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Health and Wellbeing amongst Older People Research in Northamptonshire

Poole H, Sixsmith J, Parkes J, Ward A, Pyer M, Campbell J, Machado L, Rehling T, Youell J, Carter J, Oyebode J, O'Malley M, Anthony K, Rogers S, Jones J, Siddons L, Smith L-A, Kay T, Fraser M, Score J, El Khoury, L, Hameed A, Albalbesi N, Durrant, L, Al-Zubaidi R, Al-Rayahi I, da Silva K, Taylor J.

East Midlands Research into Ageing Network (EMRAN) is a research collaboration across the East Midlands to facilitate collaborative applied clinical research into ageing and the care of older people. EMRAN was set up with support from NIHR CLAHRC East Midlands.

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1. Foreword

Foreword by Professor Judith Sixsmith, Former Director of the Institute of Health and Wellbeing and the Ageing Research Centre at the University of Northampton.

The Ageing Research Centre of the University of Northampton (2014-current), in collaboration with the East Midlands Research into Ageing Network (EMRAN) is pleased to compile this brochure on research activity associated with older people across the county of Northamptonshire. This provides a comprehensive overview of activity that is relevant and of value to practice, identifying research outcomes that have real significance to age-related health and wellbeing.

The brochure provides a summary of research activity over the last five years from academic, clinical and professional colleagues and demonstrates cross sector networks of collaboration around the common agenda of aging. Such collaboration will enhance the capacity of research understanding across the county and provide information and support for the needs of older people, their families and carers.

The translation of research outcomes into practice is essential if we are to promote wellness, independence and healthy aging within the county and beyond and I would like to thank all contributors for their commitment and hard work in the production of this brochure.



April, 2017

2. University of Northampton Researchers and Collaborators: Who we are and what we do

This brochure has been compiled by researchers working in the Faculty of Health and Society at the University of Northampton and formerly the Institute of Health and Wellbeing. During the last 5 years, a considerable portfolio of research has been undertaken into the ageing process and the lives of older people, enabled by a trans disciplinary approach and underpinned by a philosophy of inclusion and co-production that encouraged:

- Team building across university faculties, including staff as well as undergraduate and post-graduate students;
- Collaborating with external universities;
- Engaging with public, patient, carers and service users in a meaningful way throughout research, evaluation, education and consultancy processes;
- Partnering with stakeholders within the health and social care communities.

The University's emphasis on excellence in research, evaluation, teaching, training and consultancy, particularly within the Ageing Research Centre (part of the Faculty of Health and Society) provided the context for the generation of new knowledge and development of theory in social gerontology as well as biological fields.

Many of our partners, such as Northamptonshire County Council, Kettering General Hospital, Northampton General Hospital, Northamptonshire Healthcare NHS Foundation Trust, HealthWatch and the Community Engagement Research Forum alongside several private and voluntary businesses and representatives from charitable organisations, in particular, the Northampton branch of Age UK and Northampton Alzheimer's Society, have contributed to ageing research and to projects featured in this brochure. In addition, several Universities such as Oxford Brookes, the University of Bedford, the University of West London and Kings College London among others have partnered with us on the projects featured.

The research and evaluation has aimed to, and continues to, make a positive difference in people's lives. Anyone interested in finding out more about the projects featured in this brochure, or about ageing research more generally, can contact the relevant authors by the email contact information given in each section of this brochure.

3. Research Topics and Studies

The portfolio of research on ageing collected together in this brochure ranges from social to biological, psychological to medical, technological to education and training, and qualitative, quantitative and mixed methods approaches. Much of the research is designed and conducted within the framework of Public and Patient Involvement (PPI) models to ensure that PPI informs the progress of research and evaluation. As such, much of the work undertaken is applied in nature, while also creating new ways of seeing existing social problems and thus addressing the complex challenges of an increasingly ageing society in more holistic, transdisciplinary ways. The research featured in this brochure has been grouped under seven headings as follows:

- 3.1 Dementia and Alzheimer's disease
- 3.2 Public Health, Prevention and Service Evaluation
- 3.3 Ageing in Place
- 3.4 Falls and Static Balance
- 3.5 Biological Ageing
- 3.6 End of Life and Palliative Care
- 3.7 Educational Interventions

Each of these domains of work will be outlined in such a way to enable readers to gain a solid understanding of the projects involved and contact information is provided so they can request greater detail from the researchers involved.

3.1 Dementia and Alzheimer's disease

As the numbers of people living with dementia increase worldwide, nationally and in the East Midlands, research in relation to dementia and Alzheimer's disease has gathered pace in Northamptonshire. Dementia has been identified as a strand of the University of Northampton's Advancement Plan, particularly responding to the Northamptonshire County Council proposal to develop the county's first specialist dementia care village announced in December 2016. Northamptonshire based research on dementia and Alzheimer's disease is overviewed below, covering: social and health perspectives in research on awareness raising; understanding lived experience; daily living and occupational performance; young onset dementia diagnosis accuracy; post diagnosis support; and biological and medical work on understanding tau RNA processing in neurodegeneration.

Dementia Academic Action Group Tier 1 Dementia Awareness Training Project

Funder: Health Education England Thames Valley

Dates: April 2014 – July 2016

Investigators: Professor Jacqueline Parkes (in collaboration with the University of Northampton, University of Bedfordshire, Oxford Brookes University, University of West London).

Summary: This two-year project was commissioned to design and deliver Tier 1 dementia awareness training to health and social care professionals within the Thames Valley and to create a sustainable training model. This project was run in three phases. The first phase was a scoping review to understand what training was being delivered and to understand the needs of health and social care professionals and carers. The second phase developed a training package which was piloted and delivered to over 1,400 staff in the Thames Valley region. The final phase was an evaluation of the training which fed into the development of an updated training package which could be delivered in a train the trainer model and was accessible online. A final report and training materials are available on: <https://hee.nhs.uk/our-work/person-centred-care/dementia/tier-1-training>

For more information, please contact: Jacqueline.Parkes@northampton.ac.uk

Key words: *Dementia awareness training, Tier 1 training, health and social care professionals*

Understanding the value of using photography and storytelling to understand people with dementia lived experience

Funder: Winston Churchill Memorial Trust

Dates: August 2015. PhD ongoing.

PhD Student: Alison Ward. **Supervisors:** Professor Jacqueline Parkes, Professor Helen Lomax.

