

# Improving healthcare for people with long-term conditions

UWe-book: Number Two



University of the  
West of England

**At UWE our research and development is real and dynamic, identifying problems and providing solutions to issues that really matter. UWE is also the partnership university, working with partners locally, nationally and internationally to deliver excellence in teaching and research.**

Nowhere is this more evident than in our truly outstanding research and development in the area of health and well-being.

Working with a wide range of partners in the health services, industry and other universities, our research is making a real difference. Whether through improving the quality of life of those with long term conditions, or developing technologies and medicines that will lead to better treatments and save lives, our research puts people at its heart. None of our research takes place without a clear plan, and the right partnerships, to ensure that it has a route to impact, including the participation of those people we are aiming to benefit.

This is just a sample of the research in health and well-being at UWE but it gives a flavour of the work and the people who are striving to make a real difference to the quality of our lives. There can be no better ambition.

**Professor Steve West**  
**Vice Chancellor**

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# Fatigue in rheumatoid arthritis

**Sarah Hewlett, Arthritis Research UK Professor of Rheumatology Nursing in UWE's Centre for Health and Clinical Research, leads an internationally recognised research group specialising in rheumatology. Their work on the fatigue associated with rheumatoid arthritis has led to international consensus that fatigue must be measured in all clinical trials of rheumatoid arthritis treatments, putting it firmly on the international research agenda.**

*"This topic was brought up by patients themselves, during our early research to find out what outcomes were important for them. Patients considered fatigue to be an overwhelming problem that was ignored by health care teams, and that they could not manage alone".*

With substantial support from Arthritis Research UK, Sarah's research has sought to understand the nature of fatigue and its impact on patients, and to develop an accurate measurement tool for fatigue and its different dimensions. This has led to the development of successful interventions to help people manage this distressing symptom.

*"New fatigue measurement tools have been developed which have been translated into 34 languages and are in widespread use. We have also successfully tested a self-management programme based on cognitive behavioural therapy. We believe patients with other types of inflammatory arthritis would also benefit."*

The work of the UWE team, and its collaborators in North Bristol NHS Trust, University Hospitals Bristol NHS Foundation Trust, University of Bristol, and many others, has been recognised in many ways, more recently through Sarah's election as a Fellow of the Royal College of Nursing in the UK.

# Understanding chronic pain

**Professor Candy McCabe, Consultant Nurse at the Royal National Hospital for Rheumatic Diseases in Bath, is a Professor of Nursing and Pain Sciences at UWE. She is conducting research that examines the causes and treatment of chronic pain.**

*“Persistent chronic pain results when the nervous system continuously fires pain signals for long periods, often years” she says. “There may have been an initial cause of the pain such as an injury, or there may be an ongoing health complaint, but some people suffer chronic pain with no obvious source. It is this type of chronic pain - pain with no obvious cause - that my research focuses on.”*

Candy's research is funded by an NIHR (National Institute for Health Research) Career Development Fellowship for five years, which is supporting a series of projects focused on understanding the roles of the motor and sensory nervous systems in the perpetuation, exacerbation and relief of chronic pain.

Her research programme is trying to understand the underlying motor and sensory nervous mechanisms that drive chronic pain and why some people appear to be predisposed to develop it. She is also looking to pioneer new therapeutic devices to tackle chronic pain and to bring much-needed relief to potentially vast numbers of patients.

*“This programme of research would not be possible without a number of crucial partnerships that enable me to carry out the research and develop ideas for tackling such an important issue.”*

Organisations involved in the programme include Cardiff University's Brain Imaging Centre, the University of Manchester, the Bath Institute of Medical Engineering and a range of collaborators across Europe.

**Led by Professor Nichola Rumsey, UWE's Centre for Appearance Research (CAR) is a unique, multi-disciplinary research centre that strives to make a real difference to the lives of the many hundreds of thousands of people with appearance-related concerns both in the United Kingdom and across the world.**

*"Thousands of children, adolescents and adults who are visibly different face enormous challenges in our current appearance-oriented society. Many people who are living with a visible difference cope very well with the challenges they face but many others experience considerable levels of concern and distress that can negatively impact on quality of life. It is essential that the psychological and social effects of appearance concerns are studied in order to assess what can be done to help those who are negatively affected to manage everyday problems".*

CAR acts as a focus and centre of excellence for psychological and interdisciplinary research in appearance, disfigurement, body image and related studies by bringing key players together to generate practical outcomes. Although many people report extensive difficulties, some of those affected adapt positively and succeed in minimising the impact of visible difference on their lives.

With support from The Healing Foundation, CAR researchers have established a collaboration of psychologists and clinicians known as the Appearance Research Collaboration which has conducted a three year assessment of the factors contributing to successful adjustment in adults with a range of disfiguring conditions.

*'As a result of this study', states Nicky, 'we have developed a new intervention for psychologists to use with their patients to help them adjust to visible disfigurement and build their self-esteem.'*

# Helping people adjust to visible disfigurement

Around 8 million people aged over 50 years in the UK have some sort of disabling chronic degenerative joint pain. This population is increasing and placing ever greater demands on health services. Dr Nicola Walsh of UWE's Centre for Health and Clinical Research is looking to find more cost-effective ways of tackling this by encouraging long-term self-management that reduces the need to seek professional healthcare input, and helps patients to cope with their disease more effectively.

