one problem for another? (Elsie, 🙁).

On hearing the stories from the rest of the group, Jenny became emotional, as she detailed how her condition had fundamentally changed her outlook on life. Before [arthritis] she had thought of herself as an “attractive, successful beauty specialist, and a happy, fun-loving mum of two young boys.” Now she described herself as being “very different”: “no longer a positive person” and “often angry” with what she perceived as a ‘downgrade’ of her role, both as a wife and as a mother. She noted how she was “always fearful” of the condition worsening and what long-term impact this might have on her family, particularly her children. Her sense of loss was profound and undeniable:

My old identity has been compromised. I don’t feel connected to myself the same, never mind my friends [...] afraid no longer fit in. They still look so beautiful whereas I’ve pretty much given up on self-image [...] not attractive any more (Jenny, 🙁).

Jenny went on to explain how a forced career change had made it difficult for her to maintain a positive self-image: “when I think about my identity, I think about my job [...] I loved it – it was who I am – still is!”

For a number of the participants, living with IA had challenged the way they interacted with the world and completely changed the way they defined themselves. Living with the new limitations of arthritis was hard to accept, for some more so than others. As such, the themes around self-acceptance are discussed next.

4.3.4: THEME 4: Hard to accept

Accepting what cannot be changed about living with a chronic disease, such as IA, can be a difficult lifetime battle (Researcher notes, ☹). This is especially true if, like Jenny, the person experiences a long-lasting decrease in their quality of life, like having to give up the profession she really loved:

My life was great before [arthritis] but now, on the surface I’m normal [...] but it’s (arthritis) always there, under the surface and I hate it [...] hard to move on -
much, much harder than [I] thought it would be - just keep plugging along and taking one day at a time (Jenny, 🙏).

In comparison, Julie had managed somewhat, to make peace with her disease but, as she put it “acceptance does not mean giving in and giving up”. Acceptance for her involved pushing through the pain barrier and being mindful, that “when you feel disabled on one level, if you’re not careful, you can become disabled on another.”

A common phenomenon that was spoken about by two members of the group, was their determination to ignore symptoms of their disease, or at the very least, exercise concomitant control over them. Vicki admitted there was a need for her to be more “flexible and adaptable” when dealing with her condition but was not prepared to “waste too much time” on it, believing all that was needed was for her to “stay strong” and ‘tough it out.” She described how she afforded her condition “time but not necessarily all the time it needs” after which, it [arthritis] was expected to fit in around her schedule. This seemed to stem from her desire to control the outcome, rather than face a harsh truth of having a chronic condition:

[I] control my disease because I miss that freedom to do whatever, whenever – I will not be determined by pain (Vicki, 🙏).

In a similar vein, William had a hard time adjusting to his pain, which he considered to be an “intrusion” in his daily life. He explained that coming from a generation where you were told to “just get on with it” meant he was constantly fighting against his pain. At one point he referred to it being like a “battleground” whereby the “pain nearly always won” making him feel like a “failure” when it did. This was followed by his admission “it doesn’t work though; it only makes things worse but I keep doing it anyway - [I] like to be in control.” Whilst he acknowledged the key would be to “modify” his way of thinking, reality was he struggled with acceptance of “being seen as chronically ill” and the perceived ‘loss of control’ that came with it.

Julie interjected here to say how views, such as those expressed by Vicki and William, only helped illustrate “the value of letting go of unhelpful thoughts.” She continued with:

Because it won’t get better, and don’t think it does – but it eases. Like a death in the family really, it never goes away but you grieve and it eases as time goes on (Julie, 🙏).
It’s a journey when you come to a stage whereby you honour your time, your freedom and your capabilities by the moment (Julie).

Negotiating acceptance of having a chronic disease is no small feat and the ways in which participants managed, and their capacity for managing, varied considerably within the group. Most of them, however, experienced their disease as a tough transition and all relayed how the experience had disrupted multiple aspects of their lives, including loss of confidence, negativity in relationships and the ability to remain spontaneous. One common theme – in relation to the disruption arthritis had on their lives, reflected the sense of social isolation and loneliness the participants experienced. This is discussed next.

4.3.5: THEME 5: Social isolation

The social impact of living with IA emerged as an important theme; in particular the stress created in maintaining relationships with family, friends, and work colleagues. It was clear from a number of group discussions that some members no longer felt able to socialise effectively and the “drifting off” of friends because of their condition, was a sensitive topic. For some, this had led to an overwhelming feeling of isolation and loneliness. Elsie explained how, for her, losing a “ready-made infrastructure” of work friends and associates, had challenged her socially, and left her feeling “out on a limb and disconnected” despite having the valued support of a “loving, understanding family.”

Being socially isolated is not always synonymous with being lonely but there can often be a correlation between the two (Meeuwesen et al, 2001). This was reflected in Tom’s account:

[…no friends to speak of, enjoy my own company, people think I’m lonely but [I] consider myself satisfied with my own company – biggest insecurity is in how others see me […] so don’t go out much […] rely on self-deprecating humor to get by and develop friendships – flip side is [I’m] not taken overly seriously except when I come out with something reasonably intelligent (Tom).

Solitude was a matter for choice for Tom, as he considered it to be “the one aspect of life I can control.” This was despite having previously acknowledged some of the negative aspects of removing himself from society and of having only limited, or superficial social contact:

Jenny, continued the discussion by providing insights about how her support network differed considerably to that of Tom’s. Loved and supported “unconditionally” by her family, “in spite of
my own shortcomings”, she described a close family bond as her main “self-preservation” strategy. At the time of her diagnosis, however, she felt a strong sense of independence and the need to retain a sense of autonomy. This led to her seeking out support beyond the safety of the family structure. She went on to explain how she wanted to reduce her sense of ‘being alone with arthritis’ and to increase her confidence in being able to “have fun and make new friends. Unfortunately, her first experience of an AOWA self-management intervention proved to be a far more “difficult and depressing” task than anticipated. For her, the relatability of the group, particularly as regards age, was a major problem:

... youngest by forty years! [...] nothing in common with any of them [...] nothing to say to each another [...] experiences were so different [...] they were focused on their own disease experience whereas my focus was to keep going. I said you can’t just sit at home as an old age pensioner, nursing a sore hip, not an option and their answer was yes you can [...] it just wasn’t an option for me (Jenny, 🙃).

Jenny also sought the support of a local peer group, in an attempt to share experiences with others who were “actively trying to continue with their lives, rather than just surrendering”. In her description, this was not a great success and left her feeling “lonelier” and “more disconnected” than ever:

[It was] more a social café meet-up with younger ones– thought might be more my thing [...]. But a lot of them almost using it [arthritis] as a badge of honor - personally I’d rather not! Sat there thinking I want practical advice, not talk about benefits and hand-outs - like where to get things to open a jar with? How do you hold a steering wheel with mittens? [emotional] (Jenny, 🙃).

Jenny went on to explain how her perceived inability to connect with others who shared the same experiences, directly led to her decision to present a different image, one that was “intentionally withdrawn” from friends and colleagues, and “tucked away” from the external world:

I present a new face now – instead of putting on a pretty face for work I built a lovely webpage so no one had to see me. Don’t need to speak to anyone now [...] (Jenny, 🙃).

Julie’s reply below demonstrated her sympathetic but honest response to Jenny’s situation:

Listen hun - none of us is perfect [...] we’re all trying to learn something here [...] trying to be better. But if we pretend that everything’s alright and we’re in denial,
we won’t move forward. I’ve been where you are now. It doesn’t work. You need – we all need -to share in the outside world [...] let others know what we’re thinking, feeling (Julie, 📊).

The stories presented here reveal how the social relationships of participants were often fractured and unfulfilling. Group discussions revealed how being ‘cut off’ from normal social networks, with little, or no communication with friends, or family, was among the more common consequences of a life with IA.

Summary

Rather than being a comprehensive review of the lived experiences of individuals with IA, the themes discussed in this section were only intended to illustrate to the reader the social and psychological challenges more commonly faced by the participants, in relation to their disease. Relevant areas of research show how these experiences can cut across a host of chronic illnesses, not just arthritis. In many ways chronic conditions are distinct but they can also share common pathways and outcomes of physical, psychological and social health (Institute of Medicine, 2012). The commonality highlighted here, may present an opportunity for future evaluation of DRUMBEAT in other areas of chronic disease, not only IA.

4.4 The DRUMBEAT Experience

The previous section (4.3) provided an insight into the psychosocial realities of living with IA and the distress and emotional suffering it had generated for some participants. This section aims to create a detailed understanding of the perceived benefits of the DRUMBEAT program for IA participants. To that effect, five informative, over-arching themes emerged from the data analysis, supported by 18 sub-themes; summarised in Figure 28. The sub-themes address the original aims of the study. Specifically, how participation in the DRUMBEAT program: (a) met the needs of a group of individuals with IA; (b) enabled participants to enhance self-efficacy; (c) gave members an increased sense of control over self and their environment, and (d) allowed for a sense of belonging through the group support process.

Each of the themes will be discussed in the following sequence:
1) **Promotion of mental health and emotional well-being** – which broadly relates to the pleasure that participants derived from participation in the DRUMBEAT program and their perception of positive emotions elicited by the experience.

2) **Positive physical effects** – concerns how participants perceived drumming as an effective, fun means of fitness, as well as an activity that simultaneously energized and aided relaxation. Understanding that participants differed in their ability to tolerate and respond to pain, this section also makes mention of the positive effects on pain levels to a lesser, and contrasting degree “relieved the pain and anxiety and stress levels – all in one go!” (Julie, 🌟).

3) **Sense of community** – which centres around the relationships which developed and the bonding between members. The resultant sense of connectedness helped create a “memorable team building experience” (Sarah, 🌟).

4) **Enhanced self-efficacy** – which refers to the increased individual self-realisation provided through the medium of DRUMBEAT, allowing participants to have better control of their life and create positive changes.

5) **Beyond DRUMBEAT** – which concerns the perceived impact of the DRUMBEAT program beyond the study period.
The first main theme broadly relates to the pleasure that participants derived from participation in the DRUMBEAT program and their perception of positive emotions elicited by the experience; namely, feeling good, the ability of the program to promote the release of pent-up emotions and the profound effect group drumming had on psychological well-being. Participation in the DRUMBEAT program is described as positively influencing participant emotions and helped pave the way for participants to talk about, and acknowledge some of the difficult feelings they had previously suppressed.
All of the participants were unanimous in their positive support of the DRUMBEAT program and of their overall enjoyment in taking part. In focus group discussions, participants were enthusiastic in how they described their DRUMBEAT experiences. Sarah mentioned how she was already “missing my Tuesday sessions!” and how “brilliant” the program, describing it as the most “fun” she had in ages. Other common responses from the group included statements like: “What didn’t I love! It gave me something to look forward to every week, to get excited about;” and “I’d love a chance to do it again.” William described it as having “good old-fashioned fun with friends” and an experience that gave him the opportunity to “have a chat, hang-out, joke” and to ‘get rid’ of all his worries.

The enthusiasm and energy of the group throughout the intervention created a real ‘buzz’ and a great sense of camaraderie. Tom commented on how, before coming along to the sessions, he could not remember the last time he had laughed so much at anything, or with anyone:

... seriously, meeting all of you has done me a world of good [...] feel more connected and in charge now with what I’m feeling – had forgotten how good that is [laughter]” (Tom, ✉).

The pleasure the group derived from participation acted as a catalyst for positive emotional changes that outlasted and went beyond the timeframe of the study. The pre- and post-study narratives of Tom help demonstrate this. Tom confided in an early group discussion how “being happy has kinda gone by the wayside [for me] - been like that for years.” In contrast, at the post-study interview, his mood, self-esteem, and confidence all appeared to have substantially improved. He was visibly happy and greeted me with a huge smile on his face. During the interview he acknowledged that for him to maintain positivity continued to be a daily challenge but one that he now “felt more prepared for” since his involvement with DRUMBEAT. Realising it was impossible to attribute his mood changes to any one specific event, he nonetheless considered the study to have been “the best investment in my personal life that I’ve made for ages” and continued with:

“I’m excited about the changes I’ve made already; can you tell? [laughing] [...] hard to define why but since meeting you guys my life has changed so much – so much happier – know I’m getting stronger emotionally ’cos I’m doing something about it now (Tom, ✉).
Previous negative experiences of support groups had made Jenny “initially terrified” at the idea of coming together with a room full of strangers. But she later considered her fears were “unjustified” as she recalled her surprise at how quickly she was able to form relationships with the other participants and how comfortable she had felt in the group: “I quickly lost my anxieties somewhere in the drumming, my mind went blank [...] my fears of getting involved just slipped away.”

Julie interpreted her moods differently to Jenny. She was never fearful of coming along to the drumming sessions but rather, viewed them as something “to get excited about.” As a South Sea Islander, she considered the drum to be in her “blood” and an important part of her identity. Elsie, also appeared very upbeat and much more positive in her response: “bashing that drum definitely helped sort out my week’s problems”. This led to Julie smiling as she made her observation: “It’s not only the drumming though is it, that makes us feel good? It’s was also our Tuesday nights together – it’s our little family.” She added:

That’s where the group has been very beneficial to me [...] just hearing everyone else say what I’ve always felt but never voiced [...] cathartic for me – better than any drugs (Julie, ).

Unanimous in their agreement of DRUMBEAT as a feel-good program, some of the group responses included statements like: “just brilliant – no more to say!” “a very fun way to learn” and “a great way to express those pent-up emotions.” What followed, much to the amusement of the other participants, was the added admission, from the previously reticent William:

...by the end of this [...] I can talk a bit more freely about things [emotions], being amongst friends helped [...] and that’s saying something, coming from me! [laughing] (William, ).

This was followed by a genuine show of encouragement through laughter from all the participants who attended the focus group.

Further illustrative quotes demonstrating the perceived positive impact on emotional health, elicited through the DRUMBEAT program are presented in Table 9:
Table 9: Theme 1: Positive effect on emotional health

Sub-themes

Catharsis

- [Drumming] left a deep and happy impression [...] felt so much lighter in my thoughts [...] had been bottling them up. Really wish I could have come to more sessions (Vicki, ♂).
- Nothing else matters when you’re playing – all my stresses disappeared - less thinking and more feeling the music – it was a delightful release (Elsie, ♂).
- You know what they say - a problem shared [...] felt lighter [emotionally] at the end of every week (Sarah, ♂).