Summary: This project was awarded as a Winston Churchill Travelling Fellowship, which was undertaken in Aalborg, Denmark. This four week project aimed to find out about creative activities and services which are being delivered in Denmark to support people with dementia.

A project was also undertaken at VUK (Voksenskolen for Undervisning og Kommunikation), a school for adult education providing cognitive training and creative lessons for people with dementia, who attend the school as students. The project explored the students' experiences of attending the school. Students took photographs of their school activities which were used as prompts for conversations and to create storyboards and poetry.

The project highlighted the value of using creative techniques to understand the lived experience of people with dementia and provided valuable learning about the student's experiences of being at VUK, the importance they place on lifelong learning, friendships and being with 'likeminded' people. This project is now being developed further through a PhD to explore the value of using creative and visual methods with people with dementia to support them to share their stories and experiences.

The project report can be downloaded from:

<http://www.wcmt.org.uk/users/alisonward2015>

For more information, please contact: Alison.ward@northampton.ac.uk

Key words: *dementia, photography, storytelling, creative aging, photo elicitation, visual methods, creative methods*

Occupational Therapy and Cognitive Stimulation Therapy: facilitating the occupational performance of people with dementia

Funder: UK Occupational Therapy Research Foundation, a division of the Royal College of Occupational Therapists

Acting Principal Investigator: Tracey Rehling

Dates: Sept 2013 – Oct 2017

Researcher/PhD Student: Tracey Rehling **Supervisors:** Andy Pilkington, Noel Harris, Judith Sixsmith, Susan Corr (External Advisor) and Gill Chard (External Advisor)

Summary: Cognitive Stimulation Therapy (CST) is an activity-based intervention recommended for people with dementia (NICE 2006). There is evidence that CST benefits cognition and quality of life (Spector et al., 2003), but little is known about its effect on performance of Activities of Daily Living (ADL). The aim of this mixed methods study was to deliver CST, whilst examining ADL performance as an additional outcome. Ethical approval was obtained. Following a survey (n=71) and interviews (n=10) with

occupational therapists and a case study of CST (n=6), an intervention (OT-CSTdem) was developed to deliver standardised CST within the framework of an occupational therapy approach. One programme of OT-CSTdem was delivered as part of routine care by a trained occupational therapist. The Assessment of Motor and Process Skills (AMPS) was used to examine any changes that took place in the ADL task performance of participants (n=7). Wilcoxon Signed Rank tests revealed a statistically significant increase in ADL motor ability ($z = - 2.214$, $p = 0.027$) with a large effect size ($r = 0.639$). An increase in ADL process ability was also noted, that was close to significance and with a large effect size ($z = - 1.841$, $p = 0.066$, $r = 0.531$). The results of this small exploratory study are promising and provide initial evidence of added value when CST is delivered within an occupation-centred framework, in terms of supporting people with dementia in their performance of activities of daily living. Further research is recommended to investigate whether these outcomes can be reproduced with a larger sample.

For more information, please contact: tracey.rehling@northampton.ac.uk.

Key words: *Dementia, cognitive stimulation therapy, case study, Assessment of Motor and Process Skills*

“I Loves Her and She Loves Me”: A Qualitative Study into the Intimate Relational Experience of Living with Dementia

Funder: PhD Scholarship University of Northampton and (partly) funded by Funds for Women Graduates

Researcher: Dr Jane Youell CPsychol **Supervisory team:** Professor Jacqueline Parkes and Professor Jane Callaghan

Summary: The aim of this project was to better understand the relational impact of living with dementia, particularly in terms of intimacy. Using a qualitative approach, thirty-one participants were recruited and interviewed. The participant cohort included ten couples and 11 current or former carers. The interviews were analysed using interpretive interactionism (Denzin, 2001). This methodology seeks to understand the lived experience.

Three broad themes emerged, the first around home space, the second, intimacy, sexuality and dementia and the third around (re)negotiation. The theme home space explores the impact that dementia can have on community living, how the home space

took on many roles and adaptations. The second theme of intimacy, sexuality and dementia found that intimacy and sexuality remain important but, the feelings and issues around sexuality are complex and sometimes challenging. The final theme, of (re)negotiation offers evidence of the strategies used by couples in order to maintain their intimate lives together for as long as possible. These strategies cover both those couples who remain together in the community and those separated by the need for one partner to live in residential care. The co-constructions offered within this thesis give valuable insight into the intimate lives of those living with dementia in the UK.

Based on the findings of this doctoral work, Jane has developed workshops for teams working with people affected with dementia.

For more information, please contact: jyouellconsultancy@gmail.com

Key words: *Dementia, intimacy, interpretive interactionism*

The Angela Project

Funder: Alzheimer's Society

Principal Investigator: Dr Janet Carter, Professor Jacqueline Parkes, Professor Jan Oyebo

Researcher: Mary O'Malley

Dates: 2017-2019

Summary: Younger people living with dementia (YPD) have been at the forefront of the growing campaign to challenge society's attitude to dementia. Despite the increased visibility of this group, receiving a timely and accurate diagnosis and gaining access to age-appropriate support remain challenging because dementia services remain primarily focused upon the needs of older people.

To improve diagnostic accuracy and post-diagnostic support in YPD, this project aims to:

1. Develop a diagnostic algorithm to guide clinicians in assessment of YPD.
2. Identify and disseminate examples of good practice in post-diagnostic provision across the wider YPD health and social care community.

An E-Delphi approach will be used in work stream 1, to develop and design 'Diagnostic Practice Guidelines'; this 'Gold Standard' will be compared, via case-note audit, to current UK practice. In work stream 2, a survey and interviews with YPD, carers,

providers and commissioners will be used to gather examples of good post-diagnostic support, information about current service use, and a better understanding of the barriers and facilitators to providing and commissioning age- and condition-appropriate services.

For more information, please contact: Mary.O'Malley@northampton.ac.uk or Jacqueline.parkes@northampton.ac.uk

Keywords: *younger onset dementia, diagnosis, post-diagnostic support, Delphi methods*

Untangling dementia: tau RNA processing in neurodegeneration

Funder: University of Northampton, awaiting further funding outcomes

Dates: 2016-2019

Investigators: Dr Karen Anthony in collaboration with the Maurice Wohl Clinical Neuroscience Institute at King's College London

Summary: Alzheimer's disease is the most well-known of a group of diseases called the tauopathies. Their hallmark is the abnormal build-up of a protein called tau inside neurons. These deposits are called neurofibrillary tangles. The function of tau within neurons is to stabilise internal 'railway tracks' helping to move cargo around the cell. Several cellular processes are therefore disrupted by the presence of these tangles leading to the progressive degeneration and death of neurons.

