

Life after cancer treatment

Providing long-term support for survivors

Improving balance through dance

Preventing falls in Parkinson's disease patients

Improving quality of life

Giving choice to patients regarding continence products

Exercising safely for active living

Safe exercise techniques and injury prevention

In this issue

Welcome to *Health Sciences New Boundaries*, the University of Southampton's research magazine that showcases the groundbreaking research we do to inform healthcare professionals on best practice. In this issue, you will discover how our research is addressing some of the most challenging issues facing global healthcare systems and the quality of life of their patients.

Health Sciences at Southampton, brings together research and teaching in cancer, palliative and end-of-life care, active living and rehabilitation, and the organisation and delivery of care. Its researchers are committed to the improvement of health outcomes and the transformation of healthcare delivery through education for all.

On page four you can read about how our researchers are conducting the first study of its kind to gain a better understanding of the experiences and needs of cancer survivors in order to inform policy on the future care of patients.

Researchers in Health Sciences are continuously tackling the healthcare issues that truly matter. On page 10 discover how dancing can help to slow down the symptoms of neurological conditions, while on page 12 you can find out about our revolutionary research into new and existing continence products to aid over 200 million people worldwide who are living with incontinence.

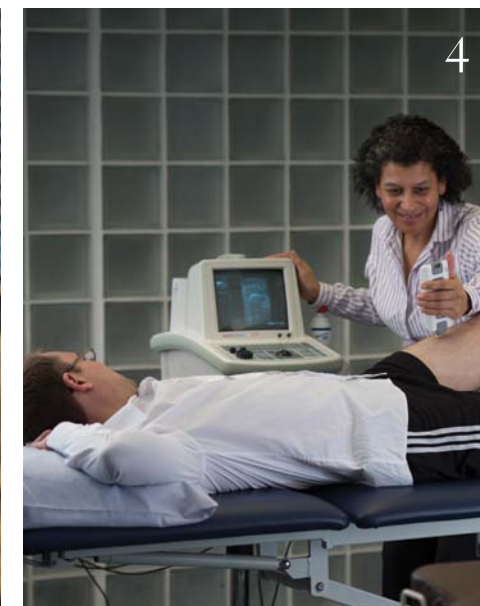
Arthritis is a common condition that causes pain and inflammation within a joint. On page 16, read how our researchers are educating people on ways to exercise safely in order to prevent the onset of osteoarthritis in future life.

For more information, visit
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We appreciate your feedback about *Health Sciences New Boundaries*.

If you have any comments or suggestions, please do send them to healthsciences@southampton.ac.uk



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Life after cancer treatment

Researchers from the Macmillan Survivorship Research Group (MSRG), funded by Macmillan Cancer Support, at the University of Southampton, have developed the first study of its kind looking at the experiences and needs of people after primary treatment of colorectal cancer.

Susan Restorick-Banks (left) CREW study participant talks to Claire Foster and Kim Seymour about the study



“People who are going through this experience are getting a chance to step forward and say these are my experiences. We can take that information and improve services in the future and that’s what it is all about.”

Kim Seymour,
CREW Researcher



The CREW study follows participants over a number of years to establish the natural history of their recovery

Advances in prevention, diagnosis and treatment mean more and more people are surviving cancer; it is estimated that around two million people are living with, or beyond, cancer in the UK, with this figure expected to double by 2030.

While increasing cancer survival rates are to be celebrated, the experiences and needs of those who have completed their treatment have been relatively neglected until now.

Influencing recovery

The University of Southampton has a long standing history of cancer research and has established the ColoRECTal Wellbeing

(CREW) cohort to look at a number of factors influencing recovery which takes into account the disease itself, the level of treatment patients receive, the type of problems they are experiencing, the support available to them and the range of coping skills they have.

Factors influencing recovery studied within the research include the time it takes a patient to return to feeling 'well', the length of time symptoms of treatment last and the range of things people can do to help return to 'normal' more quickly, explains Dr Claire Foster, Chief Investigator and Head of MSRG.

"The idea of the CREW study came from some research we did several years ago, also funded by Macmillan, involving cancer patients and people that were affected by cancer, across the UK. We asked them what was important to them in the sorts of research that we should be doing" says Claire. "And the priority for them was for us to start thinking about the impact of cancer on everyday life."

The sorts of questions that the study asks participants range from how they cope with everyday tasks, how side-effects and consequences of treatments impact on their lives, the kind of support that they and their families get from healthcare services, and how confident they feel in coping and self-managing their condition.

Informing policy

"People who are going through this experience are getting a chance to step forward and say: 'these are my experiences'. We can take that information and improve services in the future and that's what it is all about," explains Kim Seymour, CREW Researcher.

Results from this rigorous theory-based study will, for the first time, inform healthcare providers and professionals across the country about what helps or hinders rapid and effective recovery and who has the confidence and ability to manage their own challenges. It will also help identify areas for the development of interventions to aid the recovery process of those who may be at risk of experiencing problems.

More than 1,000 participants have been recruited to the study. Cancer tends to affect people in later life, so the average age of people in the cohort is 68. "So many participants are retired. We are also asking whether they are living with other conditions such as arthritis and heart disease, that might complicate their recovery," says Claire.

Make a difference

One of the CREW participants is Susan Restorick-Banks from Totton in Hampshire. Susan was diagnosed with a tumour in her colon in early 2011. Her treatments have included surgery to remove the tumour, radiotherapy, and six months of chemotherapy. She says: "It's been really important for me to participate in this study. By speaking out and giving my views, I feel I'm contributing to the wellbeing of future cancer survivors and it's really the only way researchers have of finding out how people like me cope."

Colorectal cancer has been chosen as the focus for the study as it is one of the most common cancers in the UK. It affects both men and women and can involve all three forms of basic cancer treatment: surgery, chemotherapy and radiotherapy.

"While I've had a very supportive network around me, and have continued to enjoy life throughout my treatment, I know that other people going through cancer treatment can experience things very differently," adds Susan.

Kim explains that the MSRG is working with 30 cancer centres from across the UK. "We are working with 30 cancer nurses in those hospitals that are recruiting patients locally. It is really important that we follow people over time, so the survey comes back to them at a number of different time points so we can look at how things change."

