

2020-2025 End of award report



Canolfan PRIME **Cymru**
PRIME Centre **Wales**

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Foreword

PRIME Centre Wales aims to improve health and well-being in Wales and beyond by undertaking high-quality research on topics of national policy priority, which contribute to the evidence base in primary and emergency care, and ensuring that findings are translated into policy and practice.

Primary and emergency care sectors are front page news. They provide 90% of all patient contacts within the NHS. Changes in primary care affect emergency and unscheduled care, and vice versa, and any changes in these sectors can critically affect the secondary and social care sectors.

Worldwide evidence shows that the stronger the primary and emergency care sector in that country, the stronger and more effective its whole health system is. These sectors must be supported by a strong academic and research evidence base. This is a vitally important area for research, engagement, knowledge mobilisation and impact, and PRIME is delivering this effectively and with an upwards trajectory, with £70 million total over 2020-25, including £35 million directly into Wales.

During this time, we also contributed to major research projects and priorities during the COVID pandemic such as evaluating the vaccines, effectiveness of antiviral treatments used in community settings, and the impacts of the pandemic on more disadvantaged groups in the population. We contribute now to vital research on enhancing the quality and safety of primary and emergency research in the post-pandemic context.

Our research aligns with Welsh Government Health and Social Care policies, plans and strategies, including *A healthier Wales: long term plan for health and social care* to ensure the delivery of health and care services that are fit for the future.

Together with our key stakeholders, we conduct research into:

- prevention as well as treatments,
- improving the standard and quality of treatments through generation of evidence,
- integration of health and social care,
- shifting health and care services into communities away from hospitals, and
- using NHS and social care data to better understand outcomes and prevention.

PRIME is an all-Wales Centre co-led by Cardiff University, Bangor University, University of South Wales and Swansea University, and includes significant contribution from public members, and from government, NHS and social care colleagues. We are very grateful to everyone who has contributed to making PRIME Centre a success during 2020-25 and which is now funded to continue 2025-30. We gratefully acknowledge the funding from Welsh Government, through Health and Care Research Wales to be able to do this vital research.



[Professor Adrian Edwards, Professor of General Practice,](#)
Division of Population Medicine, Cardiff University; Director,
PRIME Centre Wales, and Health and Care Research Wales
Evidence Centre

Aims and objectives

PRIME Centre Wales benefits the NHS and the people of Wales by providing a strong academic and evidence base to underpin primary and emergency care.

Our **collaborative work** between leading **academics, individuals, communities**, and organisations is essential in **co-producing** large-scale **high-quality research with impact**.















This underpins **improvements to primary and emergency services**, bringing innovative services **closer to communities, empowering patients and families** in their care, making services more **integrated and person-centred**, and ensuring that the population of Wales receives the greatest benefit from the health and social care resources available by adopting an **equitable and value-based healthcare** approach.

PRIME's **unique multi-disciplinary collaboration is a single research community across Wales** researching primary and emergency care in Wales to achieve important benefits to our group, the NHS, Welsh Government, and the people of Wales, through:

1. Creating a **centre of excellence** in primary and emergency care, crucial for attracting prestige research funding into Wales and providing a strong academic base for primary and emergency care.
2. Delivering **high-quality research** that addresses increasingly complex challenges encountered in primary and emergency care.
3. Adopting an **integrated whole-systems approach** to improve services, working at the critical interface between primary, emergency, and social care.
4. Ensuring clear **“pathways to impact”** plans are developed and implemented to maximise public and patient benefit from our research, including a high level of engagement, research co-production, and knowledge exchange with all our stakeholders.
5. **Building capacity** for primary and emergency care research in Wales, including the development of research methods, skills, patients, and members of the public and the workforce. This includes the development of new principal investigators and support for clinicians in becoming research leaders. This ensures that we can continue to have a strong academic base for primary and emergency care services in Wales in the future.

Who's who - meet the team

All-Wales Steering Committee

 Adrian Edwards DIRECTOR PROFESSOR OF GENERAL PRACTICE, CARDIFF UNIVERSITY	 Helen Snooks ASSOCIATE DIRECTOR PROFESSOR OF HEALTH SERVICES RESEARCH, SWANSEA UNIVERSITY	 Carolyn Wallace ASSOCIATE DIRECTOR PROFESSOR COMMUNITY HEALTH & CARE SERVICES, UNIVERSITY OF SOUTH WALES	 Clare Wilkinson ASSOCIATE DIRECTOR PROFESSOR OF GENERAL PRACTICE, BANGOR UNIVERSITY
 Harry Ahmed Infections & antimicrobial resistance SENIOR CLINICAL LECTURER IN EPIDEMIOLOGY, CARDIFF UNI	 Kate Brain Screening, prevention & early diagnosis PROFESSOR OF HEALTH PSYCHOLOGY, CARDIFF UNIVERSITY	 Rebecca Cannings-John Infections & antimicrobial resistance PRINCIPAL RESEARCH FELLOW, CARDIFF UNIVERSITY	 Andrew Carson-Stevens Patient safety PROFESSOR OF PATIENT SAFETY, CARDIFF UNIVERSITY
 Ivor Chestnutt Oral health & primary dental care PROFESSOR AND HON. CONSULTANT IN DENTAL PUBLIC HEALTH	 Natalie Joseph-Williams Patient-centred care READER IN IMPROVING PATIENT CARE, CARDIFF UNIVERSITY	 Marlise Poolman Supportive & palliative care READER IN IMPROVING PATIENT CARE, CARDIFF UNIVERSITY	 Alison Porter Emergency, unscheduled & pre-hospital care ASSOCIATE PROFESSOR IN HEALTH SERVICES RESEARCH, SWANSEA UNIVERSITY
 Fiona Wood Patient centred-care PERSONAL CHAIR & MEDICAL SOCIOLOGIST, CARDIFF UNIVERSITY			
 Lesley Bethell Public member MEMBER, SUPER GROUP (SERVICE USERS FOR PRIMARY AND EMERGENCY CARE RESEARCH)	 Joseph-Carter Third sector HEAD OF DEVOLVED NATIONS FOR ASTHMA UK AND BRITISH LUNG FOUNDATION	 David Ford Medical informatics PROFESSOR OF INFORMATICS, SWANSEA UNIVERSITY	 Dyfrig Hughes Health informatics PROFESSOR OF PHARMACOECONOMICS, BANGOR UNIVERSITY
 Mark Davies Health/social care education HEAD OF LEARNING, TEACHING AND STUDENT EXPERIENCE, UNIVERSITY OF SOUTH WALES	 Mari James Public member CHAIR, SUPER GROUP (SERVICE USERS FOR PRIMARY AND EMERGENCY CARE RESEARCH)	 Ashra Khanom Public involvement RESEARCH FELLOW, SWANSEA UNIVERSITY	 Ruth Lewis Methodological innovation SENIOR LECTURER IN HEALTH SCIENCES RESEARCH, BANGOR UNIVERSITY
 Mark Llewellyn Health and care policy DIRECTOR AND PROFESSOR OF HEALTH AND CARE POLICY, UNIVERSITY OF SOUTH WALES	 Nigel Rees Ambulance service ASSISTANT DIRECTOR OF RESEARCH AND INNOVATION, WELSH AMBULANCE TRUST	 Rachel North Community eye care PROFESSOR OF OPTOMETRY, CARDIFF UNIVERSITY	 Stuart Todd Intellectual disabilities PROFESSOR IN INTELLECTUAL DISABILITY, USW
 Victoria Shepherd Involving under-served populations SENIOR RESEARCH FELLOW - NURSE, CARDIFF UNIVERSITY	 Irena Spasic Medical informatics PROFESSOR OF COMPUTER SCIENCE AND INFORMATICS, CARDIFF UNIVERSITY	 Emma Thomas-Jones Trials PRINCIPAL RESEARCH FELLOW AND DEPUTY DIRECTOR INFECTIONS INFLAMMATION AND IMMUNITY DIVISION, CTU	 Alan Watkins Health data science PROFESSOR IN E-TRIALS, SWANSEA UNIVERSITY
 Richard Evans SENIOR ADMINISTRATOR, BANGOR UNIVERSITY	 Neil Jenkinson RESEARCH ADMINISTRATOR, SWANSEA UNIVERSITY	 Marina MacDonald RESEARCH & SUPPORT OFFICER, USW	 Angela Watkins COMMUNICATIONS & OPERATIONS MANAGER, CU















































Directors	Research staff
Leadership team	Administration & support

PRIME operates an inclusive and horizontal leadership model, with multidisciplinary contribution to the leadership group (Directors) and Operational Working Group and support for Early Career Researchers (ECR) in leadership roles (e.g. co-leading Work packages).

