

**Director:**  
**Professor Kate  
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**OUR RESEARCH  
THEMES:**

**Patient & Public  
Involvement**

**Experience of Health Care**

**Person Reported Outcomes**

**Translating Knowledge into  
Practice**

*This newsletter presents selected highlights of our research. For details of the full programme please see our website.*

**INSIDE THIS  
ISSUE:**

**Who - Year of the Nurse and Midwife** 1

**DrAhayalimudin Graduates - PhD** 1

**PhD Student Update** 2

**Dr Nathan Pearson Graduates - PhD** 2

**Publications** 3

**MEMVIE Programme** 4

**How WRIN Contribute** 5

## Warwick Research in Nursing and the WHO Year of the Nurse and Midwife

All staff in Warwick Research in Nursing thought that 2020 would be a bit special, as it is the first ever WHO International Year of the Nurse and Midwife which coincides with Florence Nightingale's bicentennial year. This is a real chance to celebrate nursing, reflect on nurses' diverse range of knowledge, expertise and skills, and raise the profile of nursing and research relevant to nursing, both locally, nationally and internationally.

WHO, International Council of Nurses, International Council of Midwives, Nursing Now and the United National Population Fund anticipated celebrating the work of nurses and midwives. They planned to highlight the challenging conditions in which nurses often work, and wanted to advocate for more investment in nursing and midwifery workforce.

WHO reported that the world needs 9 million nurses and midwives to achieve universal health coverage by 2030.

None of us could have anticipated just how important nursing would be during 2020 when Covid-19 struck, and just how much the working environment and commitment of nurses and other health and social care professionals would be highlighted.

This was not the celebration that was planned, but the professionalism of nurses and other health and social care professionals shone through.

For more details on the WHO International Year of the Nurse, see: <https://www.who.int/campaigns/year-of-the-nurse-and-the-midwife-2020>



## Dr. Nurul'Ain Ahayalimudin graduates with her PhD



**Nurul'Ain Ahayalimudin** passed her PhD viva with minor corrections in December 2019. The examiner has approved these minor corrections. Her PhD was titled "Sustaining nurses in a disaster: a constructivist grounded theory." Here she is with her two supervisors Professor Kate Seers and Professor Sophie Staniszewska celebrating after her viva.

We're looking forward to seeing her again and meeting her family at the degree ceremony here in Warwick in July.

**Well done Nurul'Ain, you are a star!**



@TheWRinN

## PhD Student Update

### Nathan Pearson -PhD Title: “Improving the assessment of fatigue in Axial Spondyloarthritis”

In October 2015 I started my PhD, supervised by Dr Kirstie Haywood, Dr Liz Tutton and Dr Jon Packham. My PhD aimed to improve the assessment of fatigue in a specific rheumatic disease – axial spondyloarthritis (SpA). Axial SpA patients frequently report physical symptoms of illness such as pain and reduced mobility, which can be addressed with established treatment routes. However, patients frequently report fatigue as a significant symptom of their condition, yet there is no way to assess fatigue in axial SpA.

The solution to this problem is to develop a patient reported outcome measure (PROM) specific to the needs of axial SpA patients, and their fatigue experience. To do this, it is essential to first understand ‘what’ is important for fatigue measurement to identify ‘how’ best to measure fatigue.

In my PhD, I developed an axial SpA fatigue-specific PROM called the Warwick Axial Spondyloarthritis faTigue and Energy questionnaire (WASTEd). I did this following a 4-stage, mixed methods research process:

1. Systematic review of single and multi-item measures used to assess fatigue in axial SpA.
2. Phenomenology-based semi-structured interviews (with patients) to understand what it is like for patients living with axial SpA and fatigue, and to develop a framework of ‘what’ matters for measurement.
3. Question and questionnaire development and refinement (including test ‘cognitive’ interviews with patients) to produce the WASTEd.
4. Postal survey to evaluate the quality of the new questionnaire and support statistical refinement of the WASTEd