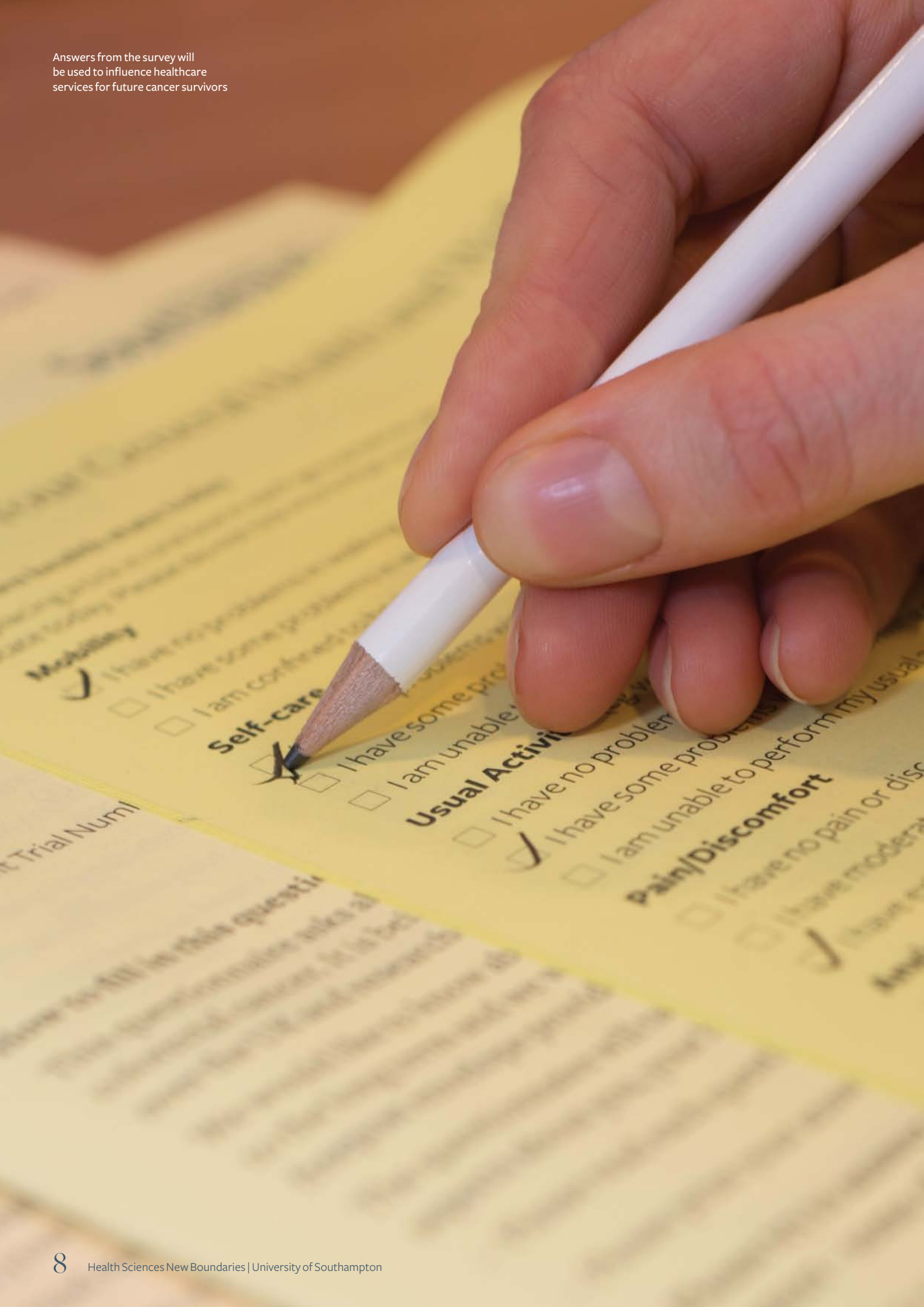
Informing patients

The longitudinal study follows participants over a number of years to establish the natural history of their recovery and wellbeing to assess how quickly they recover after colorectal cancer.

"At the moment, we don't really know what the pattern of recovery is for patients. A real strength of this study is that we are asking people to tell us how they feel even before they have started their treatment, in order to map a typical course of recovery of health and wellbeing," says Claire. ▶

"The CREW study is important in helping us learn more about bowel cancer patients and their different needs after treatment. The information gained through research will help us support and improve the lives of the increasing numbers of people who are living with and beyond cancer."

Ciarán Devane,
Chief Executive of Macmillan
Cancer Support



“This typical course of recovery could then inform patients about the recovery process and prepare them for the sorts of issues that they might face along the way.”

Globally, aftercare for patients that have a diagnosis of cancer is changing because there are limited resources to support people and yet the number of survivors is growing year-on-year. The CREW study is therefore also looking at how people self-manage their conditions. “We want to pinpoint when people are less confident to deal with their symptoms and other problems they may be facing, and how much they have to manage themselves with the continuing changes in aftercare systems,” says Claire.

International impact

The Southampton MSRG collaborates with other researchers internationally, so that comparisons can be made between different groups of patients across the world. Claire believes that the CREW study will have international significance because colorectal cancer is the most common cancer that affects both men and women. “Some of the experiences of our participants will be similar to people in other healthcare settings; it is not just the impact on the NHS, it is the impact of healthcare systems globally and the impact on the patients’ everyday life.”

Professor Jessica Corner, Dean of Health Sciences at the University of Southampton and Chief Clinician of Macmillan, says: “As a leading health sciences research-based faculty, and the only research unit funded by Macmillan, we are extremely proud to be undertaking this radical new research. Our ultimate joint-aim is to help improve the lives of people with cancer by informing healthcare providers and professionals in

practice which help care for the two million plus cancer survivors across the UK. Recruiting more than 1,000 patients is a real milestone for the study and we are incredibly grateful to Susan and all those participating and involved in the research.”

The study forms part of a programme of research projects being undertaken by Health Sciences researchers from the MSRG. This includes creating and testing an online intervention to support self-management of fatigue after treatment.

Ciarán Devane, Chief Executive of Macmillan Cancer Support, says: “Macmillan is committed to understanding and using evidence, to help the two million people living with cancer in the UK. Work with our academic colleagues is helping us to increase our knowledge and will allow us to develop our services in the future.

“The CREW study is important in helping us learn more about bowel cancer patients and their different needs after treatment. The information gained through research will help us support and improve the lives of the increasing numbers of people who are living with and beyond cancer.”