The PRIME Centre Wales [All-Wales Steering Committee](#) meets yearly and is comprised

of all co-applicants, work package and cross-cutting theme / strategy leaders, representatives from third sector and lay members. The Committee provides advice and direction for the overall Centre strategy, together with a supportive scrutiny role, and steer for fit with government, public and professional / service priorities.

Operational Working Group

 Adrian Edwards DIRECTOR	 Helen Snooks ASSOCIATE DIRECTOR	 Carolyn Wallace ASSOCIATE DIRECTOR	 Clare Wilkinson ASSOCIATE DIRECTOR
 Harry Ahmed INFECTIONS & ANTIMICROBIAL RESISTANCE	 Kate Brain SCREENING, PREVENTION & EARLY DIAGNOSIS	 Rebecca Cannings-John INFECTIONS & ANTIMICROBIAL RESISTANCE	 Andrew Carson-Stevens PATIENT SAFETY
 Ivor Chestnutt ORAL HEALTH & PRIMARY DENTAL CARE	 Natalie Joseph-Williams PATIENT CENTRED-CARE	 Marlise Poolman SUPPORTIVE & PALLIATIVE CARE	 Alison Porter EMERGENCY, UNSCHEDULED AND PRE-HOSPITAL CARE
 Fiona Wood PATIENT CENTRED-CARE	 Rabeea'h Aslam STUDY MANAGER, SWANSEA UNIVERSITY	 Fadi Baghdadi RESEARCH ASSOCIATE, SWANSEA UNIVERSITY	 Diana Beljaars RESEARCH ASSOCIATE, BANGOR UNIVERSITY
 Sara Bradley SENIOR RESEARCH FELLOW, UNIVERSITY OF SOUTH WALES	 Eleanor Clarke RESEARCH ASSOCIATE, CARDIFF UNIVERSITY	 Alison Cooper SENIOR CLINICAL RESEARCH FELLOW, CARDIFF UNIVERSITY	 Anwen Cope SENIOR CLINICAL LECTURER, CARDIFF UNIVERSITY
 Aled Davies CLINICAL RESEARCH FELLOW, CARDIFF UNIVERSITY	 Freya Davies CLINICAL RESEARCH FELLOW, CARDIFF UNIVERSITY	 Mark Davies SENIOR LECTURER, UNIVERSITY OF SOUTH WALES	 Annie Hendry RESEARCH FELLOW, BANGOR UNIVERSITY
 Julia Hiscock RESEARCH FELLOW, BANGOR UNIVERSITY	 Ashra Khanom RESEARCH FELLOW, SWANSEA UNIVERSITY	 Mark Kingston SENIOR RESEARCH FELLOW, SWANSEA UNIVERSITY	 Kate Lifford RESEARCH ASSOCIATE, CARDIFF UNIVERSITY
 Ruth Lewis SENIOR LECTURER, BANGOR UNIVERSITY	 Mark Llewellyn PROFESSOR OF HEALTH & CARE POLICY, USW	 Rachel Lowe SENIOR FELLOW & TRIAL MANAGER, CARDIFF UNIVERSITY	 Gargi Naha RESEARCH ASSOCIATE, SWANSEA UNIVERSITY
 Simon Newstead SENIOR RESEARCH ASSISTANT, UNIVERSITY OF SOUTH WALES	 Edward Oloidi POST-DOC RESEARCH ASSISTANT, USW	 Delyth Price RESEARCH ASSISTANT, CARDIFF UNIVERSITY	 Harriet Quinn-Scoggins RESEARCH ASSOCIATE, CARDIFF UNIVERSITY
 Leigh Sanyaolu CLINICAL RESEARCH FELLOW, CARDIFF UNIVERSITY	 Savita Shanbhag HCRW FUNDED EMERGING RESEARCHER, CARDIFF UNI	 Stuart Todd PROFESSOR IN INTELLECTUAL DISABILITY, USW	 Anna Torrens-Burton RESEARCH ASSOCIATE, CARDIFF UNIVERSITY
	 Denitza Williams LECTURER, CARDIFF UNIVERSITY	 Sarah Wallace SENIOR RESEARCH FELLOW, UNIVERSITY OF SOUTH WALES	
 Richard Evans SENIOR ADMINISTRATOR, BANGOR UNIVERSITY	 Neil Jenkinson RESEARCH ADMINISTRATOR, SWANSEA UNIVERSITY	 Marina MacDonald RESEARCH & SUPPORT OFFICER, USW	 Angela Watkins COMMUNICATIONS & OPERATIONS MANAGER, CU

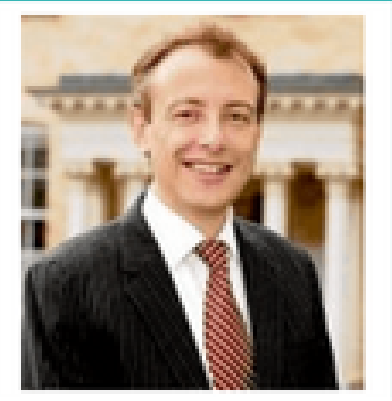
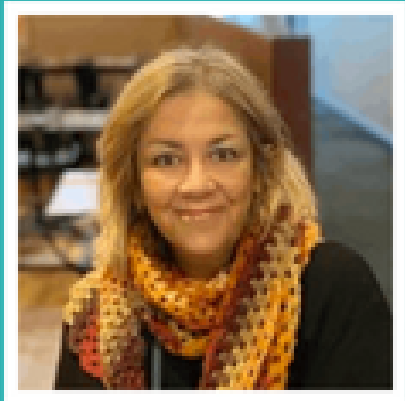
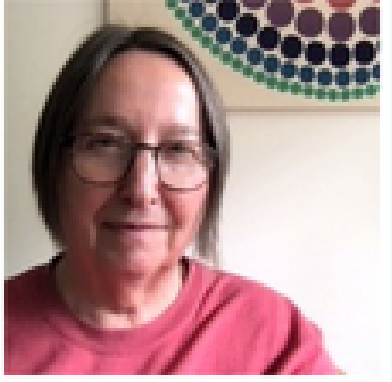










Directors	Research staff
Leadership team	Administration & support



The [Operational Working Group](#) meets monthly and is comprised of Centre Directors, work package leads and core-funded research and professional services staff.

The group ensures effective cross-university collaboration of the team towards achieving the goals of PRIME.

International Advisory Board

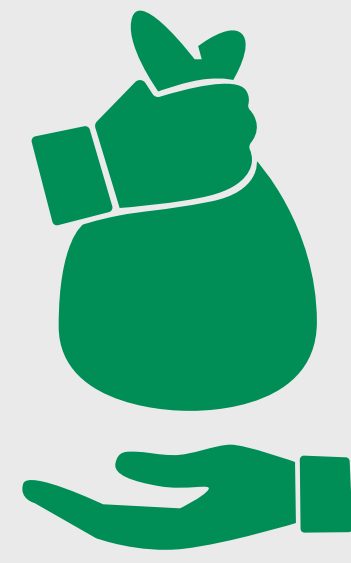
	<p>John Browne Director of National Health Research, Ireland, Health Services Researcher, University College Cork, Ireland</p>		<p>Debra Jackson Professor of Nursing University of Technology Sydney, Australia</p>
	<p>Carolyn Canfield Independent Citizen-Patient Vancouver, British Columbia, Canada</p>		<p>Peter O'Meara Professor of Paramedicine Monash University, Australia</p>
	<p>Niamh Cummins Associate Professor in Public Health Public Health Programme, University of Limerick, Ireland</p>		<p>Martin Quinn Regional PPI Lead, Public Health Agency Londonderry, Northern Ireland</p>
	<p>Martin Dawes Professor of Family Practice Medicine University of British Columbia, Canada</p>		<p>Niro Siriwardena Professor of Primary & Pre-Hospital Care University of Lincoln</p>
	<p>France Légaré Professor of Family Practice Medicine University of Quebec, Canada</p>		<p>Josep Vidal-Alaball Professor of Primary Care Medicine University of Catalonia</p>
	<p>Magnus Hagiwara Professor of Prehospital Emergency Care University of Borås, Sweden</p>		<p>Emma Wallace GP & Lecturer in General Practice University of Medicine & Health Sciences, Ireland</p>
		<p>Nefyn Williams Professor in Primary Care University of Liverpool, England</p>	

Our International Advisory Board represents **leaders in the field of patient involvement and primary, emergency, and unscheduled care** research from around the world.