Genetic information flows from DNA to RNA to protein. RNA must be correctly processed and localised within the cell in order to be 'translated' into protein. RNA processing is tightly regulated and several tauopathies are associated with its misregulation. Our focus is to understand how tau 'messenger' RNA (mRNA) is transported from the nucleus to the cytoplasm and how it is specifically targeted and localised to the site(s) of protein production. We have discovered new regulators of this process including one protein that has already been implicated in Alzheimer's disease. We are now studying the functional significance of this finding and how it contributes to the disease process. RNA-binding proteins represent novel drug targets and this project may lead to the development of new therapeutic approaches.

For more information, please contact: karen.anthony@northampton.ac.uk

Key words: *Dementia, Alzheimer's disease, tau, tauopathies, RNA processing*

3.2 Public Health, Prevention and Service Evaluation

Ensuring a strong evidence base for developing healthier lifestyles and reducing health inequalities, research across Northamptonshire has prioritised public health prevention strategies, as well as service intervention evaluation. In this respect, the programme of research in Northamptonshire currently covers the following:

Evaluation of Singing for the Brain Pilot

Funder: Alzheimer's Society Northamptonshire

Dates: September 2013- May 2014

Principal Investigator: Alison Ward

Summary: This qualitative study investigated the effectiveness of a pilot service of Singing for the Brain, which was being delivered to people who have a learning disability and a form of dementia or memory problem. The project evaluated the implementation and effectiveness of the Singing for the Brain pilot programme in order to provide an evidence base to develop this model for people with a learning disability. Singing for the Brain is a service provided by the Alzheimer's Society, which uses singing as a way to create a stimulating, fun activity within a social context. Alzheimer's Society Northamptonshire bid for, and won, funding to run a pilot scheme of Singing for the Brain sessions with local learning disability partners to provide sessions for people who have a learning disability and dementia or have problems with memory. The programme was run from October 2013 to April 2014, at two sites within the county. Sessions were delivered on a fortnightly basis at day centres for people with a learning disability. Sessions times ran for one hour and were supported by one facilitator and several members of the day care centre staff. A mixed method approach was used to evaluate the programme, including session observations, questionnaires and interviews. The evaluation found that participants reported high levels of enjoyment and engagement in the sessions. There is potential for these sessions to support communication, memory, social engagement and enable choice for participants attending the sessions.

For more information, please contact: alison.ward@northampton.ac.uk

Key words: *dementia, singing, learning disability, Singing for the Brain*

Promoting early presentation of breast cancer in women over 70 years old in general practice

Funder: Cancer Research UK

Dates: 2013-2015

Principal Investigators: Professor Jackie Campbell, Dr Stephen Rogers, Dr Michelle Pyer, Janice Jones

Summary: Delay in presentation is likely to contribute to poorer survival of older women with breast cancer. Research has shown the effectiveness of the Promoting Early Presentation [PEP] intervention when delivered by radiographers in the NHS Breast Screening Programme. This study investigated the effectiveness of the intervention when delivered by practice nurses in general practice.

A validated tool, the Breast Cancer Awareness Measure, was used to compare participants' awareness of breast cancer before, at one and 12 months after the delivery of the PEP intervention. 556 women from 18 GP practices across Northamptonshire took part.

The intervention was associated with increased awareness of non-lump breast symptoms and reported breast check frequency. There was a marked increase in breast cancer awareness which persisted for 12 months. Less than 5% of women were deemed 'breast cancer aware' before the intervention, rising to over a quarter of women three months afterwards. This percentage dropped slightly after one year to just below 20%.

It was concluded that delivery of the PEP intervention in General Practice was very effective at raising the awareness of breast cancer amongst older women. Primary care settings are well placed to enhance the reach of this kind of intervention to at-risk women.

For more information, please contact: jackie.campbell@northampton.ac.uk.

Key words: *older women, breast cancer, cancer awareness, promoting early presentation*

Northamptonshire Care Homes Improvement Programme

Funder: CLAHRC Leicestershire, Northamptonshire and Rutland/CLAHRC East Midlands

Dates: 2013-2015

Principal Investigator: Dr Stephen Rogers

Summary: This project evaluated the extent to which the toolkit, the 'Care Homes Programme', facilitates a positive organisational and cultural change in practice in care homes. This included measuring impact on quality of life among residents, impacts of the toolkit on working experience among care home staff and the feasibility of the implementation of the toolkit into practice. Pre- and post- intervention surveys assessed the quality of life of residents and staff satisfaction with their roles. Observation of the implementation of the intervention, document analysis and interviews with residents and staff were completed to better understand the process of change and factors that might enable or impede the impact on outcomes.

This is the first study of its kind to examine the feasibility of using Lean in improvement of services in the care home environment. Although we observed engagement and positive changes around specific projects were not able to demonstrate broader positive impacts on the experience of residents or staff in care homes. Lessons learned are presented and the implications for the implementation of similar programmes in the future are considered.

For more information, please contact: sr232@le.ac.uk.

Key words: *care homes; quality of life; staff satisfaction*

Exploring the decision to participate in the National Health Service Bowel Cancer Screening Programme

Funder: Cancer Research UK/East Midlands Cancer network

Dates: 2012-2014

Principal Investigator: Dr Stephen Rogers

Summary: Colorectal cancer is the third most common form of cancer in the UK and in an effort to reduce the high incidence, prevalence, morbidity and mortality rates, the National Health Service (NHS) has introduced the NHS Bowel Cancer Screening Programme (NHS BCSP). Participation rates have been low, and for the NHS BCSP to succeed in its goal of reducing the incidence and prevalence rates for colorectal cancer, individuals need to be persuaded to complete the test. We conducted a series of focus groups which revealed eight factors that affected participation in the NHS BCSP: (i) the

association of screening with entry into old age; (ii) prior experience with health systems; (iii) the support of a significant other; (iv) individual perceptions of risk (and benefit); (v) fear of becoming a cancer patient after the screening test; (vi) lack of disease symptoms; (vii) embarrassment associated with completing the test and (viii) messages that adopt a paternalistic ethos. More thought is needed as to the way that the public view this screening programme and the way it is delivered and communicated should be revised.