“As a cancer survivor, I don’t want to be wrapped in cotton wool. I want to enjoy the life and it is me the person that is controlling the cancer and not the cancer controlling me. Answering the questions in the survey really helped me understand not just what I might be feeling, but what other people might be feeling as well, so I perhaps can support others,” says Susan.

For more information about the CREW study and the work that the Macmillan Survivorship Research Group carry out, visit www.soton.ac.uk/msrg

“A real strength of this study is that we are asking people to tell us how they feel even before they have started their treatment, in order to map a typical course of recovery of health and wellbeing.”

Dr Claire Foster,
Head of the Macmillan Survivorship
Research Group



Improving balance through dance

It is estimated that 6.3 million people worldwide have Parkinson's disease (PD). Currently there is no cure – treatments are focused on reducing the symptoms of the disease. Ann Ashburn, Professor of Rehabilitation at Southampton, explains how her fall prevention research complements existing treatment methods.

Q *What does your research involve?*
My research involves interventions and activities that can help people who have PD to avoid falling. The risk of falling among people with PD is a real issue as PD is a progressive neurological condition and can lead to serious injury and in some cases death.

Q *Why is it important to do this research?*
In one year, a third of people over 65 will have a fall, but two thirds of people with PD will fall over in the same period. After an initial fall or if people start to be unsteady, they could develop a fear of falling which will then have an impact on their mobility. With impaired mobility comes more reliance on a carer or healthcare service and so improving this will increase confidence, but also reduce costs.

Q *Can you explain about your ballroom dancing study?*
We are running a feasibility study on the effects of ballroom dancing on the mobility of people with PD. Through this enjoyable, social activity we are hoping to improve people's confidence, balance and mobility.

People with PD tend to turn in a rigid way, where they turn their head, neck, upper body, pelvis and legs at the same time, making them unsteady. Dancing involves turning and stepping to a rhythmical beat from the music, so we are investigating whether asking people to dance in-hold with a partner, will help to improve their mobility. The study involves inviting people who have been diagnosed with PD to attend dance classes twice a week for 10 weeks. We will measure their mobility at the start of the study and at three and six months to test the feasibility of providing dance classes and to measure the effects. From the results, we then hope to increase the study to a nationwide clinical trial.

Q *What impact will the dance study have on society?*
The long-term implications are that in the future this might become something that people can participate in through their PD local groups and could become an encouraged activity. It might then enhance treatment regimes. The principles behind the dancing, the fact that people are dancing to rhythmical

music, that people are having to move their feet, turn their bodies and take big steps – are carefully chosen to enhance what clinicians are doing during rehabilitation.

Q *What other projects are you involved in?*
In addition to the ballroom dancing study, we have also received a large grant of £2m from the National Institute for Health Research (NIHR) Health Technology Assessment (HTA) Programme for a clinical evaluation trial, to look at the effects of exercises and fall avoidance strategies on people with PD. In previous studies we have shown there are benefits for people with less severe mobility problems when they exercise and adopt strategies for reducing fall risk.

The clinical trial will involve 600 people from four local areas and will investigate how exercises to strengthen the lower limbs, trunk and balance training affect overall confidence and mobility. The idea is to tailor the exercises to the participant and provide them with a CD to take home, so they can carry on benefiting after the study finishes. Participants will be asked to keep a diary of their experiences and falls throughout the process and we will monitor their general levels of activity over the period.

We hope the results of this study will have a major impact on future healthcare policy.

Q *What challenges do you face in your area of research?*
The biggest challenge is the nature of PD as a progressive disease. Research into rehabilitation is particularly problematic as it is difficult to measure the events such as falls that we want to influence. Long-term monitoring of people with a condition that deteriorates is also an issue and recording accurately when falls occur is difficult as we have to rely on patients or carers to provide the information.

Q *What sparked your interest in this topic?*
As a physiotherapist, I have treated people with PD and the abnormal movement that comes with the condition is something that interests me. Improving this could lead to a more stable posture and stability for many people.

Q *Is multidisciplinary collaboration important?*
Within this programme we work with occupational therapists, and physiotherapists, but we also acknowledge that part of the problem is that PD patients have concentration problems. We are therefore looking at cognitive behaviour as part of our research. In future studies, we also hope to work with engineers to develop sensors that can be installed in people's homes in order to give us vital information about fall events.

Q *Why is Southampton a good place for you to do your research?*
Southampton has enabled me to build up a very successful research programme where I have a team that has worked with me for many years. We are all experts in balance control and fall prevention in people with PD and stroke, and ultimately try to use that expertise to improve the quality of life of many people.

For more information on Ann's research, visit www.southampton.ac.uk/healthsciences/annashburn

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Improving quality of life

In 1998, the World Health Organization (WHO) reported that bladder control problems affected more than 200 million people worldwide and today bladder and bowel control problems affect between three and six million people in the UK alone. Researchers at Southampton are investigating the effectiveness of different continence products in order to inform healthcare services and patients and to enhance user quality of life.

Interactive information

Professor of Continence Technology, Mandy Fader in the Rehabilitation and Health Technologies Group in Health Sciences, and her team, are developing a website that provides information about the range of continence products available on the market for patients. “We invite user tips and comments on product designs and supply evidence on how useful and effective specific types of products are, so users can get an idea of what may work for them,” says Mandy.

The joint project with the International Continence Society and the International Consultation on Incontinence provides patients with links to the different support organisations in their countries that can give them advice on issues relating to incontinence. “We believe this interactive website will be the best way of getting the relevant information out to healthcare professionals and patients allowing them to change the way they cope and manage incontinence,” says Mandy.

Mandy’s work has focused on testing and evaluating the multitude of incontinence products available to the public on behalf of NHS organisations including the Medicines and Healthcare products Regulatory Agency (MHRA). Products range from absorbent pads and catheters, to devices specifically for men such as clamps and sheaths. “The problem is that continence products are not subject to the same stringent regulations as drugs, so it is easy for a company to produce a device, but there are few standards to qualify how effective they are or whether they represent value for money,” says Mandy. ▶



Bladder and bowel control problems affect between three and six million people in the UK alone

“Our studies aim to give patients the ability to choose products that suit their needs, as well as giving healthcare professionals the information they need to establish improved continence services tailored towards the patient.”