The Board meets yearly and is comprised of senior or experienced researchers and other stakeholders based outside of Wales.

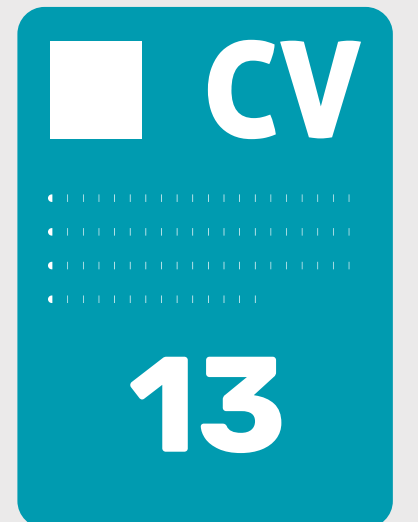
The Board provides independent advice on the quality of our work, critical comment on progress towards its milestones and outputs, and steer in the context of international developments, policy, and research priorities.

**Health and Care
Research Wales
infrastructure award
to the group**



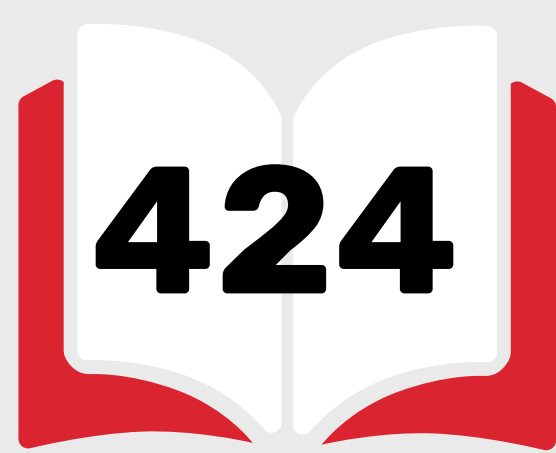
Direct
funding
awarded
£4.6m

Jobs created
through direct
funding



Grants won during reporting period

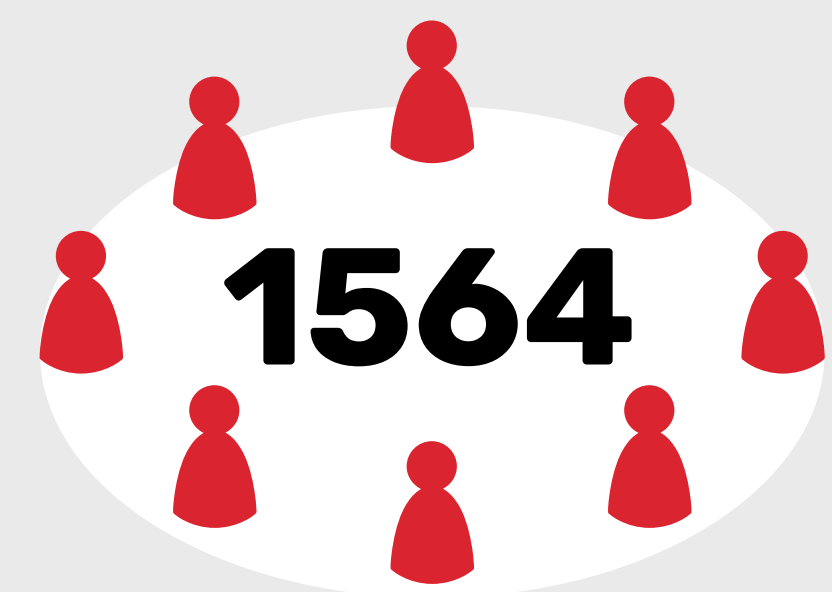
Grants won	Led by group	Group collaborating
Number	73	50
Value	£13.8m	£56.7m
Funding to Wales	£10.2m	£25.1m
Funding to group	£8.8m	£3.2m
Additional jobs created for Wales	59 52	107 30
Additional jobs created for group		



Number of publications

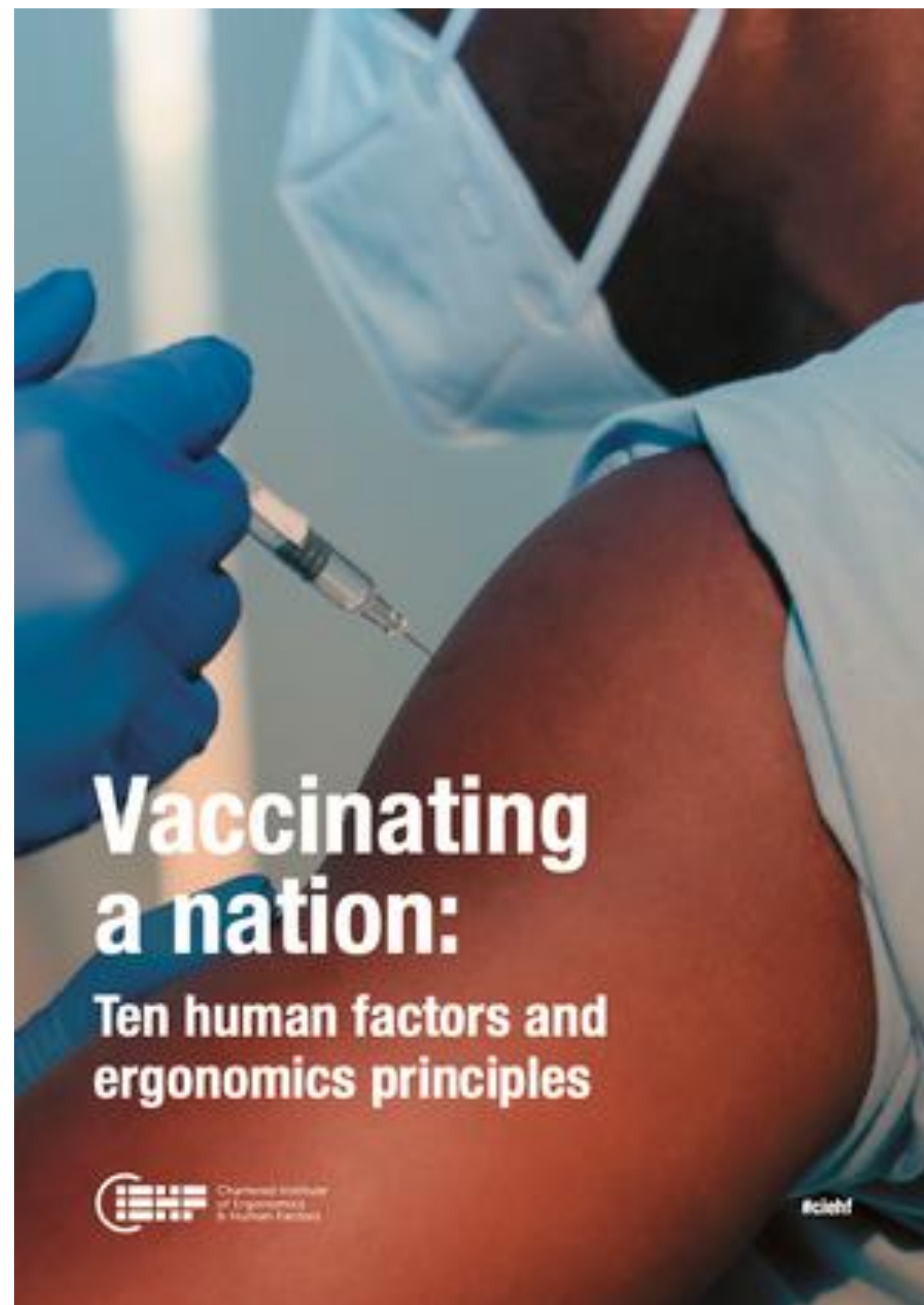


Number of public
engagement events



Number of public
involvement opportunities

News highlights and impact (all work packages)