Fun

- … so much fun! [...] you both did a brilliant job. Your sense of humour is infectious (Sarah, ♂).
- I’ve not smiled so much for ages [...] a fun program [...] helped me discuss and work through my current issues. Brilliant! (Elsie, ♂)
- Could’ve gone on longer for me - I loved it! Most fun had for ages (Julie, ♂)

Feeling good

- [...] feel better able to cope with my feelings [anxiety] now I recognize them as normal (Julie, ♂)
- Didn’t have to think about it [arthritis] so much, drumming just took me to another place (Jenny, ♂)
- [...] stress levels went right down – amazing [...] started to see I could only make the drumming feel as good as I felt [...] and I wanted it to feel good! (Elsie, ♂)
- Certainly, feel more positive [emotionally] after having a go [drumming], don’t really know why ‘cos I don’t like this fluffy self-help stuff! [laughing] (William, ♂)
- Sometimes things [emotions] are just too hard to talk about but drumming it out makes me feel so much better (Julie, ♂)
- [...] am a lot happier and less frustrated after doing this [DRUMBEAT][and] there were some hilarious times with these bunch of people! (Jenny, ♂)
- … gets you thinking…really different state of consciousness…. almost zoned out there… it’s a bit trance like… it’s lovely… I could get into this! (Tom, ♂)

In summary, participant comments suggest that participation in DRUMBEAT can play a pivotal role in providing individuals with the opportunity to gain greater social and emotional awareness. For some participants, the perceived positive impact on mental health came from the feeling of belonging to a type of ‘community.’ This is discussed next.
4.4.2 Sense of community

The second theme identified throughout the transcripts, was the communal aspect of the DRUMBEAT program and the building of a community, unified through the experience of group drumming. Under this heading, four main sub-themes emerged: the encouragement of social interaction; a sense of belonging; a feeling of reduced isolation and the ability to achieve a connection through the features of the DRUMBEAT program.

All of the participants reported how welcomed they felt in the group and how the comfortable group interaction was one of the most positive aspects of the study. Throughout the sessions, everyone was encouraged to initiate positive interactions with each other, with discussions often allowed to go ‘off-topic’ as a means for participants to get to know each other more personally and to develop a stronger sense of community. Early in the study, it was observed how quickly shared humour brought about an in-group feeling of fun and acceptance, and a communal sense of belonging (Researcher notes, §).

“Group solidarity was great, felt almost immediately I was amongst friends” (Julie, 🌟).

The foundation of the group rested on the natural inclination to share experiences, fostered by bonding-orientated discussions which gave participants an opportunity to reveal information about themselves and their own experiences with arthritis. One mutually beneficial exchange was recorded between participants, which illustrated the benefit of peer support and the value of hearing a different set of life experiences. Exchanges such as transcribed here, were commonplace throughout the study. The conversation starts with Jenny, as she spoke quietly to mask her obvious embarrassment (Researcher notes, ??):

[… when he’s (husband) away […] find it hard to cope on my own […] it’s [arthritis] relentless […] am so tired […] feel less of a mother […] feel just useless (Jenny, 🌟).

Expressing her concern, Sarah lent over to take Jenny’s hand and asked “In what way?”

[...] it’s like, well this week for example […] embarrassed to say I came up with Backwards Day […] kids had left-overs for breakfast and vegemite and cheese on toast for dinner, all week. How bad is that? (Jenny, 🌟).

Sarah’s smile seemed authentic and light-hearted when she replied by saying:
That’s brilliant! Wish I’d thought of that when my kids were little. And bet they loved you for it? (Sarah).

Hearing this response, a positive change was observed in Jenny’s whole demeanour. As the topic discussed here was not one that lent itself to professional help, it appeared that by sharing her worries outside of the clinical arena and talking with others who had been there, helped lift a considerable burden of guilt for Jenny (Researcher notes, 

They did! My youngest keeps asking now to do backwards day again [...] I thought you’d all be judging me for that! [...] so glad you lot don’t think any less of me for feeding my kids fried rice for breakfast! [laughing all round] (Jenny).

[...] sweetheart you have to laugh at it [...] having a sense of humour is the one thing that’ll keep you going [...] know it’s hard but you’re not alone - my experiences may not be exactly like yours but there are similarities – so it helps to talk, to share (Julie).

[Jenny smiling] Seriously, this time round it’s so much easier to feel connected with this group [...] feel amongst friends really [...] not so much on my own any more. I didn’t fit in at all last time [previous experience] everyone was so much older [...] it was more about sitting around with geriatrics (Jenny).

I know what you mean [...] find that hard too and I live with ‘em [laughter] [...] it’s good for me too, hearing everyone else’s opinions [...] was more than a bit skeptical at the beginning [...] and besides I hear from enough OAP’s [old aged pensioners] as it is – surrounded by ‘em! [laughter] (William).

These types of conversation offered optimistic indications of an evolving sense of community. After this particular interaction, Jenny appeared far more relaxed and happier in the group and became more actively involved from that point on: “it’s so nice coming here and just chilling every week with no expectations, no judgements.” Her views on how she felt able to fit in and relate to the other members, were endorsed by everyone else in the group.

The sense of bonding was further enhanced in week three, by the introduction of contemporary music to drum along to. The music choices were suggested by the participants themselves and were easily incorporated into the sessions. They particularly enjoyed drumming along to the likes of I’m Yours – Jason Mraz (Djembe cover version) and The Lion Sleeps Tonight.
group as a whole, when given the opportunity to contribute their own unique ideas for the music, were seen to display a real sense of ownership. So much so, they gave themselves a group name; the ‘Druarts.’ The strengthened sense of connectedness in the group was reflected by an increase in overall session rating scores from week three (section 4.1.2) and in Facebook posts. For the first time, a number of the participants continued their interactions via Facebook, after the group session had ended. Examples of some of the Facebook posts included:

Really looking forward to next week [...] see what other music we can play along to [...] even drumming along on the steering wheel on the way to work now (Elsie).

Practicing to an old favourite from home as well now! I’m on the drums hehe 😊. Have a good weekend you beautiful people😊 (Julie).

The Lion sleeps tonite? Don’t think there will be much sleeping going on when they hear our fabulous drumming! (Elsie).

Aren’t we fab and in sync – thank you Jan [researcher] and Grace [Facilitator] for another great night of sharing. I love you guys! 😊(Julie).

Not quite good enough for Hay St Mall yet but you never know! (Jenny).

Sharing a mutual interest of drumming meant the group now had some common ground on which to build friendships and connections, apart from arthritis:

We sounded like a real group tonight [...] wish the families / friends could hear us [...] (Sarah).

Already a bit like a family anyway, aren't we? (William).

... the primary reason I enjoyed it [DRUMBEAT] [...] was the connection I felt with the group, as we all joined in together. The relationships we’ve formed – you get to know how they operate – the way they feel – and suddenly that comes out in the discussions as well. For me, I think if you’re part of a group that everyone is committed to, it gives you that motivation [...] I’ve really felt connected to this group and hope we can continue in some way. (Elsie)

In order to assist the upcoming weekly discussion on identity and community, the group were asked, via Facebook, to consider the following question: ‘Are WE a community?’ William came out with
the comical response of “most definitely a community of bad drummers working towards a common goal to improve......HA! 😂 (William, ♂)

In summary, the group served a significant social role. It was a place where participants came together on levels, and in ways, that they might not have done otherwise. Upon entering the group, each participant seemed to become part of a larger community, one that included people from very different backgrounds and from different cultures, who found more common ground than they expected (Researcher notes, ♂).

The previous two sub-themes indicate DRUMBEAT as a mind-body practice that enabled participants to plug into rhythm and be a part of a community they perceived to be fun and rewarding, on both emotional and physical levels. The positive physical benefits of DRUMBEAT are discussed next.

4.4.3 Positive physical effects

This theme is explored through the three sub-themes namely: relief of pain, increased physical activity and enhanced energy levels. Understanding that participants differed in their ability to tolerate and respond to pain, this section makes mention of the positive effects on pain levels to a lesser, and contrasting degree.

Sarah expressed her surprise at finding drumming could be an effective form of exercise “both a mental and physical work-out.” Julie also described how drumming was a great way to feel uplifted, both physically, and emotionally and how, for her, it had “relieved the pain and anxiety and stress levels – all in one go!” She had initially expressed a fear that the physicality of drumming might worsen her pain but in fact, the opposite was true. She exclaimed:

...what an amazing distraction [from pain] - thinking about getting that beat right took my mind off it [pain]. Can I please borrow a drum to take home?” (Julie, ♂)

Many different styles of drumming techniques were observed in the group but Julie’s in particular, had some unique idiosyncrasies. She had the ability to become quickly absorbed in the task and arguably her energetic contribution played the biggest role in dictating the feel and pace of the group drumming sessions. Her unbridled enthusiasm was infectious and seemed to make the entire group feel upbeat and physically energised:
It was fun but a bit challenging physically, especially when introduced to different beats – I needed a boost of energy half way through but looked at Julie instead [...] go girl! [laughter] (Sarah, )

Bit more wary than I expected as hands hurt sooner than I thought. [...] great exercise though and I’m following her lead [looking across at Julie, putting a thumbs-up] she’s keeping me going [laughter] (Jenny, 😁)

I’ll just sit here and watch Julie play those drums, that’s my exercise for the night! She was so into that rhythm; she could have been our sole focus [laughter]. I’m hoping this workout will help burn some of those calories off! (Sarah, 😂)

I could only make the drumming feel as good as I felt – so Julie must have been on top of world! [laughter]. Always smiling – infectious – whilst some of [us] were deep in concentration. What a great workout! (Elsie, 🎉)

William acknowledged he sometimes over-performed his drumming but found it a way to break through his pain. Whilst not wanting to dampen his positive enthusiasm, it was essential to occasionally remind him not to play the drum harder and louder, as the pace increased, in what he described as his “new fitness workout.” William had found it difficult to come to terms with the additional diminution of vigour due to arthritis, noting that he could easily cope with getting old but the loss of his ability to swim was “just not fair.” Hence, the drumming sessions represented his only fitness regimen for the week.

Drumming also appealed to Elsie as she was actively looking for a different type of group exercise, one that was “fun and regimented” and would keep her moving and committed to a regular time. She described her experience with DRUMBEAT as having “provided all that and more.” In addition to eliciting feelings of being energised some common responses of the group included: “sharpens the reflexes;” “gets the heart rate going;” “feeling stronger, fitter” and “improving my co-ordination.”

Recalling how participation in DRUMBEAT had a positive impact on mental health (sub-theme 4.4.1) it also appears that participants viewed drumming as a welcome distraction from pain and as a good exercise option, if played at a controlled intensity, for short, intermittent periods of
time. Past research has found that individuals with arthritis, who attain higher levels of physical activity, are more likely to report feeling less pain, less fatigue, improved physical functioning and enjoy a better quality of life (Primdahl et al., 2011; Keefe et al., 2002; Keefe & Somers, 2010; Knittle et al., 2011).

Given that self-efficacy, described as one’s belief in his, or her own capabilities, to perform a specific behavior, is associated with increased physical activity among individuals with arthritis, these findings emphasise the importance of self-efficacy enhancement in the arthritis population (Bandura, 1978; Knittle et al., 2011). As increased self-efficacy was an expected positive outcome of the study, this is discussed next.

4.4.4 Enhanced self-efficacy

Enhancement of self-efficacy to encourage positive health behaviours is an essential feature of any successful self-management intervention and as such, measurement of change in self-efficacy was a key component of this study (Brady, 2011). Session notes indicated how participation in the DRUMBEAT program utilised the four major sources of self-efficacy (Section 2.2.2): mastering experiences, vicarious learning, verbal persuasion and psychological responses (Bandura, 1978). Each of these correspond with the main sub-themes that emerged under the heading of ‘enhanced self-efficacy’ (1) mastery, whereby participants gained a sense of control, through the acquisition of new skills; (2) increased motivation to change / succeed in a task, through peer modeling; (3) the improved ability to reach goals and overcome challenges as a result of verbal / social persuasion; and (4) an enhancement of self-confidence.

At the final focus group, a number of participants reported how, since participating in the study, they had felt a greater sense of control over their life and an increased motivation to change. To demonstrate, Jenny commented on how “adapting to a new skill [drumming]” had given her “newfound” confidence. She considered the program had provided her with the tools to “venture outside” of her comfort zone more often, whilst subtly reinforcing the message that learning a new skill [drumming] can be difficult. The physical act of drumming allowed her to “put aside” thoughts of pain and gave her the opportunity to “mull over” how the self-destructive recurrent thought of “I’m to blame for all this. It’s all my fault” served no functional use, other than to perpetuate her feelings of isolation from others:
This [drumming] is giving me time to think [...] I’ve decided I can’t keep blaming myself [...] it’s not useful, I need to let it go, and move forward [...] if I don’t, I’m going to stay in this dark hole and I don’t want to]. (Jenny,)

In a similar vein, Tom disclosed how, before the study, he had also struggled with self-destructive thoughts that tended to dwell more on perceived “failures”. He did not participate in a number of the drumming sessions at the risk of feeling “embarrassed” and “looking an idiot if I can’t play.” At week 1, he indicated a strong desire to continue in the study but found it “difficult to commit” and was “just not ready to take [it] on” Although he chose to avoid, rather than to embrace the challenge of something new, his concern at not being able to continue the study led to my suggestion that we kept in touch. Throughout the study he would contact me via private messaging, sometimes just to say hi, other times to keep himself in the loop, about the study. I hoped he would eventually return to the group as an active member. This he did, much to the delight of the group: “freaking awesome he’s back - now the fun can really begin!” (Elsie, ). On his return he felt compelled to offer an apology to the others participants for his absence, which elicited a sympathetic response from William:

...that’s where I go wrong [...] to really commit is difficult [...] I set myself up for failure by aiming way too high - that inner voice of mine can be very critical [...] downright cruel sometimes. But I’m back now and ready to celebrate my successes – YEAH! By successes, I just mean getting back here tonight – not much I know – sorry! (Tom,)

Why are you putting yourself down? [...] you need to stop beating yourself up. Now get drumming lad. Believe me, life is far too short and I should know, I’m farther down the track than any of you (William, ).