Mandy Fader,
Professor of Continence Technology

Informing healthcare providers

The most common incontinence product group on the market is absorbent pads. In 2008, the team compared all types of absorbent pads for men and women with both light and heavy incontinence. “One of the most important findings was that although many pads are designed to be unisex some pad designs work better for men than women and vice versa. Men in particular have needs that are not well met by current products which are based on babies’ nappies or women’s menstrual pads,” Mandy explains.

In the UK, the NHS provides patients routinely with absorbent pads via a district nurse. From previous studies, the team knows that most patients need a combination of products depending on the activities they are performing, and this suggests the NHS should be looking at a system whereby nurses offer patients more than one type of product. Mandy is heading up a pilot study looking at personal budgets for buying absorbent pads. Participants are given an amount of money that they can spend on products, allowing them to choose to use combinations of products to suit their needs. “They are also given the option to buy pads at the same price as the NHS buys them,” she says.

“If the study is successful, it will change the way pads are offered to the public, from a

system that is nurse driven, to a more patient-driven, flexible process whereby patients choose products based on testing samples and being offered advice on situations under which they are likely to work best,” Mandy says.

Improving lives

In another complementary study, the team surveyed over 100 women with incontinence and are now starting to interview men with the condition, to compare the issues that affect quality of life when coping with incontinence. Results show that there are a lot of shared issues between men and women, like leakage, smell and embarrassment, but men also have additional worries.

“Due to more men surviving prostate cancer, the number of men with incontinence has increased greatly. Men are also typically more than 50 per cent wetter than women if they suffer from heavy incontinence, so as a result they might experience more leakage and embarrassment,” says Mandy. “It is therefore vital that support is directed to men when they need it and we are working with healthcare systems to implement this.”

Improving devices

Catheters are another option for patients with incontinence and can be used as a long term solution to the problems. However, long-term indwelling catheters have their own

associated problems, such as blockage and the risk of infections.

“We are studying over 700 patient’s notes and their use of catheters over a period of a year to see what problems they had, how often they had these problems and how they coped with them,” explains Mandy. “Our aim is to develop a quality of life tool to help assess and monitor long-term catheter users and measure improvements to catheter management.”

The National Institute for Health Research are intending to fund the team to investigate the use of reusable catheters for intermittent use (passed into the bladder and then removed after urine drainage) that can be washed and used by the patient multiple times. “Our research indicates that a mixed model may work best – if people have reusable products as well as disposable ones they have the choice and ability to choose their own solutions to fit around their lives.”

Testing new materials

In partnership with researchers at University College London, Mandy and her team are also involved in testing new absorbent materials for new pad products. “We are investigating a variety of absorbent materials including new super-absorbent polymers in order to advise industry partners on improving this technology,” explains Mandy.

Working in partnership with Dan Bader, Professor of Bioengineering and Tissue Health in Health Sciences, Mandy is also investigating the effects of wearing incontinence devices and products on skin health. Specifically this means analysing how water loading on the skin can lead to pressure ulcers.

“The main focus of my work is on mechanically induced skin damage,” says Dan. “If patients are incontinent and have wet skin, they are more likely to get skin damage than if they have dry skin, and this is where mine and Mandy’s work overlaps,” he explains.

“Using our environmentally controlled room, we can look at water loading on the skin in a controlled way. If the stratum corneum of the skin gets saturated with water from urine, it is more vulnerable to friction and shear,” Mandy explains. “We analyse how people’s wet skin reacts to different support surfaces such as a mattress, spine board or just when they are sitting down, in the room, as we can control the humidity, temperature and pressure” says Dan.

“One of the ways my research aims to identify the early signs of mechanically-induced damage to the skin is to look at biomarkers in skin samples that can indicate problems before they occur. I also look at physiological markers – the way blood flows in the loaded area of skin and how the tissue in the area

metabolises, as an indicator as to whether the tissue will break down under prolonged loading,” Dan explains.

At present, the team is only analysing the skin of healthy volunteers, but Dan hopes that in the future they will be in a position to work with patients that are at risk of pressure ulcers, particularly those that are immobile or have limited sensation. “We hope to be able to inform healthcare providers on how to identify those at risk of pressure ulcers so they receive the appropriate surfaces for support in beds and chairs. We also hope to advise the makers of continence devices how they can improve their designs so that there is less leakage, so users’ skin stays dry,” says Mandy.

All the research carried out by the team has the overall aim of improving the quality of life of people that cope with a very common condition that still has a great stigma attached to it. “Our studies aim to give patients the ability to choose products that suit their needs, as well as giving healthcare professionals the information they need to establish improved supportive services tailored towards the patient,” concludes Mandy.

For more information on the website created by Mandy and her team, on continence products, visit www.continenceproductadvisor.org

For more information on this research, visit www.southampton.ac.uk/healthsciences/mandyfader

Exercising safely for active living

Maria Stokes, Professor of Musculoskeletal Rehabilitation at Southampton, explains how her research helps to minimise injuries sustained during exercise, which can lead to osteoarthritis later in life – a disease that affects around 10 million people in the UK, causing pain and inflammation in joints.



Q *What does your research involve and what are its main aims?*

The overall aim is to keep people as active as possible, for as long as possible. We use various laboratory tests of a person's ability to carry out functional activities, which helps us develop exercise programmes to protect joints from damage and improve function after injury.

Our work involves finding ways to enable the general public to exercise safely and minimise injury, but we also work with elite athletes. Heavy training schedules and injuries place significant demands on athletes' bodies. It is well known that footballers are at high risk of developing arthritis. Working in partnership with Premiership football clubs, such as Southampton FC, we aim to help players to perform well and stay injury-free.

Q *How important is this research?*

People are living longer and the cost on global healthcare systems is set to go up if people are not active and independent. Coupled with this, injuries sustained during exercise can lead to osteoarthritis later in life. This is a big issue – according to the World Health Organization, osteoarthritis is already one of the 10 most disabling diseases in developed countries. If we can educate people at an early age about leading an active lifestyle incorporating safe exercise, then arthritis in later life might be reduced.

Q *Can you explain more about your work and the impact on society?*

Much of our work requires sophisticated laboratory equipment to analyse how people move and how muscles work. Using motion analysis equipment, we can track body movement. We use ultrasound imaging to measure the size of muscles to see which ones need retraining. This technique is particularly useful for letting the patient see their own muscles contracting on the screen, which helps them re-learn how to use their muscles effectively.