Contributing to the expert guidance for COVID

Multiple members from PRIME ([Ahmed, Carson-Stevens, Cooper, Edwards](#)) have contributed to the Chartered Institute for Ergonomics and Human Factors' response to support healthcare organisations keep patients safe during the pandemic, notably advising on expert guidance to support healthcare organisations to keep patients safe, including:

- Vaccinating a nation: Ten human factors and ergonomic principles.
<https://ergonomics.org.uk/resource/vaccinating-a-nation.html>
- Guidance to help design effective and usable work procedures for health and social care teams.
<https://ergonomics.org.uk/resource/guidance-on-design-of-effective-work-procedures.html>

Prof Andrew Carson-Stevens said:

"Our patient safety research from PRIME Centre, notably examining the safety of vaccination in primary care has enabled us to provide timely research-driven recommendations to this important international guidance for keeping the public as safe as possible during the roll out of COVID-19 vaccines through mass vaccination programmes."

To support the COVID-19 vaccine research delivery agenda in Wales, Prof Carson-Stevens, [Dr Emma Thomas-Jones](#), and [Prof Kerry Hood](#) have been members of the Wales COVID-19 Vaccine Research Delivery Group at Health and Care Research Wales. They were co-recipients of the Health and Social Care Research Partnership Award with Industry for the Oxford-AstraZeneca COVID-19 Vaccine Trial in Wales awarded by MediWales.



What TRlAge model is safest and most effective for the Management of 999 callers with suspected COVID-19

During this extremely busy period, we have responded to the challenges presented by the COVID-19 pandemic by rapidly developing new research studies to support the health service and policy response.

The number of emergency ambulance calls related to COVID-19 increased enormously at points during the coronavirus pandemic.

This presented new challenges to services in terms of triage and prioritisation of response, to ensure that appropriate safe care was delivered to patients, without overwhelming hospital Emergency Departments, and services introduced new emergency protocols in response.

The [TRIM study](#), What TRlAge model is safest and most effective for the Management of 999 callers with suspected COVID-19, was awarded funding of £358,400 in June 2020 through the UKRI-DHSC COVID-19 Rapid Response Rolling Call.

The project involves Welsh, Yorkshire, East of England and East Midlands Ambulance Services.

[Alan Watkins](#), Professor of e-trials Research and [Helen Snooks](#), Professor of Health Services Research lead the TRIM study.

Findings from the TRIM study have been published in BMC Emergency Medicine.



HEAR2 study wins Health and Care Research Wales impact award and influences policy aimed at improving healthcare services for asylum seekers and refugees in Wales.

Dr Ashra Khanom is pictured accepting the award above, right said "I'm really delighted to receive this award on behalf of the team. Everybody's worked so hard; we had so many components and it was a whole team effort." Read more about the study [here](#).



COPE Cymru Study

Understanding the impact of the COVID-19 pandemic and related policies on physical health and psychological well-being is a high priority for government and public health agencies. How people respond to, and are affected by, the pandemic is influenced by an array of psychological and socio-demographic factors. These need to be understood when designing and implementing public health interventions to minimise harm across the population.

In doing so we contributed to Welsh Government's strategic aims of preventing ill health with a focus on person-centred approaches to improving health and were in line with the [Wellbeing and Future Generations Act](#) and Welsh Government's 'A Healthier Wales: Our Plan for Health and Social Care 2019'.

The project also aligned with the Chief Medical Officer for Wales' statements relating to the importance of research in order to learn from past events to prevent future pandemics and understanding wider effects of COVID-19 on health and society in Wales, including understanding effects on health inequalities in Wales (Protecting our Health, CMO Report, 2021).

The [COPE Cymru study](#) was a longitudinal cohort study which used a combination of research methods to understand attitudes, beliefs and behaviours of a large cohort of the Welsh public in response to the coronavirus pandemic.

In March/April 2020 our inter-disciplinary team carried out an online survey of 8,942 people recruited through [HealthWise Wales](#) (an online public recruitment platform for health research). Follow up surveys and interviews were conducted. The [COPE Cymru team](#) received a grant from Sêr Cymru to support research on this project between August 2020 and March 2021.

The COPE Cymru team represent a multi-disciplinary collaboration between Cardiff University and Cardiff Metropolitan University as well as lay partners as recommended by the UK Standards of Public Involvement. PRIME colleagues involved are [Dr Natalie Joseph-Williams](#), [Dr Anna Torrens-Burton](#), [Dr Denitza Williams](#) and [Prof Fiona Wood](#).

Further information is available at: <https://copestudy.yolasite.com>



Shielding from COVID-19: Unravelling the policy

A [study](#) by PRIME researchers at Swansea University's Medical School has explored the rationale behind the creation of the COVID-19 shielding policy for clinically vulnerable people and found that while policymakers intended it make a positive difference, they did not know to what extent or what other impacts it would have.

The research, which focusses on the policy in Wales, was part of the EVITE Immunity study which was a wider evaluation of the effects of shielding on health outcomes, costs and immunity.

The research team interviewed people across the many organisations involved in developing and implementing the policy and heard how they had to work together quickly to establish the policy.

The study spells out the reasoning, components and processes around the shielding policy, while also revealing that it was an untested strategy based on 'common sense' risk mitigation rather than an evidence-based intervention.

The researchers found that the shielding plan was based on some key elements:

- deciding who should be shielded based on medical criteria,
- making a list of these individuals,
- giving them advice on how to shield,
- providing a support system in place that provided help like food and financial assistance to those who were shielding.

[Dr Alison Porter](#), PRIME co-lead for emergency and unscheduled care, who led the study said:

“Naturally, this large-scale initiative created challenges both for those attempting to implement the policy and for those meant to benefit from it.

“Our study allowed us to understand the different impacts of the shielding programme on organisations and populations, and outlines the rationale, components and mechanisms.

“The input from key stakeholders has given additional insight to help us understand the causal links which will inform our evaluation of the impact of shielding and help us to understand its effect and limitations.”

The study has been published in the [BMJ Open journal](#).

Funding: The EVITE Immunity project is funded through the National Core Studies Immunity Programme - commissioned by Birmingham University on behalf of UKRI; and involves collaborations with Cardiff University, Warwick University, Welsh Government and NHS Wales.

Prisoner healthcare puts patients at risk

The first national analysis of patient safety in prisons found that prisoners experienced delayed access to healthcare services, difficulties attending healthcare appointments and problems receiving medication. The team also found poor access to healthcare during prison lockdown periods.

With prisoners using healthcare services three times more than the general population, and experiencing poorer health outcomes, this study uncovered areas to prioritise to improve patient safety.

The researchers from Cardiff, led by [Prof Carson-Stevens](#), Manchester and Nottingham Universities reviewed >4,000 incident reports from prisons in England over 12 months, analysing events where prisoners could have, or did, come to harm.

They found that:

- A third of reports related to missed doses of medication or the wrong treatment given.
- 15% of reports involved delayed access to healthcare professionals and healthcare appointments, within prisons and hospitals.
- A fifth of medication-related reports were discovered and mitigated by staff, preventing harm to prisoners.

The publication can be found [here](#).

The next phase of the study: a large-scale case note review of prison records is planned, with the published protocol found [here](#).



Incorporating shared decision making into everyday practice

In June 2021, NICE published its new guideline on shared decision making. Shared decision making is a collaborative process that involves a person and their healthcare professional working together to reach a joint decision about immediate or future care.