For more information, please contact: sr232@le.ac.uk.

Key words: *Bowel cancer, screening*

'What aspects of primary care predict emergency admission rates?' A cross sectional study

Funder: CLAHRC Leicestershire, Northamptonshire and Rutland

Dates: 2010-2013

Principal Investigator: Dr Stephen Rogers

Summary: We explored aspects of care, in addition to known demographic characteristics in general practice that are associated with emergency admissions. There were statistically significant associations between emergency admissions and age, gender, distance from hospital and proportion classified as white. There was also a statistically significant relationship between emergency admissions and being able to book an appointment with a preferred doctor; this relationship was stronger in less deprived communities. Enabling patients to book with a preferred doctor, particularly those in less deprived communities could have an impact on reducing emergency admissions.

For more information, please contact: sr232@leicester.ac.uk.

Key words: *Quality, performance, safety and outcomes*

Motor Neurone Disease – Wheelchair Service Evaluation

Funder: Motor Neurone Disease Association

Dates: 2016

Principal Investigators: Professor Jackie Campbell, Dr Michelle Pyer, Leonie Siddons and Janice Jones

Summary: Motor Neurone Disease (MND) is a progressive neurodegenerative disease. The onset of MND is sudden and it rapidly progresses and services for people with MND have to respond to these rapid changes in need. This evaluation used a mixed methods approach to including analysis of routinely collected data, service user and carer surveys and interviews, and stakeholder interviews to investigate the delivery and impact of the wheelchair service provided by the Motor Neurone Disease Association.

For more information, please contact: Jackie.Campbell@northampton.ac.uk

Key words: *Motor Neurone Disease, Wheelchair service, evaluation, mixed methods*

3.3 Ageing in Place

Governmental policy has driven a local agenda for supporting older people to age in place as a major arm of improving health and wellbeing as well as cutting health and social care costs. Ageing in *the right* place at home, in communities and institutional spaces can be successful in these respects, particularly when older people themselves are involved in the meaningful development of living spaces. This section of the brochure overviews the research conducted in Northamptonshire and by Northampton based researchers into older people and placemaking.

“Mad, Bad and Dangerous to Know”: Exploring the everyday spaces of older, mental health service users

Funder: The University of Northampton (PhD Thesis)

Dates: 2009-2012

PhD Student: Lesley-Ann Smith **Supervisors:** Dr Ian Tucker and Dr Sarah Crafter

Summary: Mental distress is an area that crosses many disciplines including; psychiatry, psychology, history, politics, philosophy, sociology and human geographies. Consequently, there are a complex set of issues to consider when discussing the experiences of being a mental health service user. Notwithstanding this diversity, representations of mental health have a tendency to position service users as a fairly homogenous and static group of bodies – e.g. the stable ‘other’. As a way of exploring the complexity, this research set out to explore the multiplex constituents and heterogeneous ways in which daily service user life is played out within everyday mental health spatial contexts. These spaces incorporate the psychiatric institution, the mental health day centre and the home.

Using interviews, ethnography, poetry and visual data, service users' experiences are analysed by exploring the relational aspects of the discursive and the material. This research data suggests that rather than the experiences of mental distress operating as a stratified set of factors, there were divergent accounts incorporating positivity, negativity and ambivalence in the ways which service users made meanings of their daily lives. Some implications of recent political changes and how these may impact upon daily service user life are discussed in this research thesis to highlight that older, service users' are always on the move.

For more information, please contact: Lesley-Ann.Smith@northampton.ac.uk.

Key words: *Qualitative, space, older mental health service user, experience*

Towards Age Friendly Communities: Place-Making with Older People

Funder: ESRC-Newton Fund

Dates: May 2016 - April 2019

Principal Investigator: Professor Judith Sixsmith

Summary: This research recognizes that simply changing the built form is not sufficient to create a more inclusive environment for ageing since places are more than physical spaces. The proposed research will identify the means to make urban environments more age friendly, socially equitable and sustainable for older adults living in Brazil.

Currently Work Package one is underway with a review of literature and policy on age friendly communities. In addition, 9 communities in the UK and 9 in Brazil have been identified and questionnaires and in-depth interviews, alongside photo-voice visual methods are being used to understand older people's social, personal, environmental and service experiences of place.

For more information, please contact: J.Sixsmith@dundee.ac.uk

Key words: *Ageing in place, age friendly communities, Intersectionality, Qualitative*

Place-Making with Seniors: Towards Meaningful Affordable Housing

Funder: Vancouver Foundation

Dates: 2014-2016

Principal Investigators: Professor Judith Sixsmith, in collaboration with colleagues from the Gerontology Research Centre at Simon Fraser University, Canada.

Summary: Housing that is not only affordable but also supportive of the psycho-social needs of seniors is fundamental to the health and well-being of our aging population. Community consultation has identified the need for housing interventions that build 'sense of place', ascribed through access to supports to keep mentally and physically active, opportunities to build social capital and facilitating an enhanced role for seniors in the design process. The research addresses these issues with the following objectives: (i) to understand how sense of place is experienced by older adults transitioning into affordable housing (ii) to translate resident experiences into formal and informal supports that foster meaningful aspects of place, and (iii) to create a role for older people as active 'placemakers' in community planning and development. The project began by developing a strong partnership of local government, planners and developers, seniors' services and Kiwanis seniors involved in the design of the affordable housing development: 'Kiwanis Towers'. To ensure the meaningful engagement of older adults, the project team developed a community-based participatory research approach, training residents as co-researchers and using participant-led research methods and an intersectionality lens. In total to date, the project has collected data in 25 semi-structured interviews with Kiwanis residents pre-move into the new Kiwanis Towers. In addition, 4 focus groups were conducted with 21 local service providers. During the transition into the Kiwanis towers, 18 photo-voice interviews were undertaken with residents and 4 mapping workshops (totalling 50 participants: 38 residents and 16 service providers). Finally, a post move 1 year feedback forum was held with 45 Kiwanis seniors.

The pre move data has been analysed to produce a Sense of Place Development Guide that has broad applicability in the domain of the design of housing supports for seniors. Further data analysis is underway. The project represents a timely opportunity to build skills and capacity and embed residents' preferences in the design process.