In terms of our impact on society, we aim to contribute to improving people's lives by finding ways of making exercise as safe and effective as possible. Our research using ultrasound imaging is already having an impact on physiotherapy practice, as more are using it to help assess and treat patients.

Q *Can you tell us more about a recent project that you are proud of?*

We have been testing a new device in partnership with Myoton Ltd (London) that shows the mechanical properties of muscles. Muscle tone increases in people after a stroke, and is usually measured by moving the limb and feeling the resistance, but this is very subjective. The Myoton device gives a gentle tap to the muscle that makes it oscillate and measurements are then made automatically, of the degree of muscle tone and other properties, such as stiffness and elasticity. Our initial work was to test how reliable the device is and the results are really promising. Four MSc students and a PhD student presented their findings at national conferences. In the future, this technology could be used in practice for people with sports injuries, back pain and neurological conditions, such as stroke and Parkinson's disease.

Q *How do you see your work informing healthcare policy?*

We hope that our work will inform future healthcare policy on rehabilitation after injury, but more important than this is prevention of joint damage in the first place. We are developing an 'MOT' testing kit for clinicians to use in the field to inform patients what their musculoskeletal health status is, how to exercise safely to improve it and how to prepare for that exercise.

Q *What do you see as your biggest challenge in your research area?*

The UK government has done a lot of work setting up initiatives to get people more active, but with more activity we all have the potential to get more injuries. Being injured can lead to people becoming less active. There are a lot of previous studies that show that exercise is good for you, but one of our biggest challenges is to find ways to motivate people to become active through a lifestyle choice and maintain it, not just see it as something you do in the short-term.

Q *What sparked your interest in the topic?*

I have always been interested in exercise and activity, but when I was training as a physiotherapist, I became interested in treating sports injuries, and more recently in preventative techniques to reduce injury. This has led on to my current research in this area and partnerships with elite sports organisations.

Q *Are multidisciplinary collaborations important in your research?*

They are absolutely vital. Within Health Sciences we have a strong team of physiotherapists, occupational therapists, podiatrists, sports scientists, engineers, psychologists and nursing colleagues. Locally, we have very close links with Medicine and Engineering Sciences through our active involvement in the Southampton Musculoskeletal Biomedical Research Unit (SMBRU). An exciting development is the part-time secondment to Health Sciences of a Senior Lecturer from Engineering and the Environment, at the University, Dr Alex Forrester. He is working to develop major collaborative projects.

Q *Why is Southampton a good place to do this type of research?*

I moved to Southampton because of its reputation of strong working relationships between health science and engineering researchers. There is a healthy interdisciplinary environment here and various initiatives, such as the SMBRU and Institute for Life Sciences, provide great opportunities for links with leading researchers, both here and at other national and international institutions.

For more information on Maria's work, visit www.southampton.ac.uk/healthsciences/mariastokes



Nurse satisfaction survey

A survey of nearly 34,000 nurses across Europe has revealed that the decrease in nurse staffing levels and workforce issues have a significant impact on both staff satisfaction levels and patient care.

The English arm of the international RN4CAST study, led by researchers at the University of Southampton and the National Nursing Research Unit at King's College London, surveyed nurses in over 400 general medical and surgical wards at 31 Trusts, as part of a research programme looking at links between nursing workforce issues and patient outcomes across 15 countries.

Professor Peter Griffiths, Chair of Health Services Research at Southampton, explains that the survey highlights how staff shortages can affect patient care because some tasks, including talking to patients and monitoring their condition, are omitted due to lack of time and resources.

"The survey showed that nurses in England had high levels of stress and job dissatisfaction compared to nurses in other European countries. It seems that they can't always perform their job to the level they'd like", Peter says. Less than half of the nurses who responded to the survey felt that they receive praise and recognition for good work and just over a quarter stated that they receive verbal abuse from patients or their families a few times a month.

"This highlights both the importance and potential benefits of both managers and the public supporting nurses to ensure that they can deliver excellent care in the face of these challenges," Peter adds.



People not patients

A researcher at Southampton in collaboration with an artist at the University of Bradford and people with dementia has developed a brand new educational resource for raising awareness about the 820,000 people in the UK currently living with dementia.

The No Limits | Re-imagining Life with Dementia Educational Resource aims to challenge misperceptions about people with dementia and to start conversations about the strengths and hopes of men and women with this condition.

The Educational Resource is the culmination of a pioneering two-year research study by Dr Ruth Bartlett from Southampton, on the rise of campaigning and 'activism' amongst British people with dementia and is funded by the Economic and Social Research Council.

The Resource, which includes a short documentary film, is for any individual or group with an interest in dementia or whose role it is to educate others about people with dementia. It covers a range of topics from active citizenship, seeing dementia as a journey, to end-of-life and advance planning.

"The ultimate aim of the original study was to challenge, inform and educate a wider community about the strengths and hopes of those living with dementia, including younger people. I am delighted that we are now at the point of being able to distribute this brand new educational resource amongst individuals and groups working within the community and look forward to igniting a longer-term debate on the issue," Ruth says.