In this article published in Guidelines in Practice, PRIME Centre Wales researchers [Dr Natalie Joseph-Williams](#), [Dr Leigh Sanyaolu](#), and [Professor Adrian Edwards](#) summarise the NICE recommendations on shared decision making for primary care practitioners.

Read the article [here](#).

Key points:

- Primary care is uniquely placed to promote and provide shared decision making to patients
 - primary care is the main point of contact for most patients,
 - strong patient partnerships with continuity are typically formed in primary care,
 - primary care provides long-term follow up and coordination across a patient's healthcare journey,
 - shared decision making in primary care can raise patients' expectations of being involved across other care pathways once they are referred.
- Healthcare professionals must gain the skills and confidence to incorporate shared decision making into routine practice, and actively encourage patients to participate; leadership from primary care organisations is also required to support and promote the uptake of shared decision making.
- Shared decision making can be undertaken without a patient decision aid (PDA), but it cannot be done without the skills to have a shared discussion in which options and preferences are shared between a healthcare professional and a patient.
- PDAs should only be used if they are quality assured, reflect evidence-based practice, and are relevant to the decision being made and the clinical setting.
- To minimise bias, consideration should be given to how risks, benefits, and consequences are presented.



COVID-19 Cancer Awareness and Behaviour Study (CABS)

Cancer is the leading cause of mortality in the UK, with symptom-based detection, screening and prevention major planks in the public health armoury that may be derailed by COVID-19. Most cancers are diagnosed symptomatically through primary care and the UK national screening programmes account for 5% of all cancer diagnoses annually.

During the first UK lockdown the suspension of cancer screening programmes, mandated avoidance of essential clinical services, and UK government message to “*stay home, protect the NHS, save lives*” were all intended to control the spread of COVID-19. However, they may have sent a strong signal to the public that “cancer can wait”.

We were awarded funding by the Economic and Social Research Council (via UK Research and Innovation) to assess the impact of COVID-19 on UK public attitudes to cancer, working closely with Cancer Research UK, Cardiff University’s Centre for Trials Research and DECIPHER Centre, Public Health Wales, King’s College London and the University of Surrey.

We found that nearly half of people with potential cancer symptoms had not contacted their GP during the first wave of the pandemic. Possible cancer symptoms were commonly experienced during the first wave, with 40.1% of survey participants (3,025 people) saying they had experienced at least one potential symptom. Worry about wasting healthcare professionals’ time (15.4%), worry about putting extra strain on the NHS (12.6%), not wanting to be seen as someone who makes a fuss (12%), difficulty with access to healthcare services (10.3%) and worry about catching COVID-19 (9.6%) were key barriers to seeking medical help.

Our [policy briefing paper](#) and press release in February 2021 called for coordinated campaigns across the UK to highlight that NHS services are open safely for anyone with unusual or persistent symptoms. The policy briefing was shared with over 40 key stakeholder organisations including the UK, Welsh and Scottish governments, NHS organisations and third sector organisations across the UK.

Software to reduce emergency hospital admissions

Welsh GPs report mixed experiences on usability and benefit for patients.

This PRIME Centre Wales led study builds on research by the same team showing that emergency admissions had gone up – not down – when the tool was introduced in Wales, which led to its rollout being halted, though similar tools continue to be used widely in England, Scotland and Northern Ireland.

The [new study](#), funded by National Institute for Health Research (NIHR) Health Services and Delivery Research Programme, reinforces the need for more evidence and research on the implementation of the software and its effects.

The software is a risk prediction tool, which in Wales is called PRISM. It identifies people who are most at risk of needing emergency care, based on past use of healthcare, diagnoses and medications. The thinking is that targeted management of these patients can reduce emergency admissions to hospital, improve patient outcomes and experience, and provide better value for money.

However, PRIME researchers based at [Swansea University Medical School](#), who evaluated the use of PRISM in Wales found that there is little evidence to suggest that it meets these objectives.

Now, to shed more light on how the tool is used in practice, the same team have published a second study, exploring the views and experiences of GPs and practice managers who used PRISM.

They interviewed 22 GPs and practice managers in 18 practices in south Wales, between three and six months after they began using PRISM and then again 18 months later.

They found:

- GPs generally judged it unlikely that PRISM had any effect on emergency admissions, with a widespread feeling that admissions initiated by GPs were already low with little scope for further reductions.
- Respondents reported the decision to use PRISM was based mainly on wanting to secure incentives offered by the Welsh Government under its Quality and Outcome Framework for improving care.
- Use of PRISM was inhibited by it not being integrated with practice systems.
- Most doubted any large-scale impact from PRISM, but cited examples of impact on individual patient care.
- The majority of respondents reported that PRISM had made them more aware of high-risk patients, flagging up some patients who had not previously been considered to be in the high-risk category.

Our research highlighted very mixed views and experiences among GPs and practice managers about use of PRISM. This was often short-term and driven by external factors rather than embedded in new ways of working.

Decision-makers need more information about the implementation and effects of such tools in primary and community settings to inform future policy on their use.



Public attitudes to death and dying in the UK

Marie Curie Palliative Care Research Centre
Division of Population Medicine
Cardiff University School of Medicine



UK survey about attitudes to death and dying that contributed to a change in legislation (England) and influences policy and service provision in Wales, Scotland, and Northern Ireland.

We are at a critical moment for improving palliative and end of life care in the UK in Wales, as the Welsh Government and its partners across the NHS, social care and the third sector are planning a refreshed approach to the delivery of palliative and end of life care through the development of a new All Wales End of Life Care Programme.

A recent review of progress made against the recommendations of the 2008 Sugar Review for the delivery of Specialist Palliative Care in Wales rightly celebrates success but it also acknowledges the opportunity to look towards the new National Programme for End of Life Care, to broaden the agenda, and continually improve outcomes for people who are dying and their loved ones over the next ten years.

By better understanding public attitudes towards death and dying – including the care and support people hope to receive – the outputs of this research will help Wales face into the challenges ahead, and to provide a palliative and end of life care system which is fit for the future so that everyone who dies in Wales has the best possible end of life experience.

The results have been published in national reports for Wales, UK, and Northern Ireland, to date.

- [Public attitudes to death and dying in the UK](#)
- [Understanding public attitudes to death talk and advance care planning in Northern Ireland using health behaviour change theory: a qualitative study](#)
- [Public attitudes to death and dying in Wales](#)

We have been able to share results from over 8000 of the UK population that challenge many of the assumptions that we make about what matters most to people, for example, the results tell us that financial support of palliative care services by the NHS is crucial, dying at home is not a priority for most. We have also highlighted the widespread lack of knowledge of death systems terminology: Advance Care Planning, access to services, trajectories of death and dying.

The UK Report has been widely quoted in both Houses of Parliament to inform the debate on the Health and Social Care Bill for England. The results of the survey have supported a change in legislation in England to specify a new legal duty to provide specialist palliative care (previously two-thirds charity funding).



TOWARDS CANCER PATIENT EMPOWERMENT FOR OPTIMAL USE OF ANTITHROMBOTIC THERAPY AT THE END OF LIFE



PRIME researchers help develop an online decision aid that could improve quality of life for terminally ill cancer patients

PRIME Centre Wales researchers ([Prof Adrian Edwards](#) & [Dr Kate Lifford](#)) are part of a European consortium, co-led by Erik Klok, Professor of Medicine at the Leiden University Medical Centre and Simon Noble, Marie Curie Professor in Supportive and Palliative Medicine at Cardiff University, that has been awarded a Horizon Europe and Innovate UK grant of 6 million Euros. The SERENITY study aims to develop and evaluate the clinical effectiveness of an online shared decision support tool (SDST) that enables shared decision-making between doctors and patients with advanced cancer regarding continuing or stopping antithrombotic medication within the last months of life. Researchers from Health and Care Research Wales funded organisations - Wales Cancer Research Centre and the Secure Anonymised Information Linkage (SAIL) Databank - are also involved in the SERENITY study, as well as researchers from the Marie Curie Research Centre, Cardiff.