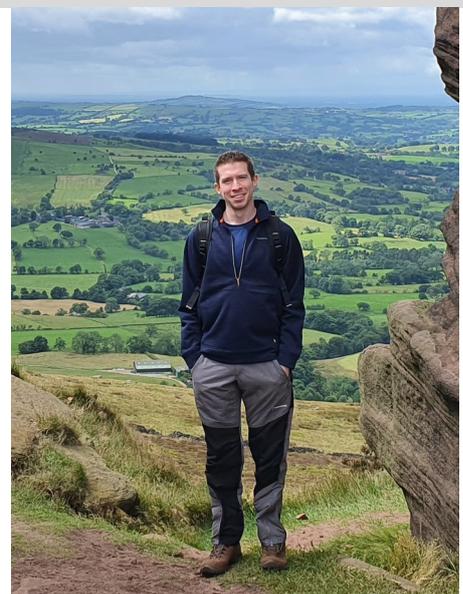
In 2019, I completed my PhD and am currently writing the publications to accompany each of the stages identified above. The next step for the WASTEd is to complete further refinement interviews followed by a final field test to confirm its readiness for use in routine practice and research.

## Dr Nathan Pearson successfully graduates with his PhD

Nathan Pearson successfully passed his PhD with very minor corrections in December 2019. The examiners have passed these with minor corrections. His PhD was entitled “**Improving the assessment of fatigue in Axial Spondyloarthritis**”. Here he is celebrating and indulging his pastime of hiking in the beautiful Peak District – a well-deserved break from study!

Nathan has now joined the WRiN team as a Research Fellow, working on developing a Core Outcome Set for Ankle Fracture (COSTA). We are looking forward to working with Nathan as he continues his health outcome journey – and to celebrating again during the degree ceremony in July!

Well done Nathan! You are fabulous!



# Publications

Boyelyn AM, Locock L, Thomson R, **Staniszewska S** (2019) Health researchers' attitudes to, and experiences of, patient and public involvement (PPI). "About sixty per cent I want to do it": Health researchers' attitudes to, and experiences of, patient and public involvement (PPI)—A qualitative interview study. *Health Expectation*. DOI: 10.1111/hex.12883

Datta S, Pink J, Medley G, Petrou S, **Staniszewska S**, Underwood M, Sonnerner P, Kelling M (2019). Assessing the cost-effectiveness of vaccination strategies for adolescent girls and boys. *BMC Infectious Diseases* 19: 552. doi: 10.1186/s12879-019-4108-y

Froud R, Grant M, Burton K, Foss, J, Ellard DR, **Seers K**, Smith D, Barillec M, Patel S, **Haywood K** & Underwood M (2020). Development and feasibility of an intervention featuring individual supported work placements to aid return to work for unemployed people living with chronic pain. *Pilot and Feasibility Studies*. 6:49. <https://doi.org/10.1186/s40814-020-00581-6> (accepted 2-3-2020)

McGregor G, Bruce J, Ennis S, Mason J, Lall R, Ji C, Sandhu H, **Seers K**, Banerjee P, Canaway A, Booth K, Taylor SJC, Robertson E, Pincus T, Singh S, Fitzmaurice D, Bowater S, Clift P, Underwood M (2020) Supervised pulmonary hypertension exercise rehabilitation (SPHERE): study protocol for a multi-centre randomised controlled trial *BMC Pulmonary Medicine* (2020) 20:143 <https://doi.org/10.1186/s12890-020-01182-y>

Mallett R, McLean S, Holden MA, Potia T, Gee M, **Haywood K**. Use of the nominal group technique to identify UK stakeholder views of the measures and domains used in the assessment of therapeutic exercise adherence for patients with musculoskeletal disorders. *BMJ Open*. 2020 Feb 18;10(2):e031591

**Nichols V**, Toye F, Eldabe S, Sandhu H, Underwood M, **Seers K** (2020) Experiences of people taking opioid medication for chronic non-malignant pain: a qualitative evidence synthesis using meta-ethnography. *BMJ Open*. 2020;10:e032988. doi:10.1136/bmjopen-2019-032988. <https://bmjopen.bmj.com/content/bmjopen/10/2/e032988.full.pdf> (accepted 7th January 2020).