Implementing healthcare

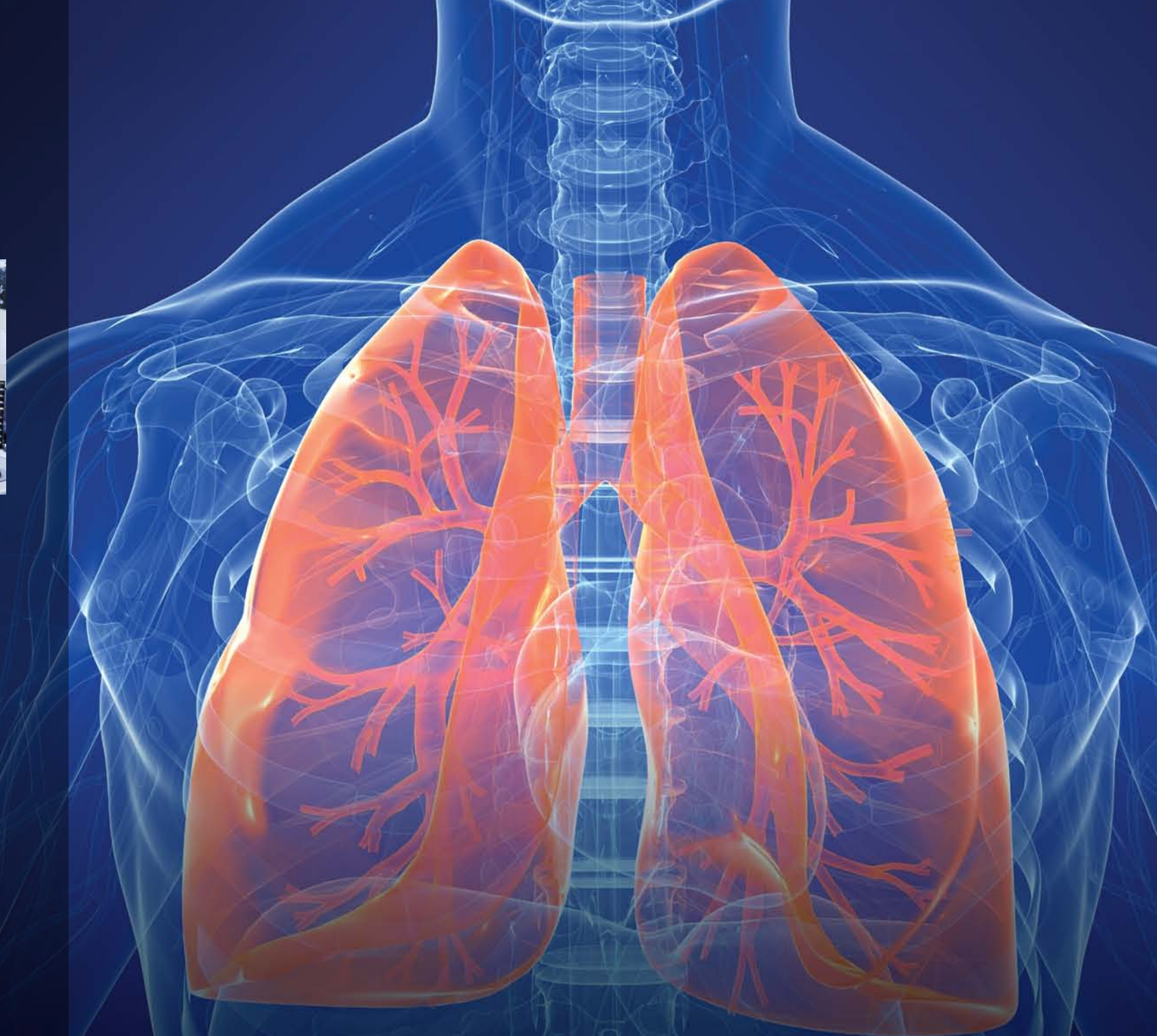
Researchers at Southampton are helping healthcare providers to implement new health technologies such as large MRI scanners, successfully in hospitals and clinical practice, with minimal disruption to patients.

Innovative technologies promise better ways of organising and delivering treatment, improvements in the cost-effectiveness of services, and reductions in the burdens of illness. Most research in this area focuses on the outcomes of innovations – measuring their impact and exploring their effects. But Professor Carl May and his team in Health Sciences have developed a web-based tool kit to help healthcare providers think through implementing innovations in practice.

With funding from the Economic and Social Research Council, the team has incorporated robust conceptual models of many elements of implementation processes in to a website (www.normalizationprocess.org). They set out the variables providers need to consider in a simple way.

"We know that healthcare professionals have used the web tool to plan and design interventions and that using the technology, they have been able to anticipate and solve implementation problems before they have happened," says Carl.

The website has been very well received internationally and has had over 45,000 visits worldwide, including interest from the USA Department of Health and Human Services. "It has also been used to reframe public health in eastern Toronto, Canada, and to look at depression care in Melbourne, Australia. So there is a lot of international excitement about it," Carl adds.



Revolutionising oxygen treatments

Research at Southampton is revolutionising oxygen treatments used at home, by developing lighter, more user-friendly oxygen cylinders that allow patients with chronic obstructive pulmonary disease (COPD) to manage their condition more effectively.

According to the World Health Organization, over 64 million people worldwide suffer from COPD, a life-threatening lung disease that interferes with normal breathing. In the UK about 85,000 people need oxygen therapy and are unable to leave their homes due to reliance

on large cylinders and compressor devices. NHS portable systems have historically been too heavy for patients to carry.

Dr Anne Bruton, Reader in Respiratory Rehabilitation at the University and partners, Luxfer Gas Cylinders, FXK Development and Graeme Maisey Ltd, have developed the Intelligent Oxygen System (IOS) with funding from the National Institute for Health Research. The new oxygen cylinders are significantly smaller and lighter than traditional cylinders; incorporating the

pressure reducing components inside the cylinder casing, so the device looks less medical.

System performance has not been sacrificed – the cylinders can last up to eight hours, which is longer than current portable systems. "With a more portable cylinder, patients can leave their homes while adhering to their oxygen prescriptions, which will ultimately improve quality of life," explains Anne, "The next step is to test IOS in clinical trials."

Personalised healthcare support at end-of-life

Research at Southampton is analysing the burden on patients of managing multiple illnesses, in order to influence the distribution of end-of-life care services.

As responsibility for managing care is increasingly assigned to the patient, at end-of-life the burden of multiple conditions and complicated treatment regimes could cause stress similar to the burn-out we see in people with high-pressure professions.

Dr Katherine Hunt, Senior Research Fellow in Health Sciences, is running a study of patients

over 70 with end-stage heart failure and at least two other diseases, to analyse how they manage their conditions, how their capacity to deal with these conditions changes over time and how their personal circumstances, such as family support, helps them manage the burden of treatment.

“The aim of the study is to identify the point when patients need healthcare service support to take over their care. It is about rationalising treatments and reducing the impact of medicine on their lives, so they can enjoy the time they have left,” says Katherine.

It is hoped that the research will inform policy relating to the distribution of end-of-life care services, in the future. “We need to allocate services based on patient-perceived need rather than prognosis or diagnosis. It might be that patients with family support and good coping mechanisms require less support, whereas more isolated vulnerable patients need more. We need a personalised service,” Katherine adds.