For more information, please contact: J.Sixsmith@dundee.ac.uk

Key words: *Housing, Home, Ethnicity, Intersectionality, Qualitative*

3.4 Falls and Static Balance

The prevention of falls is an important part of healthcare strategy to enable older people to age well and to continue to participate in society. The following projects are all based on assessing fall risk, understanding the impact of falls and preventing falls from happening:

Balance features in Alzheimer's disease and Amnesic Mild Cognitive Impairment

Funder: University of Northampton

Dates: 2007-2009

Principal Investigator: Professor Jackie Campbell

Summary: Alterations of balance were investigated using stabilometry in patients with amnesic mild cognitive impairment (aMCI) and with mild-moderate Alzheimer's disease (AD). Fifteen patients with aMCI and 15 with mild AD were recruited according to the current diagnostic criteria. Fifteen healthy subjects of the same age range were recruited as controls. Stabilometry was carried out using a commercial 4 load cell platform.

All stabilometry measures were significantly altered in mild AD patients compared to normal controls. Antero-posterior sway was found to be the most sensitive parameter, since it correlated with the ADAS-cog orientation subscale in AD patients, and also discriminated between aMCI and normal controls.

The study showed that impairment in balance is a feature not only of AD, but also of aMCI. The alterations found suggest that a progressive failure of the vestibular system, possibly linked to reduced hippocampal performance, may be responsible for such a feature. Further research must be focused on studying the predictive value of stabilometry in the conversion of aMCI.

For more information, please contact: Jackie.Campbell@northampton.ac.uk

Key words: *cognitive impairment, Alzheimer's disease, balance, stabilometry*

Falls assessment and prevention in older people: an evaluation of the Crisis Response Service

Funder: Northamptonshire County Council

Dates: 2012-2015



Principal Investigators: Professor Jackie Campbell, Dr Michelle Pyer, Alison Ward and Janice Jones

Summary: The elderly population of the world is growing with increasing trends of older people falling and accessing emergency services. The Crisis Response Falls Service in Northamptonshire (UK) was designed to identify health and social care needs, promote independence and limit the impact of falls. This study was an evaluation of this service. A mixed-method approach was used, drawing on the views of service users (via a survey and telephone interviews) and reviewing existing East Midlands Ambulance Service (EMAS) data with routinely collected data from the service.

A decrease in the numbers of patients conveyed to hospital following a fall was observed. Best estimates of financial calculations suggest savings were achieved. There were high levels of patient satisfaction and patients felt treated with dignity. Staff were considered friendly, approachable and well-informed.

A holistic approach to designing first responder services can provide positive impacts for those who fall in the community. The development and impact of the Crisis Response Falls Service shows the importance of evidence-based client centred training to inform the approaches taken to supporting those who fall, and the impact of a strong values based approach on the experiences of patients.

For more information, please contact: Jackie.Campbell@northampton.ac.uk.

Key words: *older people, falls, intervention, paramedic, crisis*

Relationship between balance and cognitive performance in older people

Funder: University of Northampton

Dates: 2010-2015

Principal Investigator: Professor Jackie Campbell

Summary: It has been demonstrated that there is a significant impairment in some balance measures in people with diagnosed Alzheimer's disease (AD) and mild cognitive impairment (MCI) compared to age matched normals, implicating damage to the vestibular pathways as the most probable cause. This study extends this to examining the relationship between cognitive ability and the vestibular component of balance in a population of older women with no definite AD or MCI diagnosis, no complaint of

memory loss, and without impairment of daily activity, with a view to future consideration of balance as a possible diagnostic or prognostic indicator.

70 physically active women with a mean age of 73 (SD=9) years were given the Italian version of the Montreal Cognitive Assessment (MoCA) test and their static balance parameters (antero-posterior (AP) and medio-lateral (ML) total sway path length) were measured on a balance platform with and without a 30mm rubber mat. This paper only considers those measurements made with closed eyes to exclude visual balance components.

The antero-posterior sway component of static balance was demonstrated to be the best predictor of the MoCA overall score in physically active older women. As visual and proprioceptive components of balance were excluded in our assessments, the vestibular system is to be considered as a putative link between balance and cognitive impairment.

For more information, please contact: Jackie.Campbell@northampton.ac.uk.

Key words: *older women, cognitive impairment, balance, sway*

Effects of unilateral eccentric exercise on age-related musculoskeletal functional decline

Funder: Wellcome Trust

Dates: Present

Principal Investigators: Dr Tony Kay (PI), Miss Millie Fraser (CoI)

Summary: Normal biological ageing compromises strength, muscle mass and balance, factors closely associated with falls. Unfortunately pain, difficulty walking, fear of falling and a low aerobic fitness often result in poor adherence to traditional forms of exercise. Thus, identifying exercises more suited to the requirements and characteristics of older people should enable individuals to exercise safely and generate meaningful improvements in health. The current project will examine the effects of a six-week seated exercise programme using unilateral eccentric-only (muscle lengthening) muscle contractions on lower limb strength, quadriceps muscle mass, standing balance and mobility. Importantly, chair-based activities eliminate fall risk during the exercise, while eccentric contractions have a lower cardiovascular demand that is better tolerated by older people, providing a safe and suitable exercise environment that should improve adherence to the exercise and therefore better outcomes for older people.

The grant will enable a 2nd year undergraduate Sport & Exercise Science student to work with Dr. Kay to experience high-level research conducted in an academic research department to give her invaluable knowledge and experience that will benefit her understanding of various biomechanical and physiological analyses, enhancing her CV, employability, prospects of postgraduate study, and future career aspirations.

For more information, please contact: tony.kay@northampton.ac.uk.

Key words: *eccentric exercise, musculoskeletal, falls*

3.5 Biological Ageing

Researchers in the University of Northampton, together with partners in other Universities and hospital and healthcare settings, have a strong interest in understanding biological aspects of ageing. Current projects in this area across Northamptonshire are:

Assessing the relationship between vitamin D (and related gene expression) and the process of lipogenesis and inflammation

Funder: Internal funding

Dates: 2015-Present

Principal Investigators: Dr Jodie Score, Dr Louis El Khoury, Dr Lee Machado, Dr Cordula Stover and Dr James Hobkirk

Summary: With colleagues in Leicester (Dr Cordula Stover) and our new collaborative partner at the University of Hull (Dr James P Hobkirk) we are engaged in some novel gene expression experiments in some very unique samples that comprise subcutaneous, intra-abdominal adipose tissue and hepatic tissue from a large cohort (n=91) of obese patients that have undergone bariatric surgery. The experiments aim to assess the relationship between vitamin D (VDR, CYP24A1 and CYP2R1) and the lipogenic and inflammatory gene expression and assess the inter-relationships between tissues. We are aiming to generate pilot data which may be suitable for publication and provide pilot data for grant applications.