A positive focus and enhanced feelings of self-efficacy were also attributed to the use of goal setting. Most of the self-efficacy-building experiences the participants discussed centred around the ability to master the art of drumming. This was evidenced in the current study through the discernible, steady rise in participants’ confidence levels, as the weeks progressed. Encouraged to ‘ditch’ any self-doubt they might have had in their musical abilities and to extend out of their comfort zones, participants were rewarded by the simple act of engagement, contribution, and freedom to express themselves to the beat of the drum. At first, the facilitator set small realistic goals that could easily be accomplished. Over time, as the group became more proficient at drumming and had learnt a few easy tunes to play along to, more difficult goals were
introduced. Regardless of ability, mistakes were inevitable and this proved a problem for Tom. As mentioned earlier, he attached shame to his mistakes and viewed them as failures. However, by week six Tom admitted to being “more willing” to accept challenges and to feeling more comfortable with the idea of making mistakes in the drumming:

 [...] even taking a shower can be a goal for me sometimes, so feeling quite pleased with myself tonight .... amazing how rhythms do go a bit off track sometimes – mainly mine. Can see how listening to the wrong people can mess you up. Is that one of the things do you think? When we connect it’s not always about what we say / do, it’s also be about who we listen to? [...] feel as though I’ve achieved something tonight. Still crap at drumming though! [laughing] (Tom, 🤣).

Week five discussions centred around ‘stepping out of your comfort zone’ and the possible benefits of doing so. To challenge the members to move past arthritis, they were encouraged to interact with others, outside the confines of the group session, to try something new; something they considered would help them gain in confidence. Some shared their stories the following week:

 ... I made a stand this week, stood up for what I thought was right and went against all others on a committee I’m a member of. Quite a few shared my view but no-one else had spoken up. It was uncomfortable but needed doing [...] it felt good! I felt a rebel! (William, 🤣).

 ... had a good challenge this week [I] was asked to help with interstate votes and it meant travelling into the city. Would have said no before - going into the city is too hard for me but this time told them send a car and I’ll do it. Thought to myself, - how many times didn’t you ask for help just because you felt like you should be able to do it on your own? Or you just said no I can’t do that? Well not this time girl! They want me, they’re gonna have to pay and the uber come and picked me up (Julie, 🤣).

 ... a good thing happened since last we met [I] managed to get out and vote. Big thing for me as was right into politics at school but lost interest ...means I voted for second time ever. Still lost so can’t win ‘em all. (Tom, 🤣).
In summary, all of the participants were observed as displaying increased confidence, whether it be through improved critical thinking, greater personal efficacy, or enhanced social responsibility.

4.4.5 Beyond DRUMBEAT
Sustained interactions, both online and face-to-face, between myself and participants have helped create an additional source of data which serves to showcase the perceived benefits of completing the 6-week DRUMBEAT program, beyond the study timeframe. Referring back to the quantitative results (Section 4.1.2), it was not until week three that some of the participants started to become more involved in the Facebook group. Most preferred, throughout the study, to simply respond only with likes, comments, or shared links, rather than to post themselves. Despite my being unable to drive many meaningful interactions on Facebook, the participants were unanimous in their request to keep the group open, so as to stay in touch with each other after the study was completed. As time goes on, there have understandably been some changes to the group cohesiveness, related to various life circumstances and changing individual needs. However, two participants have chosen to stay in touch with each other and they text me on a regular ad-hoc basis, to keep me up to date with their progress. The fact that these relationships have evolved into more meaningful friendships is a genuinely lovely and surprising take-away of the study.

This final theme, which depicts the shared stories and lived experiences of some participants “Beyond DRUMBEAT” helps to illustrate the study conclusions to the reader, in a more personal way. For this purpose, I have focussed on two members whose stories depict issues that particularly relate to four additional sub-themes of (1) continuing friendships; (2) positive changes in behaviours / lifestyle; (3) optimism for the future; and (4) reconnection with self and others.

**TOM’s Story:** When I met Tom, he entered the first drumming session with some trepidation and admitted to feeling a “fairly intense combination of nerves and excitement.” Tom, now 45, is single, has never been married and acknowledged to the group his fear of committing to any relationship, as it required him to “let people into [his] life in a meaningful way.” This difficulty in maintaining a social connection extended to his family, whom he had hardly spoken with in almost two decades; for reasons he professed to still not fully understanding. Music is
... profoundly important to him and his own early experiences with drumming sparked his interest in the study. He works full-time for a non-profit organisation and considered he had been passed over for promotion on numerous occasions, for having taken time off work due to RA.

At the first week introductions, he spoke candidly about his struggles with mental health since his late teen years and how he considered that many of the “usual” social activities available to others, that often support mental health, were “out of bounds” for him; such as close family connections, meeting friends, and intimate relationships. Tom considered his quality of life diminished further in his 30’s, with a diagnosis of RA: “just another addition to life’s many problems [...] I try to be more positive but the pain makes it hard [...]”

**TOM’s Story ‘Beyond DRUMBEAT’**: earlier in the thesis (sub-theme 4.4.1) Tom is noted as having said he viewed the study as “the best investment in his personal life.” This was in spite of his reluctance to commit to all of the sessions early on:

> [...] really regretting not making it all the way through [study] but it’s still given me that boost to the next step. Listening to the others and what they’ve gone through [...] made me realise I’m more resilient than I give myself credit for. I know a lot of my problems [...] because of health reasons but I’d also stopped caring about myself. (Tom, 🗑)

Tom also described how his inclusion in the study had encouraged him to become more socially connected and closer to the people around him: “like I was two decades ago.” He reflected back to something William had said to him in week one: “you live with the consequences of your own choices lad, no-one else’s – stop blaming everyone and everything [...] it’s up to you [...] now get on with it before it’s too late” (William, 🗑). At that time, he though William’s comment was “bit harsh”, coming from a complete stranger, but was now able to see it as a “good-intentioned wake-up call”.

He discussed how the “family-like experience” offered by the DRUMBEAT program had prompted him to seriously reconsider the outcomes he wanted for himself, in relation to a life without support of a family network. He saw this as an opportunity for a “fresh start” saying he felt empowered at starting to think about the things that would make him happy. Reconciliation with his family was an obvious marker of success:
[...]

remember I told you I was not close with my family, well I’ve been to see Mum and Dad and things are improving – could say we are reconciled – mum’s thrilled, so am I [...] have to accept it’s me not them [...] not happy being a hermit, I still like ‘me’ time but I feel ready to move on now. (Tom, 😊)

At the time of writing, he continues to maintain contact with his parents and also recently re-connected with his siblings. Despite a few setbacks, he remains committed to actively working towards a better quality of life and to being more “proactive in his decisions and choices.”

[...]

taking better care of myself, at work started to not just accept no for an answer [...] moved house, this one is lovely, my cat loves it too and that’s a bonus [laughing]. Also playing music again [...] getting out more [...]. Does that sound too much [laughing]? (Tom, 😊)

His experience of DRUMBEAT is warmly reflected below:

[...]

know I’ve said this before but meeting you [...] doing the drumming [...] changed my life so much – so much happier [...] have to let others into my life now to help me, like you’ve done! Scary stuff! (Tom, 😊)

Julie’s story: Julie has experienced a life with arthritis quite different to that of Tom. Now aged 58, and diagnosed 25 years ago, she made the decision, early on, to proactively manage her own health. Unfortunately, she described her encounters with specialists as lacking in “respect” which meant that she became somewhat untrusting and cynical about the healthcare professions involved in her treatment.

At our first meeting Julie exuded confidence in the knowledge she could control and manage most of her health problems, describing herself as “an expert in my own area [...]”. “I do my research – not too hard to research the researcher! I’m the one with the knowledge.” But life for Julie had still not been easy — far from it. In the early days, following diagnosis, her relationships with both family and her partner suffered, because of her disease. She admitted there were some “very difficult lonely years” in the beginning. Through the support of her local church, she has been able to build a “reasonably normal” life for herself. She described her new ‘normal’ as reaching a point of acceptance about the limitations imposed by arthritis:

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you set boundaries – you need those boundaries in place and you stick to them in
the knowledge that if you don’t you’re heading for a crash, or flare up whatever
you want to call it. (Julie, ⁷)

Confident in the knowledge that as a “long-time survivor” of arthritis, the study would offer her
“little more to learn,” she came along with no expectations, other than to have fun. The study
‘surprised’ her in ways she did not expect:

I’ve been living with this [arthritis] for many years and thought I’d dealt with it –
put it in the back cupboard if you like and closed the doors – but it seems there
are still some things I’ve haven’t come to terms with - this helped me look at
those – talk about those – get them out in the open. (Julie, ⁷)

JULIE’s Story ‘Beyond DRUMBEAT’: At the post-study interview I reminded Julie of her
feedback of the program:

It [DRUMBEAT] helped me articulate my own self-development […] to recognise
the other factors that accompany chronic disease and how working together with
others helps immensely to cope with daily struggles […] and to know there is a life
outside of the daily pain. (Julie, ⁷)

In the discussion that followed, she mentioned how participation in the study, had given her a
clearer sense of direction, “a shared purpose” rather than a “lonely struggle.” This is
demonstrated through an earlier group interaction on self-image, where Julie revealed one of
her biggest insecurities: “the way arthritis makes me look”; a view echoed by all the other female
participants. Never having discussed the topic before, she expressed genuine surprise at the
empathy of others in the group, for what she deemed as being “superficial.” She spoke of how
the “meaningful guidance” of the group helped gain a “newfound appreciation” of self:

[…] get good at suppressing those feelings, don’t we? Of not feeling normal, not
feeling as though you fully belong – not feeling part of the crowd. Then comes
that isolation and everything else that comes with that - avoidance of situations
which may be difficult, or embarrassing - parties, dances, weddings, etc. I look
back now [pre-study] and think why did you put so much emphasis on the way I
looked […], worrying about my pant size and never wearing dresses again - I was
stunned by my own vanity. Younger ones might benefit from this hindsight. (Julie,
⁷)
Julie summed up her overall experience of DRUMBEAT as a “ripple effect,” one that “first and most importantly” helped to reduce the negative attitudes she had towards herself and to move past the negative attitudes she believed others had about her:

[…] new friends – new alignments – the compassionate nature of the program – sitting with people who have empathy so they are not going to judge - having the opportunity to open up and talk about what’s important – this affects my ability to work, to socialize, to everything – the impact is ever-expanding. (Julie, 📻)

[…] everyone understood me […] they know firsthand what it’s like for us. That’s why having you doing this study was great as well, you are one of us – you know what it’s like to deal with this [IA]. (Julie, 📻)

I was pleased to take up Julie’s offer for a coffee meet a few months after completion of the study, so as to share in some of her most recent experiences and anecdotes. It quickly became apparent that she had lost none of her passionate attitude towards improving her life in general. She explained how the sense of empowerment felt after finishing the program continues with her to present day, despite having recently suffered the setback of pneumonia. Coming away from the study “so much more confident” the increased feeling of “self-assuredness has “spurred” her on in her pursuit to write a book. She is currently “getting the groundwork done for such a monumental task!”

While these expanded stories reflect the perceptions of only two individuals, the quantitative and qualitative data presented in this study demonstrates that participation in DRUMBEAT can empower individuals, provide valued benefits and enhance a sense of personal agency for IA survivors.

In the final DRUMBEAT session, group discussions centred around the need to set future goals. Participants were asked to consider: Where you are now? How you got there? and where do you want to be in the future? At that point in time, they were not in a position to act on those future goals and it was suggested, as a way to maintain social connection and increase accountability, they may like to share their progress through the Facebook group, either publicly, or privately. What follows is a brief account of the achievements, challenges and new directions shared by some participants, that took place over a six-month period beyond the study time-scale.
Although it is not possible to directly attribute these longer-term health outcomes specifically to DRUMBEAT, it does help demonstrate the empowering nature of the program:

**WILLIAM:** described his involvement in the study as a “double-edged sword” in that drumming had both “sharpened” his “reflexes” yet also helped identify his poor level of physical fitness:

*One thing I’ve learnt from this [study] is I need to be more proactive about looking after myself. The second thing I’ve learned is some of my old goals need a serious overhaul [laughing] [...] opened my mind to new things [...] am ready to start things that will help with my arthritis.” (William,)*

William accomplished his goal to improve his fitness level and continues to undertake regular activities:

*... walk twice a week with a friend, and go the gym and even back at the pool but only once a week. I won’t give it up now, feeling so much better. It’s working Jan thank you!! (William,)*

**SARAH:** became fully immersed in the drumming process and believed the overall experience had helped her “analyse” options for the future, with the realisation that she now needs to allocate more time for herself. By crediting participation in the program with giving her the positivity and determination to improve her level of health literacy and the ability to self-manage, she noted that the “the next steps” were entirely up to her. With this in mind, she set herself a number of short-term goals to complete within four months of finishing the study:

* [...] made me think what can I do to educate myself and not just be wholly reliant on him [specialist]. Want to keep learning now I’ve started, won’t let it [RA] beat me. It’s [DRUMBEAT] changed my entire outlook [...] want to increase [my] fitness, feel healthier, lose weight. And that’s just the start! I’ve wanted to retire for ages but haven’t had confidence up to now [...] and spend more time with my daughter in Sydney... (Sarah,)*

Within two months Sarah made contact through the Facebook group, to say she was heading to Sydney for 9 weeks to mark the start of her retirement: “Thanks again for a wonderful, confidence boosting experience X (Sarah,).”

**JENNY:** Earlier in the thesis, Jenny’s comments were used to demonstrate how she no longer felt alone and that she was “amongst friends” in the Drumbeat Program. She was particularly
grateful that she was not judged and that other members didn’t think less of her. Unable to continue her work due to arthritis, she took the opportunity to begin a new venture from home. Unfortunately, as Jenny recalled at the focus group, one of the drawbacks of working entirely online, is that it can “magnify” a sense of isolation. In speaking with Jenny via private messaging, she mentioned that she still found face to face interactions difficult, but that the DRUMBEAT experience served to make her more aware of the need to overcome this obstacle and become more actively involved in the outside community.