Measuring movement skills

Researchers at Southampton are developing a suite of quick, relatively cheap and easy tests that clinicians can use to assess mobility and skills in carrying out tasks (motor function) in people as they get older.

As people live longer, age-related problems associated with mobility and balance become more of an issue. But at present, there are few clinically useful tests to measure motor function to detect changes in health and wellbeing, such as premature deterioration with ageing.

PhD student, Sandra Agyapong-Badu (funded by the Ghana Education Trust Fund) and her supervisors Professor Maria Stokes and Dr Dinesh Samuel, in the Rehabilitation and Healthcare Technologies Research Group in Health Sciences, are analysing balance, muscle strength, muscle size, mechanical properties of muscle, lung function, hand coordination, speed of walking and ability to climb stairs, in participants from the local community.

Using cutting-edge technology, Sandra is testing 90 participants aged between 65 and 90, and 50 participants aged between 18 and 35, to compare motor function and how it changes with age. “One of the devices, the Motor Task Manager, developed by ETT Technology in Italy, measures motor coordination by analysing a person’s ability to react to targets that are presented to them,” says Sandra.

“In the future, we hope that these tests will be used by healthcare professionals to build up motor function histories of their patients. They could be used to help indicate the need for treatment to prevent someone losing their physical independence” she adds.

Relief from arthritis

Researchers at the Southampton aim to improve the health and mobility of those suffering from Rheumatoid Arthritis (RA) in the feet.

RA is the second most common form of arthritis in the UK, affecting almost 600,000 people, which results in the destruction of joints around the body caused by inflammation. Forefeet often contain some of the first joints to be affected and those with the condition often feel like they are walking on marbles.

The FeeTURA 3 study funded through a partnership between Solent NHS Trust and Health Sciences, will undertake a programme of interlinking research which helps identify, measure the impact and assess the best intervention for forefoot complications in people suffering with RA.

Led by Senior Lecturer for Advanced Clinical and Expert Practice, Dr Catharine Bowen at Southampton, localised foot health intervention treatment such as targeted steroid injections and global pharmaceutical interventions of biologics will be used, during participants’ assessments carried out at the NIHR Wellcome Trust Clinical Research Facility (WTCRF) based at Southampton General Hospital.

“Although more common in the UK than leukaemia and multiple sclerosis, awareness of the severity of rheumatoid arthritis is limited,” says Catherine. “Our linked study aims to significantly improve the lives of those affected by the condition in their forefeet, reducing the severity of the symptoms including pain, inflammation, poor sleep, fatigue and depression.”

EU-WISE

Researchers at Southampton are looking at how social networks in the community can help patients’ self-manage chronic illnesses such as diabetes.

EU-WISE is designed to focus on understanding capabilities, resources, and changes in health-related practices in community and cultural contexts across Europe and will tackle the tricky problem of how to sustain and engage people with long-term conditions and limited resources in living healthy and fulfilling lives.

The €2.9m FP7 project, is being coordinated by Professor Anne Rogers at Southampton together with Dr Ivo Vassilev and Dr Anne Kennedy Senior Research Fellows and brings together six European countries to focus on the resources and relationships within peoples’ personal communities, in order to develop interventions that are more fit-for-purpose for engaging with people who live in deprived circumstances.

“We know that lifestyle choices such as giving up smoking and losing weight are not done on your own – the support for these tasks is transmitted through social networks,” says Anne. “We want to first understand what networks there are in place already for people living in disadvantaged circumstances, establish points of contact in these so that patients can not only receive advice on the self-management of their condition, but connect up with other resources which help everyday living with a chronic condition, and identify areas where support might be lacking and develop interventions to bridge this gap.”

For more information on these stories, visit www.southampton.ac.uk/healthsciences

A selection of recent papers published from Health Sciences



D. Samuel, P. Rowe, V. Hood, A. Nicol

The relationships between muscle strength, biomechanical functional moments and health-related quality of life in non-elite older adults
Age and Ageing 2012 Vol. 41 pp. 224-230

L. Hooper, C. J. Bowen, L. Gates, D. J. Culliford, C. Ball, C. J. Edwards, N. K. Arden

Prognostic indicators of foot-related disability in patients with rheumatoid arthritis: Results of a prospective three-year study
Arthritis Care & Research 2012 Vol. 64 pp. 1116-1124

T. Chowdhury, S. Arghandawi, J. Brand, O. Akanji, D. Bader, D. M. Salter, D. A. Lee

Dynamic compression counteracts 1L-1β induced inducible nitric oxide synthase and cyclo-oxygenase-2 expression in chondrocyte/agarose constructs
Arthritis Research & Therapy 2008 Vol. 10 R35

L. Brindle, C. Pope, J. Corner, G. Leydon, A. Banerjee

Eliciting symptoms interpreted as normal by patients with early-stage lung cancer: Could GP elicitation of normalised symptoms reduce delay in diagnosis? Cross-sectional interview study
BMJ Open 2012 Vol. 2 pp. e001977

J. Elliott, A. Fallows, L. Staetsky, P. Smith, C. Foster, E. Maher, J. Corner

The health and well-being of cancer survivors in the UK: Findings from a population-based survey
British Journal of Cancer 2011 Vol. 105 S11-S20

L. H. Aiken, W. Sermeus, K. Van den Heede, D. M. Sloane, R. Busse, M. McKee, L. Bruyneel, A-M. Rafferty, P. Griffiths, M-T. Moreno-Casbas, C. Tishelman, A. Scott, T. Brzostek, J. Kinnunen, R. Schwendimann, M. Heinen, D. Zikos, I. Strømseng Sjetne, H. L. Smith, A. Kutney-Lee

Patient safety, satisfaction, and quality of hospital care: Cross sectional surveys of nurses and patients in 12 countries in Europe and the United States
British Medical Journal 2012 Vol. 344 pp. e1717

O. Minton, P. Stone, A. Richardson, M. Sharpe, M. Hotopf

Drug therapy for the management of cancer related fatigue
Cochrane Database System Review 2008 Vol. 1 pp. CD006704

G. J. Hollands, M. Hankins, T. M. Marteau

Visual feedback of individuals' medical imaging results for changing health behaviour
Cochrane Database System Review 2010 1

A. Molassiotis, C. Bailey, A. Caress, L. Brunton, J. Smith

Interventions for cough in cancer
Cochrane Database System Review 2010 Vol. 9 pp. CD007881