The study is based on previous research which indicates that patients with cancer who are on antithrombotic medications often continue on these medications until the end of life. This is despite an increased risk of excessive bleeding and poor quality of life in the last months and weeks of life. The online decision aid will provide information about the risks and benefits of stopping and continuing antithrombotic medications and guide patients in reflecting on what is important to them and what questions they can ask their doctor. It will be evaluated in a randomised controlled trial in the UK, The Netherlands, Poland and Spain.

Professor Simon Noble said:
 “Only rarely are these medications discontinued during the last phase of life. This is due to the lack of scientific evidence, but also because death and dying are often not discussed sufficiently by the treating physician.
 “The online SDST does not give advice but makes discontinuing medication negotiable. The final decision lies with the patient, giving them more control over their own disease process.”

PRIME paper wins number one most read paper in 2022 in the British Journal of General Practice

A PRIME Centre Wales publication has won the accolade of most read research paper of the year by the British Journal of General Practice for 2022. The paper was authored by medical student, Amy Clark who was supervised by PRIME GP researcher [Dr Kathy Hughes](#), along with colleagues from Cardiff, Oxford and Bristol Universities, demonstrating PRIME's commitment to developing the next generation of primary care clinical academics.

The paper shared findings from the study by PRIME, Cardiff University, which assessed the accuracy of the National Institute for Health and Care Excellence (NICE) traffic light system in children presenting to UK general practice. The team found that the tool which is used by GPs to help identify seriously unwell children may not accurately detect or exclude serious illness.

The study analysed data from more than 6,700 cases and concluded the widely used NICE traffic light system “cannot be relied upon” and is “unsuitable” for use as a clinical decision tool.

Publication [here](#).

The judges discussed the top ten papers in a special [BJGP podcast](#) and commented:

“The NICE traffic lights paper probably significantly changed practice. This paper is the absolute exemplar that you should not make assumptions that things [clinical tools] 'are good'. This is also a brilliant example, and unusual, of a medical student project winning, so congratulations to Amy and the study team.”

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🎉 Congratulations 🎉 to the research teams of the BJGP Top 10 Research Paper, and to ALL of the research teams who published papers in the BJGP in 2022 🏆🏆

[bjgp.org](#) #PrimaryCare

Top 10 research | BJGP

1 Unreliability of the NICE Traffic Light tool

This tool was found to be unreliable for identifying seriously unwell children in primary care

doi.org/10.2399/BJGP.2021.0432

Amy Clark & Dr Kathryn Hughes

1:49 / 2:19

2:38 PM · Jan 13, 2023 · 800 Views

CARiAD study wins Innovation in Practice Award

This award recognised the ways in which research teams and individuals have made an impact during development, delivery, or implementation and the value it has brought to people’s lives.

The CARiAD study explored the benefits of training family members or loved ones to give as-needed medication to someone dying at home, rather than having to wait for a doctor or nurse to give an injection.

The judging panel called this “an excellent example of a holistic approach to end of life care” with a huge impact on carers and their loved ones. It reduced waiting times for symptom control from 105 to 10 minutes, something “especially important in rural areas” of Wales.

[Dr Julia Hiscock](#), PRIME Research Fellow at Bangor University, accepted the award on behalf of [Dr Marlise Poolman](#) (pictured above) and the study team. Dr Hiscock said: “This project was just so important and we really believed in it. The carers we’ve talked to who’ve done the task with their loved ones are unanimously pleased they had the chance to do this. It feels a powerful and important study and something really helping people at a difficult time of their lives.

“When people are at the end of their lives, they could wait a really long time for district nurses to come in rural areas to help control pain. It’s also horrible for the people around them who want to care and help. So many people said the study helped them feel they did everything they could for their loved ones.”



Urgent need to restore fairness in the funding for GP practices in Wales

A study completed in 2024 has found that current funding levels for GP and primary care services are unfair – with practices based in some of the poorest areas of Wales with the highest patient demand receiving less money than those in the most affluent areas. In the first study of its kind published in October 2024 in the [British Journal of General Practice Open](#), researchers have found that for every 10% increase in patients at a GP practice from the most deprived areas in Wales, they are receiving 1% less in funding due to current funding policies.

Working with primary care researchers in NHS Wales, Public Health Wales and Northern Ireland, the team analysed funding data for general practices in Wales between 2014 and 2022. They explored the fairness of distribution using the percentage of practice patients living in the 20% most deprived small areas in Wales. The team found that although practice funding rose for all practices in this 8-year period, GP practices in Wales' most deprived areas received significantly less funding per patient than the most affluent areas.

[Dr Jonathan Currie](#), a practicing GP in Wales and Honorary Clinical Lecturer based at PRIME Centre Wales, at Cardiff University's Division of Population Medicine led the study. He said: "As the first point of contact with health services for the majority of people, primary care – our GP practises – are a key setting for improving local population health. This underinvestment in areas of the most need is likely to be contributing to existing health inequalities and needs further analysis and action."



Text message reminders can help to improve tooth brushing habits in teenagers

Researchers from PRIME Centre Wales, Cardiff University and the Universities of Sheffield, Leeds, York and Dundee, have collaborated to investigate the effectiveness of a new programme designed to encourage better brushing habits and reduce tooth decay in secondary school pupils.

The [BRIGHT trial](#) examined the effect of twice-daily text message reminders for toothbrushing on 4,680 students between the ages of 11 and 13, spanning 42 schools across England, Scotland and Wales. The researchers tracked the trial's impact over two and a half years.

Professor Zoe Marshman, from the University of Sheffield's School of Clinical Dentistry, who co-led the BRIGHT trial, said: "Tooth decay and all its negative consequences such as toothache, loss of sleep and problems eating are very common in children of secondary school age. While school-based initiatives for children between the ages of 4-11 have been delivered for decades, there is very little for secondary schools.

"However, this is a critical stage for toothbrushing practices to become an established behaviour for adulthood. This is why it is vital to help young people to improve their understanding of the importance of toothbrushing and skills to prevent tooth decay."

The study showed that text message reminders had a positive effect on brushing habits six months later, showing particular benefit for students from low-income families – as the analysis found some evidence of prevention of tooth decay for these students.

[Read more.](#)



PRIME Centre Wales researchers are examining how the use of WhatsApp could increase prostate cancer awareness

Research funded in 2024 by Cancer Research UK will fund a collaborative project at Cardiff University to examine the effectiveness of using WhatsApp as a tool for sharing cancer risk information among peers in the black community.

The funding has been awarded to [Dr Sarah Fry](#) (study principal investigator), a Senior Lecturer of Adult Nursing at Cardiff University School of Healthcare.

On receiving the funding, Dr Fry comments: "Black men have a high risk of prostate cancer, with a 1 in 4 risk of developing the disease and currently have low rates of diagnosis. We want to develop a sustainable way of increasing awareness of prostate cancer within these communities, which is essential for early detection and diagnosis."

In partnership with two lay participant co-investigators in the African-Caribbean and Somali communities in Cardiff, researchers from Cardiff University's School of Healthcare Sciences, School of Medicine and School of Computer Science and Informatics, will conduct a pilot study to test if using peer-led WhatsApp groups can improve awareness and potentially increase early detection and diagnosis amongst black men.

"We decided to use the WhatsApp platform for this project as my previous work, supported by Cardiff University Future Leaders in Cancer Research, suggested that men in the black community would prefer to receive health information from friends in WhatsApp groups. In my work, I have found that African and African Caribbean communities have a culture of learning from each other," added Dr Fry.

[Professor Kate Brain](#) (mentor and collaborator, PRIME work package_co-lead) and [Dr Harriet Quinn-Scoggins](#) (co-applicant, PRIME Research Associate), are both supporting the delivery of this project.

Think Cancer!



Continued developed from WICKED through to the ThinkCancer! Trial

The WICKED programme (2016–2019) (Wilkinson, Brain, Hiscock, Lewis) involved extensive work with primary care staff which fed into the development a behaviour change intervention to expedite diagnosis through primary care and contribute to improved cancer outcomes. The ThinkCancer! Intervention consists of three workshops aimed at the entire general practice team, with central elements including: effective safety netting at practitioner and practice system level, increased vigilance and lowered referral thresholds. Bespoke cancer safety netting plans and appointment of cancer champions are key.