**Nichols, VP**, Toye F, Eldabe S, Harbinder H, Underwood M, **Seers K** (2020). Experiences of people taking opioid medication for chronic non-malignant pain : a qualitative evidence synthesis using meta-ethnography. *BMJ Open*, 10.e032988. doi:10.1136/bmjopen-2019-032988

**Nichols V**, Abraham C, Eldabe S, Sandhu H, Underwood M, **Seers K** on behalf of the IWOTCH team (2019). Process evaluation protocol for the I-WOTCH study: an opioid tapering support programme for people with chronic non-malignant pain. *BMJ Open*, 9.e028998. doi:10.1136/bmjopen-2019-028998

Parslow RM, Anderson N, Byrne D, **Haywood KL**, Shaw A, Crawley E. Development of a conceptual framework to underpin a health-related quality of life outcome measure in paediatric chronic fatigue syndrome/myalgic encephalopathy (CFS/ME): prioritisation through card ranking. *Qual Life Res*. 2020 May;29(5):1169-1181

Patel S, Achana F, Carnes D, Eldridge S, Ellard DR, Griffiths F, **Haywood K**, Hee SW, Mistry D, Mistry H, Nichols VP, Petrou S, Pincus T, Potter R, Sandhu HK, Stewart K, Taylor S, Underwood M, Matharu M. Usual care and a self-management support programme versus usual care and a relaxation programme for people living with chronic headache disorders: a randomised controlled trial protocol (CHESS). *BMJ Open*. 2020 Apr 12;10(4):e033520.

**Pearson, N.A.**, Parsons, H., Tutton, E., Martindale, J., Strickland, G., Thompson, H., Packham, J., **Haywood, K. L.** (2020). P70 Evaluating the WASTEd: a new co-produced patient-reported measure of axial spondyloarthritis (axSpA) fatigue and energy. *Rheumatology*, 59; supplement2.

## Publications

**Pearson, N. A.**, Strickland, G., Thompson, J., Martindale, J., Tutton, E., Parson, H., Packham, J., **Haywood, K. L.** (2020). P71 Working collaboratively with patients as research partners in the co-production of the WASTeD: a measure of fatigue and energy in axial spondyloarthritis (axSpA). *Rheumatology*, 59; supplement2.

Whitehead L, Tierney S, Biggerstaff D, Perkins G, **Haywood K.** Trapped in a disrupted normality': survivors' and partners' experiences of life after a sudden cardiac arrest. Resuscitation. 2020 Feb 1;147:81-87

**Staniszewska S.** A patient–researcher partnership for rare cancer research. *Nature Medicine* volume 26, pages164–165(2020) <https://www.nature.com/articles/s41591-020-0766-y>

Weich S, Fenton S-J, **Staniszewska S**, Canaway A, Crepaz-Keay D, Larkin M, *et al.* Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. *Health Serv Deliv Res* 2020;8(21)

## MEMVIE programme

The Mathematical and Economic Modelling for Vaccination and Immunisation Evaluation (MEMVIE) programme provides second opinion modelling for the Department of Health.

<https://warwick.ac.uk/fac/sci/med/research/hscience/healthec/research/infectiousdiseases>

The primary aim is to provide a programme of dynamic and health economic modelling that will underpin opinions and advice on the effectiveness and cost-effectiveness of interventions against infectious diseases in the UK. The opinions and advice are intended for comparison with dynamic disease and health economic modelling undertaken by other groups, including Health Protection England. A key part of the MEMVIE study was to explore, capture and support the potential contribution of the public to mathematical and economic modelling, in order to identify the values that underpin public involvement in modelling and co-produce a framework that identifies the nature and type of PI in modelling and supports its implementation. We established a PI Reference Group, who worked collaboratively with the academic contributors to create a deliberative knowledge space, which valued different forms of knowledge, expertise and evidence. These deliberations generated rich discussion, through which we identified potential points of public contribution and the values that underpin PI in modelling. We iteratively developed a framework to guide future practice of PI in modelling. We developed the MEMVIE Public Involvement Framework in two forms; a short form to summarise key elements a long form Framework to provide a detailed description of each potential type of public contribution at each stage of the modelling process. We found that the public have a key role in modelling. At a macro level the public can contribute to reviewing context, reviewing relevance, assessing data and justifying model choice, troubleshooting, interpreting and reviewing outcomes and decision making. Ultimately, they can contribute to the validity of the model, potentially enhancing its relevance, utility and transparency through diverse inputs, enhancing the credibility, consistency and continuous development through scrutiny, in addition to contextualising the model within a wider societal view. We are now moving forward with the MEMVIER study which is continuing our programme of model development, including Covid 19, and will evaluate the MEMVIE PPI Framework in applied use.