It [DRUMBEAT] has helped me with talking in front of a group […] still nervous but getting out there more - craft fairs etc […] I tell myself now I just need to embrace this as my life and just get on with it. Listening to people older […] realise I’ve wasted the last few years trying to be what I was and it’s getting me nowhere (Jenny, 🧡)

ELSIE: In her feedback of the program, Elsie mentioned how the group discussions had “helped sound out issues” she was experiencing with starting a new job and creating new relationships with work colleagues. The goal she set herself, to become more organised and reduce stress levels, particularly at her new place of work, proved to be more of a challenge than anticipated:

I reduced my stress by leaving [work]! […] ended up in hospital after sustained bullying from supervisor. Still struggling a bit with what happened […] confidence taken a beating […] finding solace in fact two others have also left that toxic environment. (Elsie, 🧡)

This earlier setback did not deter Elsie from moving forward. She described how her new ways of thinking had allowed her to regain an increased level of confidence, as evidenced in her lastest message via the Facebook group:

[DRUMBEAT] left me feeling empowered and wanting more! […] felt more relaxed and less pressured in the workplace at the end […] So here’s how I am changing the way I think about my old life goals and getting my life back on track – submitted a worker’s compensation claim and pursuing part-time work […] going to do something different – I CAN DO this HA! xx 🧡. (Elsie, 🧡)

The transcripts from BEYOND DRUMBEAT suggest that the study helped some individuals, far beyond the drumming itself. In summary, this chapter indicates that participation in DRUMBEAT allowed for improved communication and social networking skills to rebuild relationships;
positive attitudes towards self and others; and enhanced well-being, by encouraging participants to tell their stories and by listening to others with similar issues. It also highlights the close connection that developed between myself, the facilitator and the participants. This connectedness was facilitated through our shared experience of having arthritis and from the ability to give and receive support in an environment that provided a safe place for those who may otherwise have been hesitant to discuss their feelings.
CHAPTER 5: DISCUSSION AND CONCLUSION

How participation in a DRUMBEAT program improves the quality of life of adults living with inflammatory arthritis

5.1 Introduction

This pilot study aimed to initially understand the unique experiences of those individuals living with IA, as expressed by the research participants in this study. The subsequent and overarching aims of the research were to extend the DRUMBEAT program to meet the needs of an arthritis population, to evaluate each individual participant’s experience of the intervention, and establish if a drumming intervention, such as DRUMBEAT, could provide an enabling environment for people with arthritis, one that may facilitate a sense of belonging and offer an opportunity to improve individual self-management skills, through participant support of those in a similar situation to themselves. The primary impetus for conducting this research was not to determine if the adapted program was feasible, or sustainable for an arthritis population, but to determine whether innovative and novel programs like DRUMBEAT, might offer benefit in terms of QoL, improved coping, and self-efficacy and be a useful addition to the treatment modalities of overall well-being in individuals living with a chronic condition.

The findings are in accord with previous studies (Faulkner et al., 2010; Faulkner et al., 2012; Ivery et al., 2009; Martin & Wood, 2017; Martin et al., 2009; Wood et al., 2013; Wood et al., 2019) and indicate that participation in the DRUMBEAT program may help promote positive enhancement of physical, psychological, emotional and cognitive functioning in an arthritis group, through a sense of community and belonging. Quantitative components of this study suggest that the unique features of the program facilitated an improvement in the QoL for participants, in both the areas of physical functioning and mental health. While quantitative data revealed limited statistical significance, the qualitative data proved to be a rich source of participant viewpoints into the positive impact of the program. A more detailed understanding of the overall benefits is achieved with the integration of both quantitative and qualitative data sets.

In the discussion that follows the five research questions will be addressed, forming a link with current academic literature. The limitations of the study will then be outlined, followed by a
short paragraph detailing engagement and impact both within and outside of academia and finally, a conclusion and any recommendations for future research will be presented.

5.2 Discussion

The research questions will now be addressed:

5.2.1 Research question 1:

*Does DRUMBEAT meet the needs of the group?*

According to Holyoake (2017) DRUMBEAT is inherently about bringing people together in a way that allows the individual to focus on their own needs, within a whole group setting. The data illustrates the intervention was well received by the group, as a whole, and that some of the participants were able to identify their own needs, through the shared experiences of others. There was mention of a feeling of safety and security within the group, in the knowledge of others around them with shared similar health goals. Participant comments suggest that DRUMBEAT could play a pivotal role in providing individuals with the opportunity to gain greater social and emotional awareness. For some participants, this perceived positive impact on mental health came from the feeling of belonging to a type of ‘community.’ Benefits of this kind were often reflected in the group discussions and were consistent with those of previous studies (Ivery et al., 2009; Martin & Wood, 2017; Martin et al., 2009; Wood et al., 2013).

Unanimous in their agreement of DRUMBEAT as a *feel-good* program, participants were often heard to reflect on how much they looked forward to coming along to the meetings. As informed arthritis consumers, their proactive role in the entire process of discovery and program content was of prime importance for the modification of any future program to be effective. Their contributions were not about altering the outcomes, or objectives of the program. It was more about modifying the program structure and content, so it reflected the participants own unique needs, as only they know them.

Consequently, group discussions were centred around key issues related to health and social outcomes of individuals living with IA. These included self-regulation and creating healthy behaviours; problem-solving; reframing attitudes e.g., challenging “black and white” thinking;
coping with stress and anxiety; dealing with, and regulating emotions; loss of identity and building resilience; the need for social support; and finally, the importance of goal setting for future direction. The adaptable approach of the program through the use of open-ended questions, helped develop a real sense of understanding of each participant’s view of life with IA and their personal needs. Being able to draw on my own experiential knowledge of living with RA meant I was also able to work from a place of genuine understanding of the group needs. While this may commonly be regarded as “bias” Maxwell cited in Robson (2002, p. 50) argues that “what you bring to the research from your background and identity” can be conceived as a “valuable component.” This was also valued by the participants, as evidenced by their quotes.

To increase the sense of belonging in the group, participants were given the opportunity to shape the content of each weekly session. Participants were given control of discussion topics (within boundaries) and musical content (within boundaries). These data evidenced how this empowerment, promoted through responsibility, ensured the relevancy of content and helped increase participant motivation and enjoyment as a group, contributing towards a group process. These findings reflect those of Carr and Walton (2014) who previously indicated how even subtle suggestions of being part of a team dramatically increased motivation and enjoyment, leading to greater perseverance and engagement.

The study was an equally valuable learning experience for myself and helped further explore my own strengths and needs. My role of observer / participant in all aspects of the group sessions was expected, and indeed actively encouraged, by the participants. There were comments of how my personal involvement assisted some participants to more easily understand the collaborative intent of the study and encourage their enthusiastic participation. This dual role added to the challenge and to the potential for bias on my part, which may well have impacted the outcome of the study. More importantly however, all the participants expressed their appreciation at having a researcher they could relate to and who understood their needs. Julie asked to sum this up on behalf of the group by saying how my involvement had helped her find “deeper meaning in the light hearted discussions.” She added:

[…] times you just don’t want to hear from others what you have to do. And you know that they don’t understand for a start as even you are trying to get your head around it yourself – they don’t know firsthand what it’s like. That’s why
All the participants were unanimous in their positive support of the DRUMBEAT program and of their overall enjoyment in taking part. This was not unexpected, as a growing body of research has observed how both psychological sense of support and actual expressions of support, through interventions such as DRUMBEAT, may play a critical role in affecting health and well-being (Helgeson & Gottlieb, 2000). According to Helgeson and Gottlieb, such supportive environments would be expected to generate feelings of reduced isolation, an increased sense of empowerment and self-efficacy, and the realisation of more effective ways of coping.

In summary, the strength of the group lay with how participants saw themselves as a family who worked together toward a shared common goal. The program feedback reflects this, showing the majority of participants considered participation in the program had helped them feel good about themselves and to become more responsible for their own behaviour, through building connections with others in the group. The perceived benefits of the program as a novel intervention to improve quality of life will be discussed next.

5.2.2 Research question 2:

Does DRUMBEAT influence quality of life?

Due to the unpredictability of disease progression in chronic arthritis, any measure of quality of life is highly subjective and multidimensional, and how and what to measure continues to be debated (Garip, Eser, & Bodur, 2011). Nonetheless, quality of life remains an important participant-reported outcome of arthritis (Garip et al., 2011); useful in interventions that target behaviour changes, such as DRUMBEAT, as they may help shed light on aspects of life that are important to the specific participant group, many of which often extend beyond supportive health interventions (Palmer & Miedany, 2016).

This study adds to the growing body of literature that demonstrate how group drumming may contribute positively to overall health and wellbeing and how the moral support that being part of a community offers, may help some to dispel the feeling of loneliness (Posner & Momenzadeh, 2002; Ivery et al., 2009; Martin & Wood, 2017; Martin et al., 2009; Wood et al., 2013). Benefits of this kind were often reflected in the group discussions.
Positive changes were observed in emotional well-being, whereby a significant reduction in a measure of depression was demonstrated. Along with this result significant improvement was observed in physical functioning. The other factors, however, did not change significantly due to the small sample size and inadequate exposure to the intervention for some participants. Any improvement, no matter how small, should be appreciated, as over half the participants experienced anxiety, depression, or both at the start of the study, from which a worsening of their functional disability and quality of life could be expected (Sturgeon et al, 2016). Another important feature of the program was the perceived reduction in pain of some participants. Sturgeon et al (2016) demonstrated how the bi-directional relationship between pain, fatigue and psychological stress can change the course and management of arthritis, in regard to overall functioning and quality of life measures (Harris et al., 2018). However, although results were positive, these data must be interpreted with caution due to the small sample size.

5.2.3 Research question 3: Does DRUMBEAT influence self-efficacy?

Self-efficacy, in the context of arthritis, is described as an individual’s belief in their own ability to make the necessary behaviour changes to control pain and, where possible, prevent deterioration of their condition over time (Keefe & Somers, 2010). It has been conclusively shown that due to the strong relationship with health behaviours, self-efficacy is one of the most important psychosocial factors to influence outcomes in arthritis self-management interventions (Brady, 2011; Primdahl, Wagner, & Hørslev-Petersen, 2011).

The results indicate that mastery of drumming was an important source of confidence for participants (see Bandura’s extensive works, e.g., 1997). It is conceivable that all four sources of self-efficacy (mastery; vicarious; verbal; and emotional) have their place in the DRUMBEAT program. However, verbal persuasion and enhanced emotional status seem particularly fitted to the DRUMBEAT program. Bandura’s self-efficacy report asserts that people can be persuaded to believe that they have the skills and capabilities to succeed. Evidence can be seen within this study of participants getting verbal encouragement from others to help overcome self-doubt and instead help focus on giving their best effort to improve their overall wellbeing. Tom, for example, at the onset of the study, tells of his incapacity to negotiate and successfully adapt to the ever-changing demands of his condition. He considered the emotional support of others in the group, especially William, to have been motivational. He related how William’s empathy and encouragement had given him the confidence to reconcile with his family and he continues to
make positive lifestyle changes, despite setbacks. Tom probably gained the most from the study, in regards to increased self-efficacy and self-confidence.

Group drumming interventions are often associated with improvements in self-efficacy. The same may be said of this pilot study, if only to a lesser degree, with all bar one participants, reporting improved self-efficacy on completion of the study. These results seem to be consistent with other research which found that participation in music, in particular group drumming, has the ability to increase self-esteem, self-efficacy and motivation (Hallam, 2005; Fancourt et al., 2014; Fancourt et al., 2016). As only small changes were reported in this study, results were not statistically significant and no firm conclusion could be drawn.

The study aimed to improve participant coping strategies through the process of enhanced emotional control and the increased ability to problem solve (Dures et al., 2012). This will be discussed next.

5.2.4 Research question 4: Does DRUMBEAT influence the ability to cope with arthritis signs and symptoms?

These data identify that participants living with IA undertake a variety of demanding tasks. It was therefore, not surprising that many of the participants were observed as finding it difficult to self-manage successfully.

Self-management refers to a person’s ability to cope with the physical, psychosocial and lifestyle changes that are associated with living with a chronic condition (de Silva, 2011) but, trying to “manage” alone can be a genuinely lonely and isolating experience. A clear message from all participants was the need for early intervention with social support, outside of the medical arena. Surprisingly, for most of the participants, involvement in the study was their first and only time of meeting others who also had IA.

The DRUMBEAT program uses drumming as a base for engagement and a metaphor for coping with real life problems. Observational analysis viewed a number of participants as developing a positive shift in response to coping and accepting their arthritis following the group discussions, that were incorporated into the program. These observations support previous research which may link the transfer of skills acquired through drumming, to other areas of their learning (Slattery, 2018). In the current study a number of participants refer to the physical act of
drumming as a way to “stay focussed” and a possible future activity to help relieve their stress and worries and release latent anger (Bensimon, Amir, & Wolf, 2008). By the end of the study there was an emerging sense of awareness from all the participants, for the need to take better control of their own health and the importance of goal setting.

Studies also show how a strong social support network can help improve the coping abilities of individuals living with chronic disease and conversely, how the lack of social support can lead to isolation and loneliness (Dures et al., 2012; Ryan, Hassell, Dawes & Kendal, 2003). Participants often expressed the importance of supportive family, friends and co-workers and the need for shared decision making with health professionals, in order for them to cope effectively with their arthritis. If DRUMBEAT helped cultivate social support within the group is discussed next.

5.2.5 Research question 5:

Does DRUMBEAT influence social support through the group?

And can social support also be successfully augmented through a closed Facebook group?

The fundamental perceived benefit of the program for some participants was the realisation that while they all had different issues and ways of coping with their condition, they all shared some very basic struggles of living with IA. This disclosure was seen to be a comforting concept, particularly for those who experienced feelings of isolation. Evidence is presented which established that some individuals experienced a reduced sense of isolation, or loneliness, as a result of giving and receiving the mutual support created.

DRUMBEAT is observed to be uniquely suited for forming strong bonds with other people from all walks of life. Diversity within the group was its greatest asset and participants were all seen to be extremely supportive and accepting of both superficial and fundamental differences, among themselves. During group discussions participants noticeably enjoyed feelings of trust toward one another, promoting an honesty and openness that led them to share, and question, without worrying about being judged. Data suggests the social support shared within the group for the duration of the study and beyond the study timeframe, both online and face-to face, corroborate the findings of previous work into how being part of a supportive group of like-minded people can bring about profound experiences and important epiphanies for those suffering from chronic disease (Posner & Momenzadeh, 2002). Posner and Momenzadeh (2002) suggest that connection of people with shared experiences, allows the opportunity to identify
with, and to hear, different perspectives on practical and emotional issues required to self-manage one’s health. By observing the relationships which developed and eventually resulted in a sense of belonging and bonding between participants, it was encouraging to see how some participants benefitted from learning how others were currently working through, or overcame, problems, similar to their own. The social support derived from the program was frequently commented on as a positive outcome of participation and a valuable means for coping with IA.

A sound sense of community quickly emerged in this study and as early as week two participants mentioned their enjoyment at being a part of something “bigger” than their own self-care. The emerging community benefits were noticeable even in those who felt unable to attend each session. Even where some participants were feeling anxious, being involved in the group seemed to provide them with a sense of connectedness with others and the interpersonal advice and support they needed to move forward in life.