The feasibility of this intervention was tested in the subsequent [Think Cancer! feasibility study \(2020–2022\)](#) (Wilkinson, Brain, Hiscock, Hendry), which has now been completed. The feasibility study was rolled out at the start of the COVID-19 pandemic and was rapidly adapted into a remote digital intervention, allowing general practices across Wales to participate despite the challenges posed by COVID-19. The team were able to recruit to the upper recruitment limit of 30 practices and deliver the study successfully. The study results revealed that a whole-practice workshop to promote cancer diagnosis in primary care is timely and appreciated by general practices across Wales. Lessons learned, participant feedback, a mixed methods process evaluation, stakeholder and patient participant involvement aided in critically evaluating the feasibility trial and findings, and the design of a definitive trial. Progression criteria indicated that a phase III trial is feasible and acceptable.

Funding has been acquired for a randomised controlled phase III trial of a novel behavioural intervention for primary care teams to promote the earlier diagnosis of cancer (ThinkCancer!; Wilkinson, Brain, Hiscock, Hendry). The phase III randomised controlled trial aims to recruit 76 general practices from all across Wales and also some from North West England. The main objective of this novel pragmatic cluster randomised controlled trial is to assess the effectiveness and cost-effectiveness of the ThinkCancer! Intervention compared with usual care, in terms of the Primary Care Interval (time between first presentation of potential cancer to primary care and referral to secondary care).



Multi-agency framework with black and minority ethnic women for violence against women, domestic abuse and sexual violence

[Dr Sarah Wallace](#) has successfully bid for funding from the Health and Care Research Wales Integrated Funding Scheme – Arm 2: Health and Social Care Services and Public Health Research. The funding has [been awarded](#) to researchers not only for their individual projects but also to support the development of their careers.

Sarah Wallace is a Senior Research Fellow at the [Welsh Institute for Health and Social Care \(WIHSC\)](#) and PRIME Centre Wales at University of South Wales (USW), and co-founder and co-chair of the [Violence Against Women, Domestic Abuse and Sexual Violence \(VAWDASV\) Research Network Wales](#).

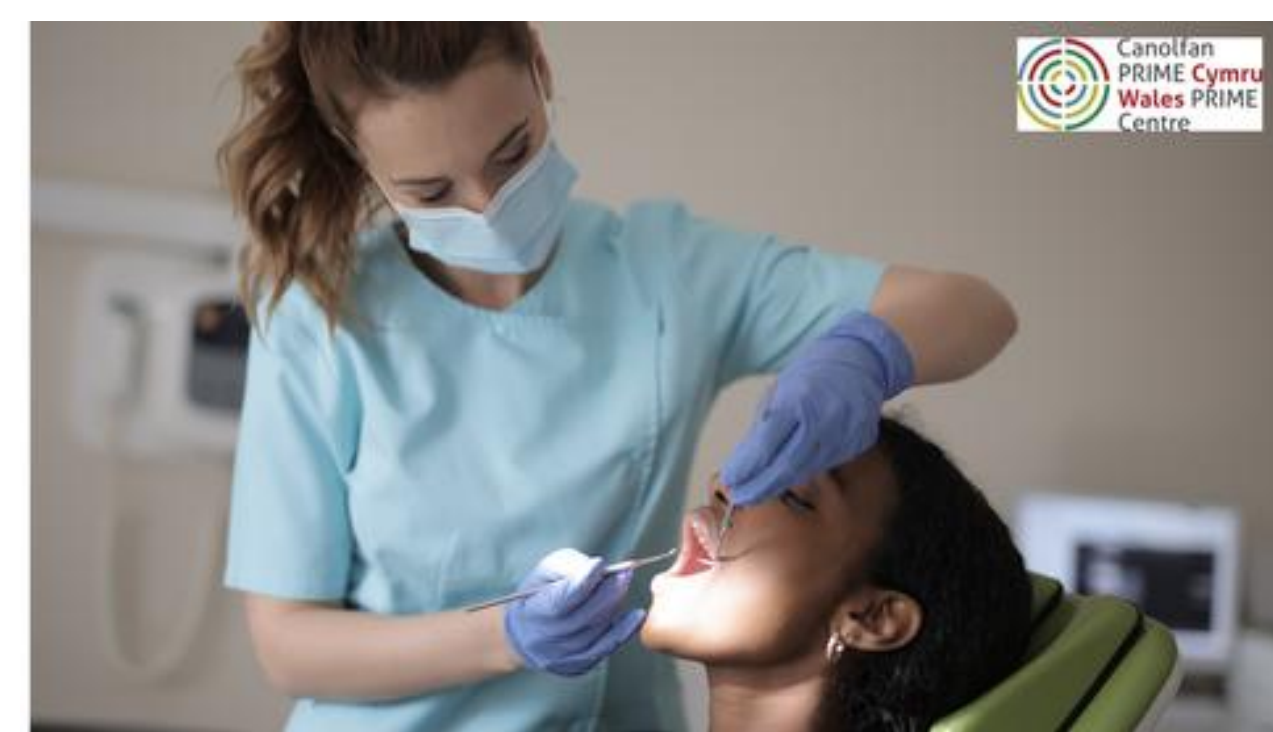
The project, '[Listening is a big step: Co-developing a multi-agency framework with Black and Minority Ethnic women for Violence Against Women, Domestic Abuse and Sexual Violence](#)', involves co-developing a multi-agency framework with black and minority ethnic women for violence against women, domestic abuse and sexual violence. Sarah has been supported with some PRIME funding, and this is her first award as PI/CI so it's especially good news.

In partnership with [Bawso](#), the study uses a qualitative multi-method design (interviews, focus groups, digital stories) using a Community Based Participatory Research approach to explore the needs and experiences of ethnic minority women, acknowledging the disproportionate impact of specific forms of VAWDASV together with additional barriers faced when disclosing and reporting abuse, including distrust of authorities, language barriers, immigration concerns, and fears of racism.

Dr Wallace comments: "This project will work directly with ethnic minority women in Wales to co-create solutions that ensure their voices are heard and their experiences shape the services designed to protect them.

"By improving how services work together, we can have a real impact on both individual well-being and societal change. Working closely with Bawso and their service users to inform this work is central and we are delighted to be able to deliver this project as a partnership".

Start date: 1 October 2024 (£329,726)



NHS patient dental charges in England, Scotland and Wales PRIME research impact

Research led by PRIME Centre Wales researchers, [Professor Ivor Chestnutt and Dr Anwen Cope](#) on patient dental charges in Wales has now been published in the [British Dental Journal](#).

This analysis aimed to: i) review how patient dental charges (PDCs) changed over time in England, Scotland and Wales; ii) determine how these changes relate to a) inflation and b) minimum wages; and iii) how the charges have varied in the devolved administrations.