**Staniszewska S, Hill E, Grant R (2020). Developing a framework for public involvement in mathematical and economic modelling: Bringing new dynamism to vaccination policy recommendations. In press, The Patient.**

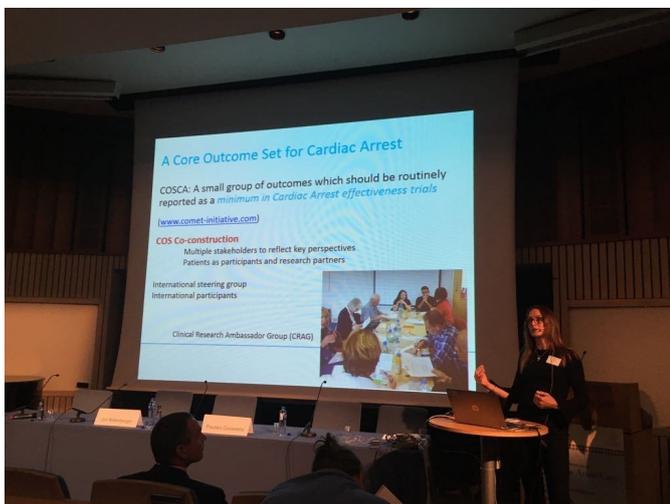
## How Warwick Research in Nursing Contributes to the wider Academic Community

In our last NEWSLETTER we featured Prof Sophie Staniszewska, this time Dr Kirstie Haywood talks about her role.

The focus of my research interests is health outcomes research, and more specifically patient-reported outcomes (PROs), contributing to the development, application and evaluation of high quality, relevant and acceptable approaches to the assessment of health and health care. Patient-reported outcome measures (PROMs) are questionnaires, which seek to assess how patients feel, what they can and cannot do, and how they live their lives, in relation to their health and associated health care. Most studies require accurate assessment of health outcomes – and the importance of ensuring that the ‘patient’s voice’ is clearly represented in these outcomes is increasingly recognised! Therefore, I often contribute outcomes guidance and expertise to studies, supporting outcome selection and leading sub-studies that seek to contribute to a developing evidence base of outcome quality and acceptability. This often involves exploring what really matters to patients and determining the relevance and quality of available measures. For example, as part of the Chronic Headache Education and Self-management Study (CHES) [<https://warwick.ac.uk/fac/sci/med/research/ctu/trials/ches/>], we actively engaged with people with chronic headache, both as patient research partners and study participants, to explore both the relevance and essential psychometric properties of widely used measures. Associated publications are currently under review.

Where guidance for outcome reporting is lacking, I have led the co-production of ‘Core Outcome Sets’. That is, working collaboratively with multiple stakeholders – including patients, health professionals and researchers – to recommend a minimum number of outcomes (core aspects of health) that should be included in future research or routine practice settings. We have provided such guidance across a range of healthcare areas including trauma and orthopaedics (hip fracture), migraine (Core Outcome Set for Migraine (COSMIG)) and cardiac arrest research (Core Outcome Set for Cardiac Arrest (COSCA and Paediatric-COSCA). We are currently developing a further core outcome set for ankle fracture (Core Outcome Set for Tibial and Ankle fractures (COSTA)).

Where appropriate outcome measures are not available, I have worked collaboratively, again with patients as research partners, to develop and evaluate new PROMs, supporting their implementation and integration into research and routine practice settings. Most recently, this has involved the co-production of new measures for: children with chronic fatigue syndrome/ myalgic encephalitis (POMME), women’s health during maternity (WOWMAT), adults with axial spondyloarthritis (the Warwick Axial Spondyloarthritis faTigue and Energy (WASTEd) questionnaire), and the survivors of cardiac arrest (Cardiac Arrest Survivorship and Health-related Quality of Life questionnaire (CASH-QoL)).



Please do get in touch if you want to know more about any of these initiatives or if you’re interested in knowing more about health outcomes!

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