The findings and feedback from this study suggest the use of a closed Facebook group aided the development of positive social connections, no matter how small. That said, it was a key challenge to engage participants into the online community, and the low response rates reflected this. Although sustained interactions, both online and face-to-face, between myself and participants serve to showcase the perceived benefits of completing the program beyond the study timeframe, it is not surprising that some participants no longer maintain social contact online, due to changing life circumstances and individual needs. A number of the participant relationships have evolved into friendships that continue today and the page remains open at the specific request of the group members.

Whilst some participants were highly motivated to join the Facebook group and made positive contributions throughout the study period, most preferred to respond with likes, comments, or shared links, rather than to post themselves. Most of the posts made were written to be entertaining and the group became more familiar with each other through humour and this added interest to the threads.

A previous study by Partridge et al (2019) indicated how the likes of Facebook may offer both individuals and groups, support and encouragement to foster self-management and behavior change in chronic disease. Contrary to expectations, this particular study did not find the
Facebook group played a significant role in facilitating such support, as the level of participant presence online was arbitrary.

**Summary**

The voice of the participants provided evidence that participation in a drumming intervention had a positive impact on their emotions and emotional regulation, helped build self-confidence and self-esteem and many experienced a sense of community, through an enhanced sense of support and a common connection with other group members.

In support of our findings, this intervention highlighted the potential value of a group drumming program, as a therapeutic tool in the management of arthritis. Furthermore, interventions such as these may also help reduce demands on mental health services, by encouraging self-management and a focus on primary prevention, rather than secondary prevention or treatment.

**5.3 Limitations**

The study adds to the evidence about the positive effects of participation in the DRUMBEAT program but, as with many pilot studies, it includes some limitations.

Although the quantity of in-depth qualitative data compiled during this study is substantial, one of the major limitations for quantitative data, was the small sample size. The total number of participants was guided by a recommendation from Holyoake of between 6-10 participants. Eight participants were recruited into the study and of those, seven went on to complete the study. Retention rate was an issue in this study due to the unpredictable and fluctuating nature of IA. This relatively small number of participants was never intended to produce statistically significant information, as the participants were not a representative sample. The participants were also predominantly female and this may have limited the range of perspectives obtained. Hence, this study may be criticised for lack of generalisability. However, participants did cover a wide age range and have the shared experience of living with IA. They also presented with a number of different conditions within the definition of IA, helping capture experiences of a more diverse nature.
As participation in the study was voluntary, it is possible that only those participants who had an interest in, or were already motivated to improve their health outcomes, were likely to attend but there was a range of people varied and some fearful of commencing the study. This limitation means findings may not be indicative of the arthritis population in general, creating a possible participant bias (Bowling, 2009).

Duration time may also have had an impact on the outcomes of the study, as the DRUMBEAT program is designed as a 10-week program, which, for the purpose of this study was shortened to 6-weeks. Consequently, only four of the core elements (Figure 14) were incorporated into the program to achieve the study objectives. Although the weekly session times were extended to allow for more in-depth discussions, this could potentially have impacted the outcome of the research.

All the participants said they would have liked more time, specifically to incorporate a final concert. In hindsight, participants may have benefitted from the teamwork needed to make the performance happen and the acknowledgement that comes with it may have further enhanced their personal development and self-esteem. But as time was limited due to the study timelines, it was felt there could be a possible sense of anti-climax, or ‘let down’ after the performance, especially for those study participants dealing with self-esteem issues.

The exploratory nature of the research meant that translation of data from the Facebook group, specifically in connection to positive social support, was limited, due to the closed nature of the page not allowing for a broader, real world context (Lim et al, 2016). I believe my own inexperience with Facebook meant I lacked the necessary set of skills to manage the group effectively, and to keep the members engaged in more meaningful social interactions. As time progressed, members remained unwilling to share their personal thoughts on the Facebook page, preferring to wait for the group sessions. However, the page was more about having fun, with a small number of members posting some hilarious videos on drumming. In this respect, it did allow for genuine engagement and help build the sense of community within the group. Although the period of time to observe the closed Facebook group interactions was extended beyond the study period, changes to the group cohesiveness meant that the full potential of developing social connection was not maintained via the Facebook group, to any great degree.
While my active involvement was of benefit to the study by allowing an insider’s perspective, it also demanded reflexivity. It was important for me to be aware of subjectivity and its impact on the study. Knowing the possibility of bias on my part, especially as a member of the group I was studying, I needed to constantly be mindful of how my practices and ideas were perceived by other group members, in order to avoid the possibility of omitting valuable data.

5.4 Engagement and impact

In order to translate the perceived benefits of drumming discussed in this thesis, plans are being made to roll out the program to the community. It is anticipated this will be achieved through collaborative partnerships with both Holyoake WA, Arthritis and Osteoporosis WA (AOWA) and ECU, all of which will be able to translate the research into real-world impacts, such as a self-management program through AOWA and through the Holyoake CIA-adaptation of DRUMBEAT program. To facilitate this I am currently collaborating with Holyoake to develop the Facilitator’s Manual for delivery of the specific CIA-adaptation of DRUMBEAT. The dissemination of the manual will include a two-day facilitator training course that will allow people who work in the area Chronic Inflammatory Arthritis [CIA] conditions to undertake training. Holyoake has moved to a more sustainable train-the-trainer model and a supported accreditation process for facilitators to continue their professional development, whilst continuing to deliver the program to their client groups. This new Facilitator’s Manual will also allow people working in other areas of chronic disease management to be up-skilled in the CIA-adaptation of DRUMBEAT. The Training Manual will support state-wide, nationwide and international health capacity building by providing DRUMBEAT facilitators with the essential resources required to deliver the contextualised program. Through ongoing requests for feedback from new facilitators, it is anticipated that the Facilitator’s Manual will continue to evolve into a wider reaching manual for the delivery of the DRUMBEAT program for a range of chronic conditions. This will ensure ongoing suitability and quality improvement of this novel intervention that will benefit individuals in this group.

The set of drums obtained through the Heathway’s grant will help continue to build further sustainability for resources for the program. AOWA and ECU will be the joint recipient of the drums, to enable newly trained facilitators to have equipment to initiate DRUMBEAT programs from the AOWA facility in Shenton Park and for future use of post-graduate ECU students.
AOWA have indicated it is their wish that involvement continue from 2021 and beyond. AOWA have also expressed an interest in the possibility of a program being used across all arthritis, osteoporosis and related conditions.

As this research marks the beginning of a new collaboration between Holyoake and ECU, future post-graduate students will have access to and use of the program, allowing for further contextualization in other health domains. It is anticipated that this will result in a RCT that will allow an examination of the efficacy of the DRUMBEAT adaptation, and also explore those components that contribute most to any reductions in psychological distress, mental wellbeing, in addition to those aspects that increase self-efficacy, resilience, QoL, better self-management and an internal locus of control regarding the symptoms of the condition. These data may also have implications for the program being delivered to people with other chronic diseases. There are also plans for the program to be incorporated into the ECU staff Health and Wellness program, from 2021.

5.5 Recommendations and Conclusion

These findings add to the growing evidence on how engagement in the Holyoake DRUMBEAT program may influence some participants to utilise experiences drawn from their own lives to find solutions to challenges, and promote healthy behaviour changes (Faulkner, 2016).

To further extend this work it would be useful to understand the barriers to participation. The findings from this work have led to the development of a manual to provide the content in a way that is appropriate to the population and is expected to be used by AOWA. This will allow for the opportunity to produce more evidence and to determine the effects of confounding factors. More broadly, it would be useful to include key differences of purposively selected samples, that could possibly focus on more diverse groups of arthritis populations, age, sex, timing of diagnosis and others.

Conclusion

Although the potential therapeutic impact of music can be significant, for the current study, it was not possible to establish a direct causal link between drumming and enhanced ability to cope with arthritis signs and symptoms. Rather, the aim of this study was to address the gap in the academic literature to demonstrate if a group drumming program, such as DRUMBEAT,
could be integrated into traditional healthcare within the chronic disease arena, rather than being viewed purely as an enjoyable add-on. Of equal importance is that the study may lead to more research into the relationship between group drumming participation and a wider range of improved health outcomes. Interventions such as this may also help reduce demands on mental health services by encouraging self-management and a focus on primary prevention, rather than secondary prevention or treatment.

Based upon the findings and recommendations of this study, DRUMBEAT would appear to be an easily accessible, fun, sustainable program that may help participants gain the social support and skills necessary for them to thrive, learn, work, earn and participate in community life. Although results cannot be generalised from this small-scale study, it has provided a detailed understanding of how participants experience DRUMBEAT, as a novel and unique intervention for arthritis, one that could be made available to help others cope with the psychosocial stressors of IA. As Julie so aptly put it:

*What’s not to love about DRUMBEAT! No-body wants this study to end!*


depression, anxiety and stress scale (DASS) and the hospital, anxiety and depression scale (HADS). Bmc Psychiatry, 12(1). doi:10.1186/1471-244X-62-6


Hawker, G., Mian, S., Kendzerska, T., & French, M. (2011). Measures of adult pain: Visual analog scale for pain (VAS pain), numeric rating scale for pain (NRS pain), McGill pain questionnaire (MPQ), and measure of intermittent and constant osteoarthritis pain (ICOAP). Arthritis Care and Research, 63(Suppl. 11), 252. doi:10.1002/acr.20543


## APPENDICES

## APPENDIX 1: FOCUS GROUP

<table>
<thead>
<tr>
<th>NAME</th>
<th>POSITION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jan Warhurst</td>
<td>Researcher</td>
</tr>
<tr>
<td>Amanda Devine</td>
<td>Professor Public Health and Nutrition, Director of Public Health. School of Medical and Health Sciences</td>
</tr>
<tr>
<td>Leesa Costello</td>
<td>Senior Lecturer School of Medical and Health Sciences</td>
</tr>
<tr>
<td>Ros Sambell</td>
<td>Lecturer School of Medical and Health Sciences</td>
</tr>
<tr>
<td>Rachel batten</td>
<td>Occupational Therapy Lecturer School of Medical &amp; Health Sciences</td>
</tr>
<tr>
<td>Stephen Bright</td>
<td>Senior Lecturer Addiction School of Medical &amp; Health Science</td>
</tr>
<tr>
<td>Alan Beattie</td>
<td>Social Enterprise Manager Holyoake</td>
</tr>
<tr>
<td>Jean McQuade</td>
<td>Manager Health, Education and Research Programs Arthritis WA</td>
</tr>
<tr>
<td>Jack Edelman</td>
<td>Rheumatologist</td>
</tr>
<tr>
<td>Mai-Ling Tay-Kearney</td>
<td>Ophthalmologist Lion’s Eye Institute</td>
</tr>
<tr>
<td>Caitlin Gibbs</td>
<td>Student – RA patient sub-group</td>
</tr>
</tbody>
</table>
APPENDIX 2: FOCUS GROUP SUMMARY REPORT

DATE: MONDAY 26th March, 2018

Discussion of key points:

**Patient age group** - Ages 21-31 were discussed in some detail. After careful consideration age group is to be 18 – 30 years. This ensures the study does not ‘lose’ those transitioning into adult health services and also takes into account the current views on later emerging adulthood into 30s.

**Recruitment of sample**: Additional recruitment avenues were kindly offered via Arthritis Foundation of WA [AOWA]. Participants are to be recruited via a primary, purposive sampling approach and secondary snowball sampling, if required:

- Primarily via **Paediatricians / Paediatric Rheumatologists** based at AOWA
- Through advertising on members only website/newsletter for young people with arthritis operated by AOWA
- Through advertising to a large membership base of AOWA via – [https://www.arthritiswa.org.au](https://www.arthritiswa.org.au) and monthly e-newsletter.
- Via referral from specialist Rheumatologists and Ophthalmologists in WA public hospitals and private sectors, and The Lion’s Eye Institute, WA.
- Research brochures and flyers – made available to clinicians, AOWA, Support groups, Holyoake and ECU
- Existing social networks, Facebook and personal contacts

**Inclusion / exclusion criteria:**

- *Inclusion of those with pre-existing or current clinically diagnosed depression*. This point was discussed in some detail. After feedback from Dr Edelman it is decided the exclusion will remain, as although depression is common with RA, it is not necessarily diagnosed.
- *Presence of any co-existing musculoskeletal conditions that prevent participation in the program*. Participants who experience limitations in range of movement, in particular, the hands and feet and neck, will not necessarily be excluded but will be identified within the screening checklist to enable modification of drumbeat techniques, such as the use of drum brushes, to prevent further exasperation to musculoskeletal problems.
- *What happens if you can’t attend all of the sessions?* The only thing we do know is that at the end of the first session Holyoake give participants the option to withdraw but everyone else who agrees to stay must make a commitment to attend every session until the program finishes. To establish with Holyoake.
- *It was suggested those in most need [i.e. without/with little social support] be identified within the screening check list*. Decision has been made to not screen. However, as ‘social support’ is a main factor for this age group, it will be measured using an additional questionnaire - UCLA loneliness scale.
- *Those who self-refer*. Mentioned these will need to supply a letter from their doctor, or give permission for researcher to contact GP/ specialist on their behalf. This is now addressed within the screening list.

**Duration / Location**: Original idea was to run 2 groups over 6 weeks but following input from Holyoake it has been decided we will get more out of it if we run for the full 10 weeks and finish with a performance. Programs will run consecutively. Locations agreed on – Arthritis Assoc and ECU Joondalup Campus. Timeline October – December depending on recruitment.

**Questionnaires**: It was suggested a pain scale be completed at end of each DRUMBEAT session. Agreed - this will now be included with session rating scale. As ‘social support’ is being covered using UCLA loneliness scale the ‘health distress’ and ‘social activity’ questionnaires now considered redundant. A 3-month follow-up questionnaire was suggested at meeting. It was decided that as this is only a small exploratory study there will be no follow-up.

**Ideas on central themes / issues.** More to be done on this -researcher to work with Holyoake to contextualize the DRUMBEAT program to young adults with RA – need to ensure the study does not impact on the integrity of
DRUMBEAT. The idea of sessions 7 and 8 being about long-term future plans as a standalone topic was put to the group and accepted.