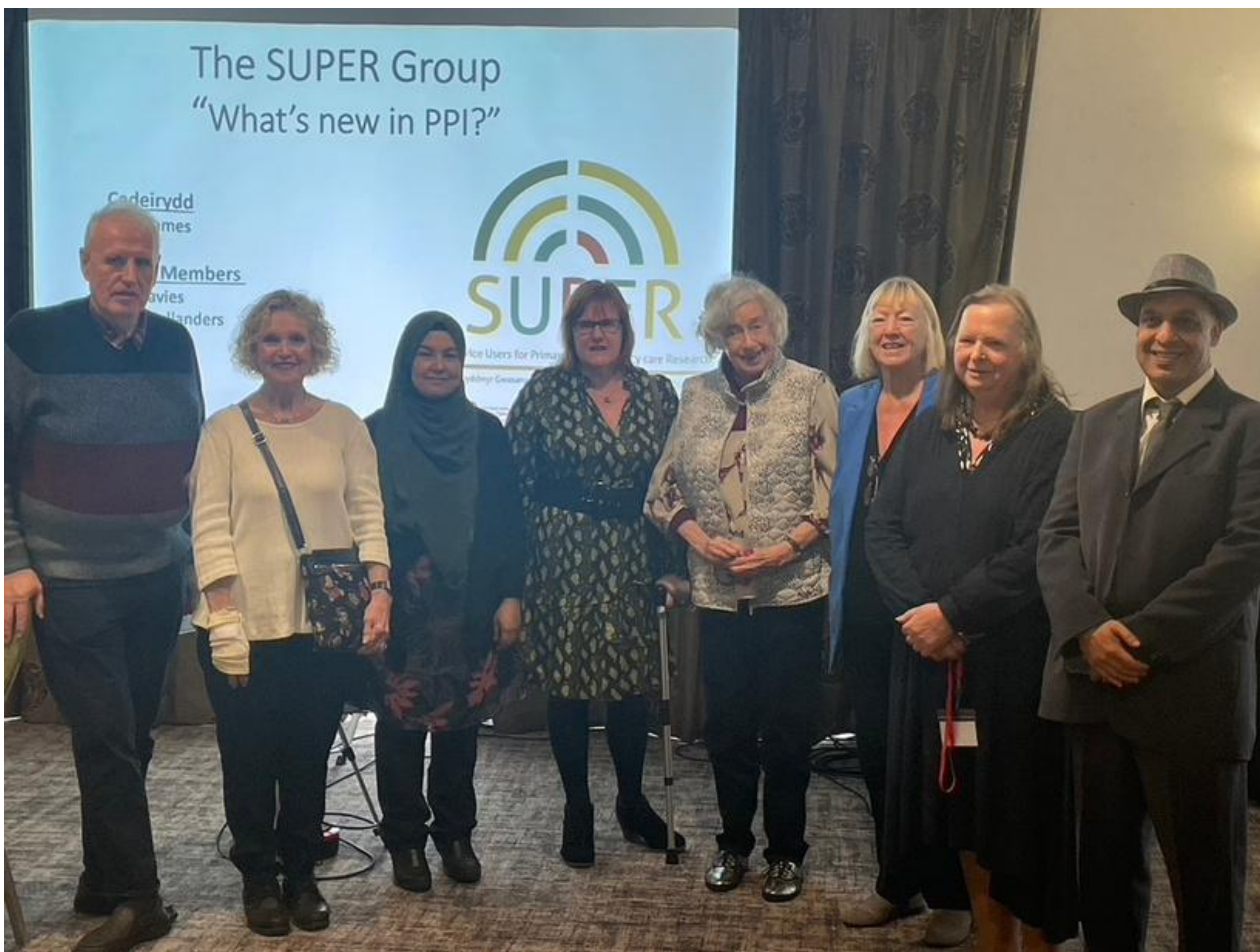
The study found that there has been significant variation in the approach to PDCs across Great Britain both in terms of nominal costs and the degree to which these have kept pace with inflation.

The policy in Wales had been not to increase those charges to the same extent that they have done in England, which has been costing NHS Wales approximately £14 million per year. As a result of this work, patient charges in Wales were increased earlier this year to address the imbalance with changes in England.

Professor Chestnutt commented: "This work has demonstrated the cumulative effect of the differences in NHS patient dental charges between Wales and the rest of the UK over a decade. The discrepancy was such that a substantially above inflation rise in charges in Wales was inevitable. Given the current cost pressures facing the NHS, maintaining such a large differential was unsustainable".

Publication citation and link:
Chestnutt I, Cope A. [A retrospective analysis of NHS patient dental charges in England, Scotland and Wales](#). British Dental Journal (2024).

Public involvement, engagement and collaboration



PRIME is strongly committed to novel public involvement, ensuring that the public's voice is interwoven into every stage of the research process.

The PRIME SUPER (Service Users in Primary & Emergency care Research) group and other public panels (ethnic minorities and people with disabilities - see below) not only enhance the quality, relevance, and impact of our research but also create a sense of shared ownership and trust between researchers and the public.

SUPER Group members have been flying the flag for the [UK Standards for Public Involvement](#) and this has enabled PRIME researchers to focus much more on PPI in their research. Over the past 3 years, 41 PRIME researchers have presented to SUPER at quarterly meetings. These discussions have been invaluable in supporting researchers who have presented their study ideas, recruitment and dissemination methods, and lay

summaries/patient facing documents to the Group. Researchers have received insightful feedback in a way that helped their research be better understood and received by the public and funders.

A recent survey of PRIME researchers who presented their research proposal to the SUPER group prior to funding were successful in securing £4,920,321 of funding. Successful funding awards following early discussion with SUPER group include [STALLED](#) ('What works to improve patient flow, SafeTy, experience, outcomes and costs of ambulances queuing and delayed handovers at Emergency Departments' funded by NIHR HS&DR) and [PREPARE](#) ('Preparing healthcare providers and the public for Multi Cancer Early Detection (MCED) blood tests: towards equitable implementation through co-creation' funded by Cancer Research UK).



Pan-Wales Ethnic Minority Research Advisory Group meeting

Several projects have also recognised the value of including a diversity of views and have set up PPI advisory panels with support from project PPI co-applicants. For example, the [STRETCHED](#) study looking at people who call 999 frequently carried out across England and Wales set up an extended PPI group to ensure interpretation of research findings was realistic and relevant. A publication from the study in Health Expectations was in the top 10% most read paper for 2024 and can be read [here](#).

The [Avoidable Harm in Prisons \(healthcare\) study](#) recruited a panel of people with lived experience of incarceration. Governance panels such as the Confidentiality Advisory Group have also favoured wider PPI involvement when undertaking research with a large population, for example, the [BE SURE study](#) (Black, Ethnic and Asian populations' Service Use Relating to Emergency services for accidents and injuries: multi-method study of presentation, care delivered, outcomes and stakeholder perspectives), and [ThinkCancer!](#) (ThinkCancer! Phase 3 trial of a novel behavioural intervention promoting earlier diagnosis of cancer for primary care teams).

The recently established [EMRAG - Ethnic Minority Research Advisory Group](#), based at the University of South Wales led by [Dr Edward Oloidi](#) and [Dr Juping Yu](#) (pictured below) are building on our PPI work and extend engagement and involvement to include people from underrepresented groups. PRIME members across institutions are involved in this group including the PRIME PPI Lead [Dr Ashra Khanom](#).

Last year the EMRAG also held a research conference dedicated to Equality, Diversity and Inclusion. The event was held on 19th July 2024 at the University of South Wales Conference Centre. The EMRAG's 'Trust Matters. No One is Hard to Reach' event brought together over 100 delegates from diverse communities, third-sector organisations, and universities. It fostered knowledge exchange, strengthened trust, and built relationships with minoritised and underserved groups, creating a welcoming and inclusive environment for open dialogue and learning.

The University of South Wales also provides a public involvement (research) opportunity for people with disabilities ([Unit for Development in Intellectual and Developmental Disabilities \(UDIDD\)](#)). This illustrates the mutual enhancement of minority group involvement through combining experiences.



Dr Edward Oloidi and Dr Juping Yu, co-leads for EMRAG - Ethnic Minority Research Advisory Group, University of South Wales

Conclusion

I hope you have enjoyed this report of PRIME Centre's activities, success and impact on primary and emergency care through 2020-25.

Once again we gratefully acknowledge the wide-ranging contributions to our work from colleagues at the University of South Wales and Bangor, Cardiff and Swansea Universities, and particularly also from public members, and from government, NHS and social care colleagues.

It has been my pleasure and privilege to lead PRIME Centre as Director since 2015 to now, working with such a wonderful group of colleagues and contributors, all motivated to make a difference for the quality and experience of primary and emergency care services. We gratefully acknowledge the funding from Welsh Government, through Health and Care Research Wales to have been undertaking this vital research since 2015 and are delighted that PRIME Centre is now funded to continue until 2030.

Professor Andrew Carson-Stevens will lead PRIME Centre as Director in this new funded period, and collectively we look forward to working with you all to continue and develop our successful work further.



A handwritten signature in black ink, appearing to read 'A. Edwards'.

*[Professor Adrian Edwards, Professor of General Practice,](#)
Division of Population Medicine, Cardiff University;
Director, PRIME Centre Wales;
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