*"Older people with chronic degenerative joint pain such as osteoarthritis are not considered a priority, in fact these conditions are often incorrectly seen as an inevitable consequence of aging that people just have to live with," Nicola says. "But as our population gets older and heavier it is exactly this group who are going to place more and more demands on health and social care services. Patients are offered very little currently, which isn't acceptable particularly as people are not only living longer but expected to work later in life."*

Nicola's research, funded by Arthritis Research UK and the Chartered Society of Physiotherapy Charitable Trust, is investigating the potential for community-based care delivered by trained exercise practitioners. In partnership with Professor Mike Hurley at St George's, University of London and Kingston University, Nicola has developed an exercise and self-management programme for people with chronic knee pain, delivered by a physiotherapist based in the primary care service, and now hopes that this programme can be provided by exercise practitioners to increase its availability.

The programme has already been included in National Institute for Health & Clinical Excellence (NICE) guidelines on osteoarthritis care and been implemented as standard care in several physiotherapy departments in England and Northern Ireland. Nicola's research was supported by a UWE Early Career Researcher Award that helped her to win more than half a million pounds of funding.

# New approaches to treating joint pain

# Staff Profiles

**Professor Sarah Hewlett** is Arthritis Research UK Professor of Rheumatology Nursing in UWE's Centre for Health and Clinical Research. She spent the first 14 years of her nursing career in clinical care, with many years as a ward sister. She then moved primarily into research, whilst continuing to provide a small clinical practice at Bristol Royal Infirmary, and now heads up an internationally recognised research group specialising in rheumatology - adaption, coping, flare, managing fatigue and an interest in measuring patient reported outcomes.

Sarah and her UWE team of six researchers are based with collaborators from University of Bristol, and University Hospitals Bristol NHS Foundation Trust, who work together to provide integrated rheumatology care, education and research. Her work has been recognised through election as a Fellow of the Royal College of Nursing. "Being elected a Fellow is recognition of a substantial contribution to the nursing profession, which for me, relates to my research

on fatigue, the patient perspective and the importance of involving patients in research", she says. "This award reflects the great work of the whole team, including our patient collaborators".

**Professor Candy McCabe** is a Consultant Nurse at the Royal National Hospital for Rheumatic Diseases in Bath, and Professor of Nursing and Pain Sciences at UWE. Her specialist area is Complex Regional Pain Syndrome and she leads a national service for this condition at the Royal National Hospital for Rheumatic Diseases, Bath. Her multidisciplinary clinical research team work closely with a large number of UK institutions and collaborate with colleagues in Europe and Canada. Her research is supported by an NIHR (National Institute for Health Research) Career Development Fellowship for five years, which will fund a series of projects focused on understanding the roles of the motor and sensory systems in the perpetuation, exacerbation and relief of chronic pain.

As Candy says, "this programme of research would not be possible without a number of crucial partnerships that enable me to carry out the research and develop ideas for tackling such an important issue". Organisations involved in the programme include Cardiff University's

Brain Imaging Centre, the University of Manchester, the Bath Institute of Medical Engineering and a range of collaborators across Europe.



**Professor Nichola Rumsey** is Co-Director of UWE's Centre for Appearance Research, a multi-disciplinary research centre that acts as a focus and centre of excellence for psychological and interdisciplinary research in appearance, disfigurement, body image and related studies. Nicky was an honorary senior lecturer in the Department of Psychiatry and Behavioural Sciences, University College London and is regularly requested for interview by national, overseas, and regional radio and TV programmes. She has played a key role in numerous documentaries and in the recent Trinny and Suzannah programme "The Great British Body". Of her work she says: "The pressures on people to look good are considerable in current society, and can result in psychological distress, and often extreme behaviours. These include changes to diet, extremes of exercise, debt from buying the 'right' clothes and/or beauty products, and increasing numbers seeking cosmetic surgery or treatments. The pressure on those with disfigurements is even more extreme." The UWE Centre

for Appearance Research comprises 30 psychologists who investigate a wide range of topics including the assessment of psychosocial needs of those distressed by their appearance, and developing and evaluating interventions to meet these needs.

**Dr Nicola Walsh** is an Arthritis Research UK Career Development Fellow and a Senior Lecturer at the University of the West of England. Her specialist area is novel interventions and models of care for people with chronic degenerative joint pain and osteoarthritis. The focus of her research is exercise and self-management interventions, and making these widely available within the community whilst ensuring treatment costs are achievable within healthcare budgets.

Nicola is collaborating with a variety of other institutions including St George's University of London, Peninsula Medical School and the University of Bristol to produce high quality, rigorous research that will have a direct impact on patient management. Nicola says, "At UWE there is a supportive environment especially in rheumatology and pain research where we are fortunate to have some internationally-eminant experts and strong partnerships with the health services".

## **Research Series: Health and Well-being**

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