**APPENDIX 3: RESEARCH MATRIX**

<table>
<thead>
<tr>
<th>RESEARCH QUESTIONS</th>
<th>OUTCOME MEASURES</th>
<th>DATA SOURCES</th>
<th>PRE</th>
<th>POST</th>
<th>Weekly</th>
<th>QUALITATIVE / QUANTITATIVE DATA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does participation in a 6-week DRUMBEAT program (1) meet the needs of a group of individuals with chronic inflammatory arthritis and (2) indicate any Improvement in overall quality of life?</td>
<td>OVERARCHING measure of QoL</td>
<td>RAND 36-item Short Form Survey Instrument (SF-36)</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td>QUANTITATIVE – general health</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Exit focus group meetings</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>QUALITATIVE</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Adapted DRUMBEAT Adult Program Feedback</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>QUALITATIVE</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Researcher’s personal reflections</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>QUALITATIVE</td>
</tr>
<tr>
<td>PSYCHOLOGICAL</td>
<td>SELF EFFICACY</td>
<td>ANXIETY / DEPRESSION</td>
<td>ENHANCE COPING</td>
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<tr>
<td>Does participation in a 6-week DRUMBEAT program increase self-efficacy?</td>
<td>Rheumatoid Arthritis Self-Efficacy [RASE]</td>
<td>Hospital Anxiety and depression scale [HADS]</td>
<td>Locus of control of behaviour scale [LoCBS]</td>
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<tr>
<td>Does participation in a 6-week DRUMBEAT program enhance coping with the signs and symptoms of chronic inflammatory arthritis? (Psychological)</td>
<td>Locus of control of behaviour scale [LoCBS]</td>
<td>RAND 36-item Short Form Survey Instrument (SF-36)</td>
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</tbody>
</table>

**QUANTITATIVE** – self-efficacy

**QUANTITATIVE** – internal/external locus of control

**QUANTITATIVE** – anxiety, depression

**QUANTITATIVE** – overall emotional well-being

**QUANTITATIVE** – internal/external locus of control
<p>| HEALTH (BIO) | Pain &amp; fatigue. Does participation in a 6-week DRUMBEAT program enhance coping with signs and symptoms of chronic inflammatory arthritis? (Physical/Biological) | PAIN/FATIGUE | RAND 36-item Short Form Survey Instrument (SF-36) | ✔ | ✔ | QUANTITATIVE – Limitations due to physical health Energy/fatigue/pain | ✔ | QUANTITATIVE – Measure of pain after each session |</p>
<table>
<thead>
<tr>
<th>Does participation in a 6-week DRUMBEAT program provide social support through the group?</th>
<th>Level of GROUP SOCIAL SUPPORT/FUNCTIONING</th>
<th>Session Rating Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can social support be successfully augmented through a closed Facebook group to provide a health promoting environment?</td>
<td>Level of GROUP SOCIAL SUPPORT/FUNCTIONING</td>
<td>QUANTITATIVE/QUALITATIVE</td>
</tr>
<tr>
<td></td>
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<td>QUANTITATIVE</td>
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<td>QUALITATIVE</td>
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</table>

- UCLA Loneliness Scale [Version 3]
- RAND 36-item Short Form (SF-36)
- Adapted DRUMBEAT Adult Program Feedback
- Facebook insights
NOTES FROM TASTER SESSION 1: 9th February 2019

Unfortunately, only 2 people turned up for the meeting and several cancelled at the last minute. We decided to view this meeting as a *learning curve* for future meetings! But not all was lost as did manage to (a) get some photos and a short video for David Gear (ECU media) to use to advertise future events and (b) get some constructive feedback from TAG organiser (Gloria Nicolosi) in regards practicalities of running the program for 18-30-year group with IA. Her comments/suggestions:

- It seems very unlikely we will recruit 18-30 years if we specifically direct our attention to them. Open study out to everyone and anyone - all ages and that way might spark some interest from individuals in the group. There are also a number of ‘double-ups’ (parent/children) with same condition. A number of TAG members have shown interest in the study that are 35/40 years of age who have stayed on with the group, although no new members are allowed to join who are over 30.

- Newly diagnosed, or a condition from childhood? Suggestion was made that we don’t discriminate either but they do tend to take a different approach to self-management. So, might be useful when collecting data to separate out. It was thought the former would be more likely to benefit as they would be older and constantly searching for answers.

- TAG member’s lives/families/jobs/travel/uni all take priority and generally are very ‘anti’ arthritis courses/studies. Rightly, or wrongly, the majority prefer to only think of their condition when specialist appointments are due, or they are in a flare-up.

- Most prefer to hide the fact they have a disease. They prefer to be VERY private about their condition, as many have found in the past it affected their chances of gaining employment/making friendships/finding a partner. Hence the reason why Fb group page is tightly regulated.

- Incentives don’t work! As an example, the TAG group run an annual ‘weekender’ all expenses paid by AOWA. The maximum attending in the past 6 years has been 22, which represents less than 25% of members turned up and that included a core group of 10. A suggestion the core group might like to do the study was rejected as a number are FIFO and one runs his own business, working all over WA and very rarely in Perth metro. AOWA even offered to fly 2 ex-WA members back for the annual get-together.

- The weekenders include fun activities/guest speakers etc. Suggestion was made we go along to next weekender (date TBA) and run hour session – active audience.

- Even if we could get numbers, her discussions with the group on our behalf show they won’t commit 10 sessions over 5 weeks. Need to look at shorter time frame and run all out of AOWA – once a week

- Bring a friend – good idea

- Need more notice/advert in AOWA newsletter too late the next phase needs to be run later than planned end February.

- To expect to start study 25 FEB – setting ourselves up for failure
NOTES FROM TASTER SESSION 2: 11th March 2019

Recruitment again proves to be a problem – only 1 attendee on this occasion but she does want to participate in the study - 1 down 9 to go – and another learning curve for future meetings!

COMMENTS/SUGGESTIONS:
It could be helpful to ask participants about current Complementary Therapy use and exercise regime at both beginning and end of the study - to help establish if anything else of significance has changed during the time of their involvement with the Drumbeat program.

PROPOSED:
Additional question to be added into both screening questionnaire and telephone exit questionnaire:

Screening Questionnaire Q15: Conventional treatment often does not result in resolution of symptoms and we look for alternative treatment options. Which, if any, of the following natural health products and therapies do you currently use (Check all that apply)

- Acupuncture
- Aromatherapy
- Herbal medicine
- Homeopathy
- Osteopathy
- Reiki
- Reflexology
- Relaxation/Breathing technique
- Yoga, tai chi, qi gong
- Exercise therapy. If yes, during a usual week, what activities do you participate in and how often? _______________________________________

- Chiropractic
- Magnetic therapy
- Massage
- Relaxation techniques (meditation, guided imagery, hypnosis, progressive relaxation, deep breathing exercises)
- Music/Art therapy
- Vitamins and minerals. If yes, please list _______________________________________

- Other ______________________
APPENDIX 5: PROGRAM DESIGN

[Diagram showing key learning areas and prompts/guiding questions]

**Key Learning Areas**

- **Week 1: The Rhythm of Life**
  - Rhythms happen in/around us all the time. When they are in harmony things are ok. When they are conflicting things go wrong e.g. fighting with/ignoring symptoms of arthritis.

- **Week 2: Relationships**
  - Review learning outcomes from previous session
  - Explore the definition of relationship
  - Extend the meaning to include the relationship they have with their own condition.

- **Week 3: Harmony**
  - Review learning outcomes from previous session
  - Explore the definition of harmony
  - Extend the meaning of harmony to include personal inner harmony—one’s own health and wellbeing.
  - Demonstrate the concept of harmony in making music.

- **Week 4: Individuality and Self-Expression**
  - Review learning outcomes from previous session
  - Explore the concept of loss of self in regards to having a chronic condition
  - Explore the benefits of individual strengths and how they can be successfully maintained with community.

- **Week 5: Emotions and Feelings**
  - Review learning outcomes from previous session
  - Practice identifying emotions
  - Recognize how our emotions impact on our health
  - Identify healthy strategies for dealing with strong feelings in healthy ways.
  - Explore what happens when people shut down their feelings.

- **Week 6: Teamwork**
  - Review previous key learning areas
  - Learning about the change process
  - Learning about the importance of goals.

**Prompts/Guiding Questions**

- What do we mean by the rhythm of life?
- What are some rhythms around you?
- How easy is it to fall into unhealthy rhythms?
- How hard is it to get out of an established rhythm?
- What are some of the negatives not having a healthy rhythm?
- What are some of the ways you could calm yourself in everyday situations?

- How do we connect with all things, in all aspects, every day—even those that are not always beneficial/good?
- How do you connect with your arthritis when things aren’t going well?
- How do you communicate with yourself particularly during flare ups?

- What are some of the ways in which you managed/or are still managing to get back in importance to get up and stretch/走 around as needed anytime during the session. If hands begin to hurt there are percussion tools to use.

- What is Community? Are we a Community?
- Do you think arthritis community could be/needs to be seen in a more positive light?
- Do you think there is too much negativity out there re arthritis community as a whole [Internet etc.?]
- Do we need the support that comes from others living with this condition?
- Do we ever think about me? About my identity?
- How do we make sure we listen to ourselves?

- Everyone has a wide range of emotions and feelings and how we express those emotions is important to our wellbeing.
  - Finding out you have a chronic condition can change things. Sometimes this can affect your outlook and mood. How did you feel when you first got your diagnosis? Tell us about your journey so far.

- Thinking about our overall health/overall wellbeing:
  - What stage of change are you in at the moment?
  - What are some of the areas where you feel you want to make changes?
  - What do you think might help you make those changes?
  - What are some of the triggers that might stop you reaching your goals/making those changes?
APPENDIX 6

CONSENT FORM

For participation in the Masters research project:

DRUMBEAT©

Can the quality of life of adults aged >18 years with chronic Inflammatory Arthritis be improved through participation in a DRUMBEAT program?

I __________________________ (name of participant), would like to participate in this study being conducted by:

Student researcher: Jannette Warhurst
Student Email: jwarhurs@our.ecu.edu.au
ECU Faculty: School of Medical and Health Sciences

Principal Supervisor: Professor Amanda Devine PhD, AN, RPHNutr.
Professor Public Health and Nutrition, Director of Public Health
Phone: +61 8 6304 5527
Email: a.devine@ecu.edu.au
ECU Faculty: School of Medical and Health Sciences

1. I have received a copy of the information letter explaining this study.

2. I have read and understood the information provided.

3. I understand that participation in this study will involve completion of six drumming sessions which make up the DRUMBEAT program; answering a number of questionnaires before/after/during the program; my active involvement in a closed Facebook group and a final telephone interview, or invitation to a final focus group meeting, depending on the group’s preferences.

4. I permit my specialist /doctor’s health care staff to share, with the above-named researcher (1) my contact information (2) my medical diagnosis, only in regards to:
5. Confirmed clinical diagnosis of chronic Inflammatory Arthritis.

6. The presence of a major depressive disorder recently, or previously diagnosed, that has not been stabilised through treatment.

7. The presence of any co-existing musculoskeletal conditions.

5. No additional information about me will be accessed and this authorization will expire immediately after the information is shared. I am aware my information and any comments made by me will be kept private and confidential and remain anonymous for the purpose of this study and will not identify me in any way. Any information collected via FB site will also be de-identified and any information referred to in the study will use a pseudonym, instead of using my real name.

6. I understand you may take some photos, videos, or recordings of the sessions and that Holyoake may also like to share them on their website and/or social media accounts. If I feature in these photos, I will be asked to sign a permission slip before any photographs, or videos are released outside of the closed Facebook group.

7. I am aware that information provided by me for the purpose of this study is to be reported in a Masters by Research Thesis and associated publications or presentations.

8. I agree to all the information provided by me for the purpose of this study being securely stored until December 2021, after which time all data will be destroyed.

9. I have been given an opportunity to ask questions and all questions asked have been answered to my satisfaction.

10. I am aware that if I have additional questions I can contact the research team.

11. I freely agree to participate in this study and am aware that I may withdraw at any time, without penalty or explanation.

Participant’s Signature for Consent

Date
Again, thank you for your participation in this study.

The ethical aspects of this study have been approved by ECU Human Research Ethics Committee (HREC). If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the number listed below. Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

Research Ethics Officer
Edith Cowan University 270 Joondalup Drive JOONDALUP WA 6027
Phone: (08) 6304 2170
Email: research.ethics@ecu.edu.au
Dear Participant

Thank you for your interest in this study. Your time and commitment will be an invaluable contribution into finding better ways to manage Rheumatoid Arthritis in young adults. Before we can begin, we need to know a little about you and the following guidelines will help you complete and return the consent form and questionnaire.

This information package includes:
- Participant Information Sheet. This will explain the research involved. Knowing what is involved will help you decide if you want to take part.
- Consent form.
- Questionnaire.
- Post-paid envelope.

In order to participate in the study please:
- Read the information sheet carefully.
- Complete and sign the Consent Form.
- Fill in the questionnaire.
- Once completed, please place both the consent form and questionnaire into the pre-paid envelope and post back to ECU, postage paid.
- Let me know if you have any questions or comments on any part of the study. Please post back the comments page [if applicable] with the consent form and questionnaire.

Jan Warhurst
Masters Candidate
School of Medical and Health Sciences
Edith Cowan University
jwarhurs@our.ecu.edu.au

Amanda Devine, PhD, AN, RPHNutr.
Principal Supervisor
School of Medical and Health Sciences
Edith Cowan University
a.devine@ecu.edu.au
Tel: +61 8 6304 5527

Dr Leesa Costello
Principal Supervisor
School of Medical and Health Sciences
Edith Cowan University
l.costello@ecu.edu.au
Tel: +61 8 6304 5459

ANY FURTHER COMMENTS.

Please feel free to share your thoughts on the comments sheet and return this page with your consent form and questionnaire.
APPENDIX 7: PARTICIPANT INFORMATION SHEET

PARTICIPANT INFORMATION SHEET

<table>
<thead>
<tr>
<th>Study Title</th>
<th>Can the quality of life of adults aged 18+ with chronic Inflammatory Arthritis be improved through participation in a DRUMBEAT© program?</th>
</tr>
</thead>
</table>
| Name of Researcher | Jan Warhurst Masters Student (Medical Science)  
This research is being conducted as part of a post-graduate Masters (Medical Science) degree at ECU. |

Before you decide whether or not you wish to come and join us in this study, it is important you understand why the research is being done and what it will involve. Please take the time to read this information sheet carefully and ask questions about anything that you don’t understand, or want to know more about.

What is the study about?
We know that music can make us feel better both physically and psychologically. Research shows it can relieve stress, reduce pain perception and help rid us of negative emotions and behaviours. For this reason, many health professionals are recognising the therapeutic benefits of music, and drumming is gaining popularity. Once you have a go, you will know why!