For more information, please contact: lee.machado@northampton.ac.uk.

Key words: *Obesity, vitamin D, lipogenesis, inflammation*

Characterization of the glycome biosynthesis gene clusters involved in lipooligosaccharide and capsular polysaccharide biosynthesis in *Campylobacter sp.*

Funder: Supported by a self-funding PhD studentship

Dates: 2014-Present

PhD Student: Amber Hameed **Supervisors:** Dr Gemma Marsden, Dr Lee Machado

Summary: *Campylobacter* species are involved in numerous cases of food poisoning and understanding their underlying genetics is valuable in disease prevention. The lipooligosaccharide (LOS) biosynthesis gene cluster in *Campylobacter* has been classified based upon its gene and sequence diversity between different *Campylobacter* strains. This research is focused on comparative sequence analysis of the LOS biosynthesis loci for the determination of variability within the genes and between the compared sequences. This sequence diversity may influence the pathogenicity of *Campylobacter* strains including adhesion, invasiveness and innate immune responses.

This work has resulted in the identification of novel sequence variation within the *campylobacter* LOS gene cluster. Our preliminary data will allow us to define the role for the different genes within the lipooligosaccharide synthesis clusters in the development of *Campylobacter* pathogenesis.

For more information, please contact: Amber.Hameed@northampton.ac.uk.

Key words: *Campylobacter*, genetic variation, lipooligosaccharide, food poisoning

Downregulation of the citrullinating enzyme Peptidyl-arginine deiminase type-2 in ovarian cancer indicates poor prognosis

Funder: This work was funded in part by Nottingham Hospitals Charity via the charitable fund N0432 and a self-funding PhD studentship.

Dates: 2012-Present

PhD Student: Nina Albalbeisi **Supervisors:** Dr Lee Machado

Summary: Citrullinating enzymes including peptidyl-arginine deiminases (PADs) have been implicated in the pathogenesis of cancer. However, there have been no studies examining the expression of PAD2 protein and its association with overall survival outcomes in discovery and validation cohorts in ovarian cancer. Our work shows that PAD2 expression is associated with markers of autophagy and immune modulation

including HLA, IFNGR1, HMGB1 and BCL2 expression. We show that downregulated PAD2 expression represents an independent prognostic marker of poor prognosis for ovarian cancer. These findings suggest that therapeutic strategies designed to enhance autophagy/citrullination in ovarian cancer cells may provide a rational approach in the therapeutic targeting of ovarian cancer.

For more information, please contact: Lee.Machado@northampton.ac.uk.

Key words: *Ovarian cancer, autophagy, citrullination, cancer*

Understanding the genomic structure of copy number variants of the low-affinity *FCGR* region allows confirmation of the association of *FCGR3B* deletion with rheumatoid arthritis

Funder: Supported by prior Wellcome Trust funding

Dates: 2013-2016

Principal Investigators: Dr Lee Machado, Dr Ed Hollox

Summary: Fcγ receptors are a family of cell-surface receptors that are expressed by a host of different innate and adaptive immune cells and mediate inflammatory responses by binding the Fc portion of immunoglobulin G (IgG). In humans, five low affinity receptors are encoded by the genes *FCGR2A*, *FCGR2B*, *FCGR2C*, *FCGR3A* and *FCGR3B*, which are located in an 82.5kb segmental tandem duplication on chromosome 1q23.3, which shows extensive copy number variation. Deletions of *FCGR3B* have been suggested to increase the risk of inflammatory diseases such as systemic lupus erythematosus and rheumatoid arthritis. In this study we identify the deletion breakpoints of *FCGR3B* deletion alleles in the UK population and endogamous Native American populations, and show that some but not all alleles are likely to be identical-by-descent. We also localise a duplication breakpoint, confirming that the mechanism of CNV generation is non-allelic homologous recombination, and identify several alleles with gene conversion events using fosmid sequencing data. We use information on the structure of the deletion alleles to distinguish *FCGR3B* deletions from *FCGR3A* deletions in whole genome aCGH data. Reanalysis of published aCGH data supports association of *FCGR3B* deletion with increased risk rheumatoid arthritis in a large cohort of 1982 cases and 3271 controls (Odds Ratio 1.61, $p=0.0029$).

For more information, please contact: Lee.Machado@northampton.ac.uk.

Key words: *Copy number variation, Genetics, rheumatoid arthritis*

High-mobility group protein B1 is an independent predictor of poor survival in ovarian cancer

Funder: This work was funded in part by Nottingham Hospitals Charity via the charitable fund N0432

Dates: 2012-Present

Principal Investigators: Professor Lindy Durrant, Dr Lee Machado

Summary: HMGB1 is a known positive regulator of cancer cell survival by upregulating autophagy within cancer cells. HMGB1 has been implicated in the pathogenesis of ovarian cancer. However, there have been no definitive studies confirming that expression of HMGB1 protein is associated with overall survival outcomes in large test and validation cohorts. HMGB1 expression was shown to be associated with clinic-pathological variables including stage, histology and administration of chemotherapy as well as known regulators of autophagy including STAT1 and p53. We show that HMGB1 represents an independent prognostic marker of poor prognosis for ovarian cancer. These findings suggest that strategies designed to inhibit autophagy may provide a rational approach in the therapeutic targeting of ovarian cancer.

For more information, please contact: Lee.Machado@northampton.ac.uk

Key words: *Ovarian cancer, autophagy, cancer*

Obesity as a modulator of the tumour microenvironment and anti-tumour responses

Funder: Supported by a sponsored PhD studentship

Dates: 2015-Present

PhD Student: Rafah Al-Zubaidi **Supervisors:** Dr Lee Machado, Dr Cordula Stover

Summary: Obesity has become a serious public health concern in industrialised nations in the last two decades. Clinical studies support a link between obesity and cancer progression and development.