M. Fader

Absorbent products for urinary/faecal incontinence: A comparative evaluation of key product designs
Department of Nursing and Midwifery, University of Southampton, UK 2008

J. H. Burrridge, R. Turk, S. V. Notley, R. M. Pickering, D. M. Simpson

The relationship between upper-limb activity and impairment in post-stroke hemiplegia
Disability and Rehabilitation 2008 Vol. 30 pp. 1-9

E. J. Boger, S. Demain, S. Latter

Self-management: A systematic review of outcome measures adopted in self-management interventions for stroke
Disability and Rehabilitation 2012 Vol. 00 pp. 1-14

D. Fenlon, J. Corner, J. Haviland

Menopausal hot flushes after breast cancer
European Journal of Cancer Care 2009 Vol. 18 pp. 140-148

C. Foster, D. Wright, H. Hill, J. Hopkinson, L. Roffe

Psychosocial implications of living five years or more following a cancer diagnosis: A systematic review of the research evidence
European Journal of Cancer Care 2009 Vol. 18 pp. 223-247

C. Green, K. Gerard

Exploring the social value of healthcare interventions: A stated preference discrete choice experiment
Health Economics 2009 Vol. 18 pp. 951-976

R. Campbell, P. Pound, M. Morgan, G. Daker-White, N. Britten, R. Pill, L. Yardley, C. Pope, J. Donovan

Evaluating meta-ethnography: Systematic analysis and synthesis of qualitative research
Health Technology Assessment 2011 Vol. 15 DOI: 10.3310/hta15430

J. Bridges, M. Flatley, J. Meyer

Older people's and relatives' experiences in acute care settings: Systematic review and synthesis of qualitative studies
International Journal of Nursing Studies 2010 Vol. 47 pp. 89

S. Latter, A. Sibley, T. C. Skinner, S. Cradock, K. M. Zinken, M. T. Lussier, C. Richard, D. Roberge

The impact of an intervention for nurse prescribers on consultations to promote patient medicine-taking in diabetes: A mixed methods study
International Journal of Nursing Studies 2010 Vol. 47 pp. 1126-1138

J. Conway, J. Fleming, C. Majoral, I. Katz, D. Perchet, C. Peebles, L. Tossici-Bolt, L. Collier, G. Caillibotte, M. Pichelin, V. Sauret-Jackson, T. Martonen, G. Apiou-Sbirlea, B. Muellinger, P. Kroneberg, J. Gleske, G. Scheuch, J. Texereau, A. Martin, S. Montesantos, M. Bennett

Controlled, parametric, individualized, 2-D and 3-D imaging measurements of aerosol deposition in the respiratory tract of healthy human subjects for model validation
Journal of Aerosol Science 2012 DOI: 10.1016/j.jaerosci.2012.04.006

C. T. Freeman, A. M. Hughes, J. H. Burrridge, P. H. Chappell, P. L. Lewin, E. Rogers

A model of the upper extremity using FES for stroke rehabilitation
Journal of Biomechanical Engineering 2009 Vol. 131 pp. 031011

D. A. Lee, M. M. Knight, J. J. Campbell, D. L. Bader

Stem cell mechanobiology
Journal of Cellular Biochemistry 2011 Vol. 112 pp. 1-9

A. Bowling, J. Windsor

The effects of question order and response-choice on self-rated health status in the English longitudinal study of ageing (elsa)
Journal of Epidemiology and Community Health 2008 Vol. 62 pp. 81-85

K. A. Mamun, M. Mace, L. Gupta, C. A. Verschuur, M. E. Lutman, M. Stokes, R. Vaidyanathan, S. Wang

Robust real-time identification of tongue movement commands from interferences
Neurocomputing 2012 Vol. 80 pp. 83-92

A. M. Hughes, C. Freeman, J. Burrridge, P. Chappell, P. Lewin, E. Rogers

Feasibility of iterative learning control mediated by functional electrical stimulation for reaching after stroke
Neurorehabilitation and Neural Repair 2009 Vol. 23 pp. 559-68

G. Verheyden, H. J. R. Van Duijnoven, M. Burnett, J. Littlewood, D. Kunkel, A. M. Ashburn

Kinematic analysis of head, trunk, and pelvis movement when people early after stroke reach sideways
Neurorehabilitation and Neural Repair 2011 Vol. 25 pp. 656-663

V. Williams, A. Bruton, C. Ellis-Hill, K. McPherson

The importance of movement for people living with chronic obstructive pulmonary disease
Qualitative Health Research 2011 Vol. 21 pp. 1239-1248

J. Adams, J. Burrridge, M. Mullee, A. Hammond, C. Cooper

The clinical effectiveness of static resting splints in early rheumatoid arthritis: A randomized controlled trial
Rheumatology 2008 Vol. 47 pp. 1548-53

C. Sanders, A. Rogers, C. Gately, A. Kennedy

Planning for end of life care within lay-led chronic illness self-management training: The significance of death awareness' and biographical context in participant accounts
Social Science & Medicine (1982) 2008 Vol. 66 pp. 982

T. Long, M. Sque, J. Addington-Hall

Conflict rationalisation: How family members cope with a diagnosis of brain stem death
Social Science & Medicine 2008 Vol. 67 pp. 253-261

A. Rogers, S. Kirk, C. Gately, C. R. May, T. Finch

Established users and the making of telecare work in long term condition management: Implications for health policy
Social Science & Medicine 2011 Vol. 72 pp. 1077-1084

C. May, T. Finch

Implementing, embedding, and integrating practices: An outline of normalization process theory
Sociology 2009 Vol. 43 pp. 535-554

L. Hassan, L. Birmingham, M. A. Harty, M. Jarrett, P. Jones, C. King, J. Lathlean, C. Lowthian, A. Mills, J. Senior, G. Thornicroft, R. Webb, J. Shaw

Prospective cohort study of mental health during imprisonment
The British Journal of Psychiatry 2011 Vol. 198 pp. 37-42

M. A. Mullee, P. G. Coleman, R. S. J. Briggs, J. E. Stevenson, J. C. Turnbull

Self-rated activity levels and longevity: Evidence from a 20 year longitudinal study
The International Journal of Aging and Human Development 2008 Vol. 67 pp. 171-186

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