Drumming, however, has never been trialled for people diagnosed with any type of chronic Inflammatory Arthritis. So, we have teamed-up with Holyoake WA – through their DRUMBEAT program - to find out if it can improve health outcomes. The specific aim is to determine whether DRUMBEAT can provide therapeutic benefits for those participating in the program. It will also help us understand what is important for those living with a chronic Inflammatory Arthritis.

What does the DRUMBEAT study involve?
The study will include 10-12 adults aged 18+ years. The DRUMBEAT program itself will comprise of six x 2.5 hour combined discussion/drumming sessions, run once a week on a Tuesday evening from 6.00pm – 8.30pm. The sessions will run from the Arthritis Foundation of WA Shenton Park, with an expected start date of Tuesday 16th April, 2019 (yet to be confirmed). Light refreshments will be available. Before the study starts why not come along to one of our ‘INTRO to DRUMBEAT & ARTHRITIS’ sessions and try it for yourself? Open to all ages. Feel free to bring along a friend. NO OBLIGATION, RHYTHM or TALENT required!! Numbers are limited so get your name down quick. To register please email Jan.jwarhurs@our.ecu.edu.au or follow the link to our events https://www.facebook.com/groups/1964224540556329/

What do I have to do?
If you are interested in participating in the study, the first steps involve completing a general Health Survey and Consent Form. You will need to complete both and sign the Consent Form and either scan and email back to (jwarhurs@our.ecu.edu.au) or take a screenshot and text to mobile number 0410 486 281. We also need a letter of support from your GP/Rheumatologist, unless, when you spoke with the researcher, you opted for her to contact the doctor on your behalf. Once we have your written consent, together with a letter of support from your GP/ Rheumatologist, and provided you meet all the selection criteria, you will be allocated a unique code number to be used to de-identify you throughout the study. You will use this number, instead of your name, when we ask you to complete some questionnaires at specific times during the study.

If you join the study, here is what to expect:

1. You will be asked to fill in a general health survey.
2. We will also ask you to join our closed FB group. This will enable you to connect and share comments with other drummers from the research group.
3. At the beginning of the first week before we start drumming, everyone will need to complete three questionnaires. These will be repeated at the end of the study.
4. This study is being done to help you and others that come along in the future, so your feedback throughout the study is very important, as it means we can modify the program to meet your needs as we go along. So, we will ask you to write a few words/lines on a form provided at the end of each session and to also record if you have experienced any pain during the session using a simple pain scale [0 (no pain) to 10 (unbearable pain)].
5. There will also be an overall rating of DRUMBEAT after the final session.
6. In the two weeks following the end of the study, the researcher will contact you to arrange either a convenient day and time for a short 5-10-minute telephone call, or invite you to a final focus group meeting, depending on the group’s preferences. Whether a phone call, or group meeting the researcher will ask your permission before recording your conversation.

How much time does it take to complete the questionnaires?
It might sound like a lot of questions to answer but not including time spent voluntarily online with the FB group, or the actual drumming sessions, completion of the questionnaires should take you no more than 40 minutes in total.

Do I really need to let my doctor/Specialist know?
Yes. It is mandatory that your GP/specialist be advised of your decision to participate in this research project.

What about my confidentiality? What happens to my data?
Apart from your physical presence in the DRUMBEAT sessions, your identity will only be recorded during the screening and consent stages of this research. From then on, your data will be collected using your unique code number. This means that your name will never appear in research outputs, or publications. If you have joined the FB group, any posts you make will be allocated a pseudonym for use in any research outputs or publications.

We may take photos, videos, or recordings of the sessions. Holyoake may also like to share these on their website and/or social media accounts. If you feature in the photos, you will be asked to sign a
permission slip before any photographs, or videos are released outside of the closed Facebook group.

All of your data will be stored in a secure manner, either on the researcher’s password-protected computer (for electronic data) or in a lockable filing cabinet (for hard-copy data). After 5 years, all your data will be destroyed and disposed of in accordance with laws related to data-disposal.

Can I withdraw from the study?
Participation in this study is completely voluntary and you may withdraw at any time. If you do withdraw your consent, any data already collected will be destroyed and disposed of in accordance with laws related to data disposal.

Reimbursement and Costs
There are no costs associated with participating in this research project, nor will you be paid. Tea/coffee and light refreshments will be provided during the program sessions.

Will I be able to find out the results of the project?
If you wish to know the results of the study, you can email the Principal researcher and request research outputs or publications.

Are there any risks involved?
Whilst any type of physical exertion involves some possible risk of injury, or complication, group drumming, based on previous studies, is considered extremely low risk. We will take all necessary steps to minimise any discomfort by including appropriate warm up routines and by selecting alternative exercises previously used in other DRUMBEAT interventions. Measures will also be in place to make sure the noise level of the drumming is kept within a safe limit. Also, some of the questionnaires may contain questions of a sensitive nature and could cause emotional discomfort, particularly if they are in relation to how your arthritis has impacted your life. If this happens to you the research team will assist you in contacting the appropriate support group. A contact list of confidential services based in WA is attached.

This is your opportunity to get involved and to share your experiences of living with chronic inflammatory arthritis. Your contribution will be extremely valuable in helping gain a better understanding of what complementary therapies work for this type of arthritis.

Jan Warhurst  
Principal Researcher  
School of Medical and Health Sciences  
Edith Cowan University  
jwarhurs@our.ecu.edu.au

Amanda Devine, PhD, AN, RPHNutr. Principal Supervisor  
School of Medical and Health Sciences  
Edith Cowan University  
a.devine@ecu.edu.au

Dr Leesa Costello  
Principal Supervisor  
School of Medical and Health Sciences  
Edith Cowan University  
l.costello@ecu.edu.au
What if I have a complaint or any concerns?
The study has been approved by the Human Research Ethics Committee. If you have any complaints or concerns about your participation in the study, please contact the number shown below. Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.
Research Ethics Officer, Edith Cowan University
270 Joondalup Drive JOONDALUP WA 6027
Phone: (08) 6304 2170 Email: research.ethics@ecu.edu.au
APPENDIX 8: SCREENING QUESTIONNAIRE

1. Date of Birth (ddmmyy)

2. Are you male or female?
   ○ Male
   ○ Female
   ○ Elect not to answer

3. How would you describe your marital status?
   (Please tick one box only)
   ○ Single (never married)
   ○ Divorced
   ○ Separated
   ○ Married
   ○ In a Defacto relationship
   ○ Widowed

4. Which of the following best describes you?
   (Please tick one box only)
   ○ Australian/Caucasian
   ○ Australian/ Indigenous/Torres Strait
   ○ African
   ○ Asian
   ○ Pacific Islander
   ○ Other (Please specify: ____________)

5. How old were you when you were first diagnosed with Rheumatoid Arthritis?
   (To the closest year: ______________)

6. What is the highest level of education you have completed?
   ○ High school
   ○ TAFE
   ○ University degree
   ○ Not applicable

7. (a) Do you work? Yes ☐ No ☐

   (b) If yes, what is your occupation? ______________________________

   (c) If yes, how many hours on average do you work per week? ☐

8. Are you undertaking any courses of study at the moment? Yes ☐ No ☐

   If yes, please tick whether it is part-time or full-time. P/T ☐ F/T ☐

Can a DRUMBEAT program be modified to suit my specific needs? Absolutely! But first there are just a few details we need from you.
9. Do you experience limitations in range of movement, in particular your hands, feet and/or neck? 

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.1</td>
<td>Hands</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.2</td>
<td>Feet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.3</td>
<td>Neck</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.4</td>
<td>Other? Please specify</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

10. Are you affected by loud noise? (Measures will be in place to make sure the noise level of the drum circle will be kept < 85Db)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
</table>

11. Do you have any other musculoskeletal condition(s) other than Rheumatoid Arthritis?

If yes (Please tick all applicable boxes).
- Osteoarthritis.
- Ankylosing spondylitis.
- Psoriatic arthritis.
- Fibromyalgia.
- Gout.
- Polymyalgia Rheumatica.
- Lupus.
- Other (Please specify: ..........................)
- None

12. Have you ever been diagnosed with a major depressive disorder?
- Yes (Please say when: ..........................)
- No
- Unsure

For those of you who have not been referred by your Doctor/Specialist, the first step is to let them know that you are participating in a DRUMBEAT study.
Please indicate your preferred way to inform your doctor that you are to be involved in a DRUMBEAT study (Please choose one option only).

- Option 1 – I will inform my doctor about the study and obtain a letter of support confirming my eligibility to take part.
- Option 2 – I give permission for the ECU researchers to inform my doctor about the study and seek their approval.

My doctor’s contact details are:
- Doctor/Specialist Name:
- Address:
- Suburb:
- Post Code:
- Telephone:

Thank you for completing this questionnaire.
APPENDIX 9: GP/SPECIALIST LETTER

Date

Dear Dr < GP Name>

Exploratory study to contextualize a DRUMBEAT® program to suit the needs of a chronic inflammatory Arthritis population group to ascertain if there is any therapeutic effect.

Your patient, named above, has requested to enrol in an exploratory study to identify if there are any therapeutic benefits of participating in a DRUMBEAT program for adults aged 18+ with chronic Inflammatory Arthritis. He/she has given consent [attached] for their contact information and medical diagnosis to be shared with myself as researcher for the study.

The study is a novel intervention where individuals will be asked to participate in a drumming program which will run over 6 weeks. Participants will also be asked to complete a number of questionnaires, pre and post intervention and to join a closed Facebook group.

This is a drumming intervention whereby techniques can be modified to suit most needs and all participants will be asked if they experience limitations in range of movement, in particular hands, feet and/or neck. The modifications possible can then be discussed and participants themselves are able to decide whether or not to participate, if they deem their own ability lacking in this regard.

Inclusion/exclusion criteria for enrolment into the study include:

**Inclusion criteria:**
2. Aged 18+ years
3. The ability to speak and understand English.
4. Able to make a commitment to complete the six-week DRUMBEAT program.

**Exclusion criteria:**
6. Disclosed presence of a major depressive disorder recently or previously diagnosed that has not been stabilised through treatment.
7. Presence of any co-existing musculoskeletal conditions that may prevent participation in the program.

*If you consider your patient to not be eligible for the study please let me know as soon as possible.*

Thank you for your kind co-operation. If you require any further information do not hesitate to contact either myself jwarhurs@our.ecu.edu.au or Amanda Devine, Professor Public Health and Nutrition, Director of Public Health, Edith Cowan University Joondalup a.devine@ecu.edu.au | Tel: +61 8 6304 5527. And if you would like to know more about the DRUMBEAT® program, visit Holyoake website https://www.holyoake.org.au/drumbeat.

Kind regards
Jan Warhurst  Professor Amanda Devine
Are you living with chronic inflammatory Arthritis?
Are you over 18 years of age?
If so, we are looking for people like you to join a fun research study about group drumming and wellbeing

Research shows that drumming:

• Reduces anxiety and stress
• Helps control chronic pain
• Boosts the immune system
• Releases negative feelings

This study is the first to investigate the benefits of group drumming specifically in adults with chronic inflammatory arthritis and is a new initiative between Edith Cowan University and Holyoake WA

TO FIND OUT MORE or to TRY DRUMMING BEFORE WE START

Find our Facebook Group: DRUMBEAT & ARTHRITIS

https://bit.ly/2U4jPY0

Or email
Jan Warhurst
jwarhurs@our.ecu.edu.au

Principal Researcher
School of Medical & Health Sciences
Edith Cowan University
APPENDIX 11: BROCHURE
APPENDIX 12: RAND 36 HEALTH SURVEY

RAND 36 ITEM HEALTH SURVEY 1.0

Patient Name: __________________________

1. In general, would you say your health is:  
   (Circle One Number)
   Excellent ........................................ 1
   Very Good ...................................... 2
   Good ............................................ 3
   Fair .............................................. 4
   Poor .............................................. 5

2. Compared to one year ago, how would you rate your:  
   general health right now?  
   (Circle One Number)
   Much better than one year ago .......... 1
   Somewhat better than one year ago ..... 2
   About the same ............................. 3
   Somewhat worse now than one year ago 4
   Much worse now than one year ago ..... 5

| The following items are about activities you might do during a typical day: |
| Does your health now limit you in these activities? If so, how much? | Yes | Yes | No |
| (Circle One Number on Each Line) | Limited | Limited | Not Limited | At All |
| 3. Vigorous activities, such as running, lifting heavy objects, mastering strenuous sports | 1 | 2 | 3 |
| 4. Moderate activities, such as moving a table pushing a vacuum cleaner, bowling or playing golf | 1 | 2 | 3 |
| 5. Lifting or carrying groceries | 1 | 2 | 3 |
| 6. Climbing several flights of stairs | 1 | 2 | 3 |
| 7. Climbing one flight of stairs | 1 | 2 | 3 |
| 8. Bending, kneeling or stooping | 1 | 2 | 3 |
| 9. Walking more than a mile | 1 | 2 | 3 |
| 10. Walking several blocks | 1 | 2 | 3 |
| 11. Walking one block | 1 | 2 | 3 |
| 12. Bathing or dressing yourself | 1 | 2 | 3 |

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?:  
(Circle One Number on Each Line)  
Yes | No
| 13. Cut down the amount of time you spend on work or other activities | 1 | 2 |
| 14. Accomplish less than you would like | 1 | 2 |
| 15. Were limited in the kind of work or other activities | 1 | 2 |
| 16. Had difficulty performing the work or other activities (for example, took extra effort) | 1 | 2 |

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems?:  
(Circle One Number on Each Line)  
Yes | No
| 17. Cut down the amount of time you spend on work or other activities | 1 | 2 |
| 18. Accomplish less than you would like | 1 | 2 |
| 19. Didn't do work or other activities as carefully as usual | 1 | 2 |
| 20. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors or groups? | Not at all | Slightly | Moderate | Quite a bit | Good |
| (Circle One Number) | 1 | 2 | 3 | 4 | 5 |
21. How much bodily pain have you had during the past 4 weeks:  
   (Circle One Number)  
   None .......................... 1  
   Very Mild ..................... 2  
   Mild ........................... 3  
   Moderate ...................... 4  
   Severe ........................ 5  
   Very Severe ................... 6

22. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?  
   (Circle One Number)  
   Not at all .......................... 1  
   Slightly .......................... 2  
   Moderately ....................... 3  
   Quite a bit ........................ 4  
   Extremely ........................ 5