This project examines the relationship between obesity, tumour growth and the immune microenvironment of tumours. Although the influence of obesity on different types of cancers, such as liver, colon and breast cancers has been widely investigated, the effect of obesity on subsequent responses to treatment (i.e. immunotherapy) for cancer

remains largely unexplored. Therefore, this study will also determine whether obesity modifies immune responses to tumours elicited by strategies including vaccination and checkpoint blockade inhibition.

For more information, please contact: lee.machado@northampton.ac.uk.

Key words: *obesity, cancer, immunotherapy*

Population genetics inferences of multilocus Copy Number Variation (software CNVice):
The case of Native Americans

Funder: Supported by a funded PhD studentship

Dates: 2011-Present

Principal Investigators: Dr Lee Machado, Dr Maíra R Rodrigues (Brazil), Dr Ed Hollox (Leicester)

Summary: Gene association studies indicate that human genetic variation is important in susceptibility to disease. This work led by a group in Brazil has developed software to accurately analyse forms of genetic variation in humans implicated in disease processes including autoimmunity and HIV infection.

While Copy Number Variation (CNV) loci are a major component of genomic variation, quantifying the individual CN of a locus and defining genotypes is challenging. Few methods exist to study the population structure of CNV, which is critical in small populations such as Amerindians that may not fit the Hardy-Weinberg model.

We propose a likelihood-based method that simultaneously infers CNV allele frequencies and the population structure parameter f , which quantifies the departure of homozygosity from the Hardy-Weinberg expectation. The accompanying software also infers individual genotypes using information both from the population and from trios, if available. We studied the population genetics of five immune-related CNV loci associated with complex diseases (beta-defensins, CCL3L1/CCL4L1, FCGR3A, FCGR3B, FCGR2C) in 12 traditional Amerindian populations, showing that the population structure parameters inferred for these CNVs are comparable to but lower than for SNPs studied in the same populations.

Availability and Implementation: CNVice is implemented in R and the source code can be found at <http://www.ldgh.com.br/index.php/cnvice>.

For more information, please contact: lee.machado@northampton.ac.uk.

Key words: *Population genetics, copy number variation, immunity*

The Role of Complement Properdin in Tumour Development and Cell Recruitment

Funder: Supported by a self-funding PhD studentship

Dates: 2013-Present

PhD Student: Izzat Al-Rayahi **Supervisors:** Dr Lee Machado, Dr Cordula Stover and Dr Mike Browning

Summary: In recent years, the role of some components of the immune system in the establishment and progression of malignant lesions has been analysed. It has been shown that complement factors (a series of innate immune proteins) are some of the factors which in part determines the outcome of cancer progression. Properdin, as the only positive regulator, amplifies complement activation. Therefore, this project investigates the role of complement protein properdin in the control of tumour growth and inflammatory cell recruitment.

For more information, please contact: lee.machado@northampton.ac.uk

Key words: *Properdin, cancer, complement, immunity*

The Neuropsychology of Visual Hallucination in Parkinson's Disease

Funder: The Marie-Curie Foundation for Young Researchers in Sleep Research; the Grindley Foundation; and the British Academy

Dates: 2007-2013

Principal Investigator: Ksenija da Silva

Summary: The study presents a series of studies investigating neuropsychological aspects of visual hallucinations (VHs) in Parkinson's Disease (PD). The aim of the project was to investigate the risk factors, implicated in hallucinating PD patients. To this end, new instruments were designed to assess the nature of VHs in PD. PD patients with and without VHs, and age-matched normal controls, were assessed on visual memory and executive tests from the CANTAB test battery, alongside tests examining personality factors, sleep patterns, and demographic factors. The findings suggest that VHs in PD are associated with a combination of different factors, particularly aspects of visual

processing and sleep patterns. Results from the five studies are interpreted with the multifactorial models of VHs, suggesting that both VHs in PD stem from concurrent neuropsychological dysfunctions of several processing systems.

For more information, please contact: Ksenija.DaSilva@northampton.ac.uk.

Key words: Visual Hallucinations, Parkinson's Disease, Neuropsychology.

3.6 End of Life/Palliative Care

Enabling people in palliative care and at the end of their life to achieve a good death is hugely important to the person themselves and to their family members and carers. Enacting the choice to live and die according to personal beliefs and expectations, religious and spiritual holds a key to the good death. Such requirements need to be understood and supported by health and social care professionals to ensure that services are tailored to both needs and desires. The following projects unpack the implications of these issues of identity, requirements and the provision of a 'fit for purpose' and see how they better enable the good death.

Sharing Stories for Wellbeing: An Evaluation

Funder: University of Northampton

Dates: April 2015- September 2015

Principal Investigators: Alison Ward, Jane Youell

Summary: Sharing Stories for Wellbeing was set up by a storyteller and biographer and is a series of facilitated workshops for people in palliative care. Their technique is one which allows people to share their life stories in a group workshop. The central objectives of Sharing Stories for Wellbeing are:

- a. To recount and record own life stories;
- b. Provide opportunities to reflect, accept and understand;
- c. Provide opportunities to acknowledge the value of life and the contribution made;
- d. Provide opportunities to make sense of experiences, express emotions and be able to move on.

The evaluation was based on a five weekly programme run at a hospice in May-June 2015, using observations and interviews to understand the way Sharing Stories for Wellbeing sessions were run, as well as their impact on participants, family members

and hospice staff. The workshops created a friendly, relaxed social space for participants to engage in storytelling and engendered a sense of positive wellbeing for those who took part, with participants enjoying the sessions and finding value in attending. Participants were given a sense of autonomy and control in what they shared with the group and found the sessions provided a social occasion where they could share similar interests and enjoy a sense of togetherness. The sessions also provided a way to explore their self-identity, to be valued as a person and not just as a patient.

For more information, please contact: Alison.ward@northampton.ac.uk

Key words: *hospice, palliative care, storytelling, life story*

End of Life Scoping Review

Funder: Canadian Virtual Hospice, Canada.