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

<table>
<thead>
<tr>
<th>How much of the time during the past 4 weeks . . . (Circle One Number on Each Line)</th>
<th>All of the Time</th>
<th>Most of the Time</th>
<th>A Good Bit of the Time</th>
<th>Some of the Time</th>
<th>A Little of the Time</th>
<th>None of the Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>23. Did you feel full of pep? ......................................</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>24. Have you been a very nervous person? ................................</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>25. Have you felt so down in the dumps that nothing could cheer you up? ................................</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>26. Have you felt calm and peaceful? ................................</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>27. Do you have a lot of energy? .....................................</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>28. Have you felt downhearted and blue? .............................</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>29. Did you feel worn out? .............................................</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>30. Have you been a happy person? ....................................</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>31. Did you feel tired? ................................................</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
| 32. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities like visiting with family, friends, relatives, etc.?  
   (Circle One Number) | All of the time .......................... 1  
   Most of the time .......................... 2  
   Some of the time .......................... 3  
   A little of the time ........................ 4  
   None of the time .......................... 5

How TRUE or FALSE is each of the following statements for you?  
   (Circle One Number on Each Line)  
   Definitely True | Mostly True | Don't Know | Mostly False | Definitely False
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>33. I seem to get sick a little easier than other people</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>34. I am as healthy as anybody I know</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>35. I expect my health to get worse</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>36. My health is excellent</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
## APPENDIX 13: HADS

<table>
<thead>
<tr>
<th></th>
<th>I feel tense or ‘wound up’:</th>
<th></th>
<th>I feel as if I am slowed down:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Most of the time</td>
<td></td>
<td>Nearly all the time</td>
</tr>
<tr>
<td></td>
<td>A lot of the time</td>
<td></td>
<td>Very often</td>
</tr>
<tr>
<td></td>
<td>From time to time, occasionally</td>
<td></td>
<td>Sometimes</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td></td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>I still enjoy the things I used to enjoy:</th>
<th></th>
<th>I get a sort of frightened feeling like ‘butterflies’ in the stomach:</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td></td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Definitely as much</td>
<td></td>
<td>Not at all</td>
</tr>
<tr>
<td></td>
<td>Not quite as much</td>
<td></td>
<td>Occasionally</td>
</tr>
<tr>
<td></td>
<td>Only a little</td>
<td></td>
<td>Quite often</td>
</tr>
<tr>
<td></td>
<td>Hardly at all</td>
<td></td>
<td>Very often</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>I get a sort of frightened feeling as if something awful is about to happen:</th>
<th></th>
<th>I have lost interest in my appearance:</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td></td>
<td>6</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Very definitely and quite badly</td>
<td></td>
<td>Definitely</td>
</tr>
<tr>
<td></td>
<td>Yes, but not too badly</td>
<td></td>
<td>I don’t take as much care as I should</td>
</tr>
<tr>
<td></td>
<td>A little, but it doesn’t worry me</td>
<td></td>
<td>I may not take quite as much care</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td></td>
<td>I take just as much care as ever</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>I can laugh and see the funny side of things:</th>
<th></th>
<th>I feel restless as though I have to be on the move:</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td></td>
<td>8</td>
<td></td>
</tr>
<tr>
<td></td>
<td>As much as I always could</td>
<td></td>
<td>Very much indeed</td>
</tr>
<tr>
<td></td>
<td>Not quite so much now</td>
<td></td>
<td>Quite a lot</td>
</tr>
<tr>
<td></td>
<td>Definitely not so much now</td>
<td></td>
<td>Not very much</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td></td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Worrying thoughts go through my mind:</th>
<th></th>
<th>I look forward with enjoyment to things:</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td></td>
<td>10</td>
<td></td>
</tr>
<tr>
<td></td>
<td>A great deal of the time</td>
<td></td>
<td>As much as I ever did</td>
</tr>
<tr>
<td></td>
<td>A lot of the time</td>
<td></td>
<td>Rather less than I used to</td>
</tr>
<tr>
<td></td>
<td>From time to time but not too often</td>
<td></td>
<td>Definitely less than I used to</td>
</tr>
<tr>
<td></td>
<td>Only occasionally</td>
<td></td>
<td>Hardly at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>I feel cheerful:</th>
<th></th>
<th>I get sudden feelings of panic:</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td></td>
<td>12</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td></td>
<td>Very often</td>
</tr>
<tr>
<td></td>
<td>Not often</td>
<td></td>
<td>Quite often</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td></td>
<td>Not very often</td>
</tr>
<tr>
<td></td>
<td>Most of the time</td>
<td></td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>I can sit at ease and relax:</th>
<th></th>
<th>I can enjoy a good book or radio/TV program:</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td></td>
<td>14</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Definitely</td>
<td></td>
<td>Often</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td></td>
<td>Sometimes</td>
</tr>
<tr>
<td></td>
<td>Not often</td>
<td></td>
<td>Not often</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td></td>
<td>Very seldom</td>
</tr>
</tbody>
</table>
# APPENDIX 14: RHEUMATOID ARTHRITIS SELF EFFICACY

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither disagree nor agree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I believe I could use relaxation techniques to help with pain.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I believe I could think about something else to help with pain.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I believe I could use my joints carefully (joint protection) to help with pain.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I believe I could think positively to help with pain.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. I believe I could avoid doing things that cause pain.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I believe I could wind down and relax before going to bed, to improve my sleep.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. I believe I could have a hot drink before bed, to improve my sleep.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. I believe I could use relaxation before bed, to improve my sleep.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I believe I could pace myself and take my arthritis into account to help deal with tiredness.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I believe I could accept fatigue as part of my arthritis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. I believe I could use gadgets to help with mobility, household tasks or personal care.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
12. I believe I could ask for help to deal with the difficulties of doing everyday tasks.

13. I believe I could do exercises to deal with the difficulties of doing everyday tasks.

14. I believe I could plan or prioritize my day to deal with difficulties of doing everyday tasks.

15. I believe I could educate my family and friends about my arthritis to help with the strains that arthritis can make on relationships.

16. I believe I could explain to friends and family when I do or do not need help.

17. I believe I could discuss any problems with my partner or family.

18. I believe I could make time for leisure activities, hobbies or socializing.

19. I believe I could save energy for leisure activities, hobbies or socializing.

20. I believe I could focus on the positive when I am feeling down.

21. I believe I could use relaxation to deal with worries.
22. I believe I could allocate time for relaxation.

23. I believe I could use a relaxation CD or instructions to help me relax.

24. I believe I could use regular exercise.

25. I believe I could be aware of my limits in exercise.

26. I believe I could manage my medication, knowing how and when to take it.

27. I believe I could look out for and avoid side-effects of my medication.

28. I believe I could seek help with persistent side-effects.
INSTRUCTIONS: Indicate how often each of the statements below is descriptive of you.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>*1. How often do you feel that you are &quot;in tune&quot; with the people around you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. How often do you feel that you lack companionship?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. How often do you feel that there is no one you can turn to?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. How often do you feel alone?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>*5. How often do you feel part of a group of friends?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>*6. How often do you feel that you have a lot in common with the people around you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. How often do you feel that you are no longer close to anyone?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. How often do you feel that your interests and ideas are not shared by those around you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>*9. How often do you feel outgoing and friendly?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>*10. How often do you feel close to people?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. How often do you feel left out?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. How often do you feel that your relationships with others are not meaningful?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. How often do you feel that no one really knows you well?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. How often do you feel isolated from others?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>*15. How often do you feel you can find companionship when you want it?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>*16. How often do you feel that there are people who really understand you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. How often do you feel shy?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. How often do you feel that people are around you but not with you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>*19. How often do you feel that there are people you can talk to?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>*20. How often do you feel that there are people you can turn to?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
APPENDIX 16: SESSION RATING SCALE [SRS] with COMBINED SESSION VISUAL ANALOGUE SCALE (VAS) TO CAPTURE PAIN INTENSITY / SEVERITY DATA

WHAT DID YOU THINK OF TODAY’S SESSION?
HOW MUCH PAIN DO YOU FEEL?

We have nearly come to the end of our session but before we go I would be grateful if you could take a minute to fill out this form, which asks your opinion about today. We rely on your feedback so we can keep on track, or to let us know if any changes are needed to make sure you are getting the best out of this intervention. There might be some small point that you think is not important but your feedback on even the smallest thing could make all the difference!

YOU WILL BE DOING ME A BIG FAVOUR, SO PLEASE FEEL FREE TO GIVE YOUR HONEST OPINION.

Instructions: Please place a mark on the line nearest to the description that best fits your experience.

Goals and Topics

We did not work on or talk about what I wanted to work on and talk about.

We worked on and talked about what I wanted to work on and talk about.

Approach or Method

The supervisor’s approach is not a good fit for me.

The supervisor’s approach is a good fit for me.

Supervisory Alliance

I did not feel heard and understood.

I felt heard and understood.

Overall

There was something missing in the session today.

Overall, today’s session was right for me.

Instructions: Please place a mark on the line nearest to the description that best fits your pain level.

PAIN SCORE

<table>
<thead>
<tr>
<th>(No pain) 0</th>
<th>10 (unbearable pain)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No pain</td>
<td>Worst possible pain</td>
</tr>
</tbody>
</table>
# APPENDIX 17: DRUMBEAT FINAL QUESTIONNAIRE

## ADULT Program Feedback

Circle the number which best indicates your feelings about that statement. For example, if you strongly disagree with a statement, circle "1". If you are neutral, circle "3", and if you strongly agree, circle "5", etc. There are no wrong answers.

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I enjoyed being part of the DRUMBEAT program</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>2</td>
<td>My input was encouraged in sessions</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>3</td>
<td>I felt part of a team while doing DRUMBEAT</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>4</td>
<td>The drumming skills I have learnt in DRUMBEAT have helped me to feel good about myself</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>5</td>
<td>I find some problems easier to work through since doing DRUMBEAT</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>6</td>
<td>DRUMBEAT has helped me learn how to talk with others</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>7</td>
<td>I find it easier to work out what I am feeling since doing DRUMBEAT</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>8</td>
<td>I feel more responsible for my behaviour since doing DRUMBEAT</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>9</td>
<td>DRUMBEAT has assisted with improving my relationships with other people</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>10</td>
<td>DRUMBEAT has assisted with improving my relationships within my family</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>11</td>
<td>Since doing DRUMBEAT I aim for more harmony in my relationships</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>12</td>
<td>DRUMBEAT has helped me identify my main beliefs and a 'safe place'</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>13</td>
<td>DRUMBEAT has helped me learn about myself</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>14</td>
<td>I will pass on some of what I have learnt though DRUMBEAT to other friends or family</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>15</td>
<td>I would recommend the DRUMBEAT Program to others</td>
<td>1 2 3 4 5</td>
</tr>
</tbody>
</table>

## 16 The 3 main things DRUMBEAT has helped me with are:

1. 

2. 

3. 

## 17 Please let us know any other comments you have about DRUMBEAT
APPENDIX 18: LOCUS OF CONTROL

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Disagree</th>
<th>Generally Disagree</th>
<th>Somewhat Disagree</th>
<th>Generally Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) I can anticipate difficulties and take action to avoid them</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4) I can control my problem(s) only if I have outside support</td>
<td>Strongly Disagree</td>
<td>Generally Disagree</td>
<td>Somewhat Disagree</td>
<td>Generally Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>5) When I make plans, I am almost certain that I can make them work</td>
<td>Strongly Disagree</td>
<td>Generally Disagree</td>
<td>Somewhat Disagree</td>
<td>Generally Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>7) My mistakes and problems are my responsibility to deal with</td>
<td>Strongly Disagree</td>
<td>Generally Disagree</td>
<td>Somewhat Disagree</td>
<td>Generally Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>8) Becoming a success is a matter of hard work, luck has little or nothing to do with it</td>
<td>Strongly Disagree</td>
<td>Generally Disagree</td>
<td>Somewhat Disagree</td>
<td>Generally Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>13) I believe a person can really be the master of his/her fate</td>
<td>Strongly Disagree</td>
<td>Generally Disagree</td>
<td>Somewhat Disagree</td>
<td>Generally Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>15) I understand why my problem(s) varies so much from one occasion to the next</td>
<td>Strongly Disagree</td>
<td>Generally Disagree</td>
<td>Somewhat Disagree</td>
<td>Generally Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>16) I am confident of being able to deal successfully with future problems</td>
<td>Strongly Disagree</td>
<td>Generally Disagree</td>
<td>Somewhat Disagree</td>
<td>Generally Agree</td>
<td>Strongly Agree</td>
</tr>
</tbody>
</table>
APPENDIX 19:
SUMMARY OF NOTES FOR THE FOCUS GROUP STRUCTURE:

- Brief overview of my research objective/goal
- Explain that this focus group is to get more specific feedback for the study to identify any areas of the program that require further customization for the specific health needs of this group
- Explain guidelines so that focus group runs smoothly: want you all to join in but as this is being recorded, please don’t all talk at once, don’t start side conversations – give everyone a chance
- Quick summary of what was pre-adapted already given the known health needs of the group – process only sticks/percussion/duration/more breaks/more stretches – self-care
- Feedback to the group that overall the session feedback ratings were very positive and comment on the pain scales pre and post.
- Explain there are 2 areas of customization of the DRUMBEAT program:
  1. Content: actual session content
  2. Process: the practical aspects and considerations specific to sufferers of Inflammatory Arthritis – i.e. location, engaging participants, offering different instruments etc.

CONTENT REVIEW Tell me about your experiences in the sessions:

- Go through the session basic run sheets (cheat sheets) individually with the group to jog their memory of the key theme, discussions, activities and ask:
  - Does everyone remember this session?
  - Does anything stand out for anyone?
  - What worked well?
  - Anything you really enjoyed?
  - Was there anything you didn’t like?
  - Is there any way you think we can improve it?

- Looking at the program in general:
  - What did you love about the drumming?
  - Anything you didn’t like?
  - What, if any, were the challenges of this program?
  - How did the drumming make you feel?
  - What do you feel you have gained from these sessions?
- How do you think this program has helped you deal with your condition?
- What do you think it is about the sessions that help with that?

PROCESS REVIEW

- What motivated you all to be here?
- Has your motivation changed?
- How did you all hear about it?
- Any feedback about how you felt coming into the group at the beginning?
- How has this changed?
- What is your sense of the group now?
- How was the experience of having people from different backgrounds/ages in the group?
- What do you think are the barriers for people attending the program?
- How can these be overcome? Any suggestions?
- Did you have to overcome any challenges or barriers to get here?
- Any suggestions for future program delivery – i.e. location, marketing, frequency and length of session (Was 2.5 hours x 6 good or would 1.5 hours x 10 be better?)

FINISH:

- What happens next?
- Thank you’s all-round and hand out personalized Drumbeat Certificates