Dates: July – September 2014

Principal Investigator: Professor Judith Sixsmith

Summary: This comprehensive scoping review was undertaken to assist in the creation of a new tool that will support culturally sensitive end of life care. Multiple factors influence low-uptake of End-of-Life (EoL) care and experiences of poor quality of care services by culturally and spiritually diverse groups. This paper presents findings from an international scoping review of peer reviewed academic publications and grey literature. A systematic search of published and unpublished print and digital material focused on barriers and enablers encountered by people when accessing palliative and EoL care, particularly concerning cultural, religious and spiritual issues. The searches, conducted between July – September 2014, aimed to capture barriers and enablers at the systems, community and personal/family levels. Primary barriers highlighted in the findings include: cultural disconnection between health care providers; persons approaching EoL and family members; under-utilization of culturally-sensitive models designed for improved EoL care; language barriers; lack of awareness of cultural and religious diversity issues; exclusion of families in the decision-making process; personal racial and religious discrimination and lack of culturally-tailored EoL information to facilitate decision-making. This review established that much of the research has focused on decision-making rather than experiential aspects of care. The research found that there were relatively few studies exploring in-depth, the experiences of different cultural and religious persons at the end of their life, limited interventions aimed to improve culturally-sensitive EoL care and interventions largely focused on education for medical

and nursing students and health care providers. This project was funded by the Canadian Virtual Hospice, Canada.

For more information, please contact: J.sixsmith@dundee.ac.uk

Key words: *End of Life, palliative care, religious, beliefs, cultural practices, scoping review*

Exploring the value of providing home-based end-of-life care: A study of the Rennie Grove Night Service

Funder: Rennie Grove Hospice Care

Dates: December 2015 – August 2017

Principal Investigators: Professor Judith Sixsmith, Alison Ward

Summary: Rennie Grove Hospice Care offers care and support for patients diagnosed with cancer and other life limiting illness and their families. Every year through their 24/7 Hospice at Home service, Family Support services and the range of Day Services at Grove House they give thousands of patients the choice to stay at home, surrounded by their families and friends. The Hospice at Home service is unique in the Buckinghamshire/ Hertfordshire area and offers practical nursing care and advice 24 hours a day to help control symptoms and avoid unnecessary hospital admissions, keeping people at home with their families.

Rennie Grove offers access to nurses from 9.15pm-7.15am via face-to-face visit or telephone. It was decided that it would be timely to conduct an assessment of this night service and identify the benefits of running the night service, what impact it has on patients and/or carers/family members and to identify what cost benefits the service may offer. This evaluation used a mixed method design including a carer questionnaire, carer interviews, carer diary, staff interviews and case reviews.

For more information, please contact: Alison.ward@northampton.ac.uk

Key words: *Hospice care, palliative care, night service*

3.7 Educational Interventions

The final section in the brochure related to educational interventions aimed at encouraging and enabling older people to participate in social life and broader aspects of

society through educational provision which takes into account different cultural, national contexts as well as age-related and gendered requirements.

Knowledge is Power, Age ain't Matter

Funder: Erasmus +, European Funding

Dates: 2016-2018

Principal Investigator: Professor Judith Sixsmith

Summary: The purpose of the "Knowledge is Power, Age ain't Matter" project is to provide more opportunities for people aged 50+, making them more active and counteracting social and digital exclusion by developing and disseminating knowhow on how to commence and conduct non-vocational education at higher education institutions within the framework of the Academic University of the Third Age.

Five universities from different parts of Europe are taking part in the project: from Poland – the Poznan School of Banking; from Turkey – Kutahya Dumlupinar University; from the United Kingdom – the University of Northampton; from Italy – the University of Salerno; from Spain – the University of Vigo.

A scoping review was conducted to identify the key issues around social participation through education and community activity for the 50+ age group. This was followed by a series of interviews and focus groups were held in each of the 5 participating European countries to find out about the interests of older people, their thoughts on education, studying and joining activity groups and clubs, as well as the role of the U3A or equivalent. Gender and age related similarities and differences were explored. A questionnaire was devised based on the focus group data and was conducted in a particular area of each participating country. The questionnaire covered interests, hobbies and group memberships, barriers and facilitators to participation as well as thoughts and feelings about learning and education and the U3A. Data collected was analysed and compiled into country specific reports.

The country reports were used to identify 50 courses which could be developed for the age group, taking into account issues of gender. The courses were then developed in outline. Currently, the outline courses are being assessed for development into offers for people aged 50+ in Poland and turkey where the courses will be trialled and evaluated.

For more information, please contact: J.Sixsmith@Dundee.ac.uk

Key words: *Learning and education, participation, 50+ age group, gender, European*

4. Patient and Public Involvement

Public and Patient Involvement (PPI) was a cross cutting theme within the Institute of Health and Wellbeing enabling patients, carers, service users and the public to play an important role in shaping the services and support they access in order to improve their lives. PPI is a consistent feature of research and evaluation, facilitating representation in a fair, transparent and collaborative manner. The Faculty of Health and Society PPI forum, Community Engagement in Research Forum (CERF), meeting termly to ensure that research questions derived from issues identified within the community and/or health and social care sector. Such involvement is critical in recruiting research participants in appropriate and sensitive ways, and establishing advisory groups of representatives of the population to guide the research process. These groups, where possible, also provide critical review of data collection tools in data analysis and dissemination too.

For more information on CERF and becoming involved as a patient or public representative, please contact Jane Taylor, Chair of CERF:
jane.taylor@northampton.ac.uk.

5. Training and Researcher Development

The University of Northampton provides a wide range of researcher development and training opportunities, available both to academic staff of the University of Northampton, and wider colleagues across the health and social care sector.

These include seminar series where speakers share their research with a broad audience of academics, students, medics and clinicians. Speakers are both internal to the University, and external. We also run a variety of research focussed programmes, for example our Doctor of Professional Practice in Health and Social Care.

For further information please contact: michelle.pyer@northampton.ac.uk

6. Final Comments

We hope that you find this brochure both useful and interesting in showcasing the research undertaken in Northamptonshire and involving researchers and other partners based in Northamptonshire. Please do feel free to get in contact with members of the

research team, or any of partners whose work is featured in this brochure if you would like to know more about, or get involved in the work we do.

The University's commitment to research in the area of ageing and older people will continue and will be located primarily in the Faculty of Health and Society, under the Aging Research Centre. For further information about faculty research, please contact Dr. Helen Poole, Deputy Dean of the Faculty of Health and Society (Helen.poole@northampton.ac.uk). At EMRAN, we look forward to seeing how this body of research will develop and to exploring collaborative working in the future.

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