2021 - 2022
Annual report

Canolfan PRIME Cymru
PRIME Centre Wales
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Foreword

Centre Director, Professor Adrian Edwards

I am very pleased to welcome you to the 7th PRIME Annual Report. We have much excellent progress to share, across our workpackages and themes. The Report focuses on the last year’s activities and impact, although of course research usually takes place over longer timescales, and achieves its impact that directly benefits patients, people in Wales and health and social care services more gradually over years.

Our excellent research outputs, environment and impacts have recently been recognised and validated in strong performances from our groups (via their individual universities) in the recent UK Research Excellence Framework results. I certainly want to congratulate our colleagues on their contributions to this ‘league table’ assessment.

Our COVID related research also showed that – as in other research departments – that research can be initiated and conducted more quickly than those usual research timescales, including taking through to impact and effective ‘knowledge mobilisation’ stages.

To be able to do this, we benefited hugely from the infrastructure funding – that is, direct funding for people in posts – that enabled us to write the grants, undertake complex ‘study set-up’ navigating all the regulations and requirements, deliver the research, and the knowledge mobilisation stages, all the while working with our key partners including patient and public contributors (foremost SUPER group members), and representatives from health or social care organisations.

It is unquestionably a team sport, and we have all worked together, and we particularly thank Health and Care Research Wales for their financial support for the infrastructure that enables this wide range of high-quality research.
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:

- 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
- Delivering high-quality research that addresses increasingly complex challenges encountered in primary and emergency care
- Adopting an integrated whole-systems approach to improve services, working at the critical interface between primary, emergency, and social care
- 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
- 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 will include the development of new principal investigators and support for clinicians in becoming research leaders. This will ensure that we can continue to have a strong academic base for primary and emergency care services in Wales in the future.
Aim:
To improve the health and well-being of people in Wales by producing world-leading, locally relevant high-impact research in primary and emergency care.

Themes & Workpackages:

Theme 1: Value-based primary & emergency care
WP1. Infections & antimicrobial resistance
WP2. Emergency, unscheduled & prehospital care
WP3. Patient safety

Theme 2: Seamless health & social care closer to home
WP4. Care closer to communities
WP5. Person-centred care
WP6. Supportive & palliative care

Theme 3: Reducing health inequalities
WP7. Screening, prevention & early diagnosis
WP8. Oral health & primary dental care

Infrastructure wide activities:
Engagement, collaboration and co-production
Public and patient involvement & engagement
Knowledge translation, stakeholder engagement and impact
Communications, publicity, impact & knowledge transfer
Research portfolio development
Methodological development
Workforce development & capacity building
Who's who: meet the team

Governance structure

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).

Our all-Wales emphasis is evident in our rotating Annual Meetings at Cardiff University, Swansea University, Bangor University and the University of South Wales (hosted virtually in 2020). The Leadership group (directors) derives substantial support and strategic direction from the "SUPER" group (patients and public), the All-Wales Steering Committee (policymakers, domain and discipline stakeholders), and the International Advisory Board (overseas academics and PPI contributors).

All-Wales Steering Committee

The PRIME Centre Wales All-Wales Steering Committee meets once 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 Group

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

With a change in membership in 2021, 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.
Core Metrics
Reporting period: 2021/2022

Health and Care Research Wales infrastructure award to the group

Direct funding awarded: £0.9M

Grants won during reporting period

<table>
<thead>
<tr>
<th>Grants won</th>
<th>Led by group</th>
<th>Group collaborating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>12</td>
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</tr>
<tr>
<td>Value</td>
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<td>£6M</td>
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<tr>
<td>Funding to Wales</td>
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<td>£0.9M</td>
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<tr>
<td>Funding to group</td>
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<td>£3K</td>
</tr>
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<td>Additional jobs created for Wales</td>
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<td>1</td>
</tr>
<tr>
<td>Additional jobs created for group</td>
<td>8</td>
<td>1</td>
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Number of publications: 89
Number of public engagement events: 1
Number of public involvement opportunities: 80

Reporting period:
1 year, 1st April 2021 to 31st March 2022

Public involvement opportunities include projects which have recruited public member partners and events open to members of the public.
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 earlier 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 it continues 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.

Professor Helen Snooks, PRIME Associate Director, who led the study said:

“Tools like PRISM are used widely by the NHS in primary and community care, with the aim of reducing emergency hospital admissions. However, there is a lack of evidence to support the view that they enable proactive care and improve patient outcomes.

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.

Given the current context of rising emergency admissions, and Department of Health incentives in England to use these risk tools in community services, our findings are important and timely.”

The study was published in the British Journal of General Practice.

Listen: Professor Helen Snooks being interviewed about the research by British Journal of General Practice

Episode 52 • 16th November 2021 • BJGP Interviews
Welsh research could find new triggers of heart attacks and strokes

A PRIME Centre Wales researcher has been awarded funding for a project to investigate any links between patients having urinary tract infections (UTIs) and suffering a heart attack or stroke.

Dr Harry Ahmed (pictured opposite) is a GP from Rhondda Cynon Taf, Lead for Infections Antimicrobial Resistance WP in PRIME Centre Wales, and Senior Clinical Lecturer in Epidemiology at Cardiff University’s School of Medicine.

He hopes the study, funded by British Heart Foundation (BHF) Cymru, could lead to better outcomes for patients in the future. Dr Ahmed said:

“When a person has an infection, the immune system responds in a way that could affect the circulatory system; these changes may increase the risk of having a heart attack or stroke.

“Researchers previously found that the risk of heart attack or stroke is significantly higher following a respiratory tract infection, like influenza or pneumonia. This work led to a clinical trial where people leaving hospital after pneumonia will be given aspirin to see if it protects against heart attack.”

Dr Ahmed is leading a team of researchers at Cardiff University who have been awarded almost £220,000 by the BHF over three years to explore whether a connection can be made between patients who have been diagnosed with UTIs and an increased risk of heart attack or stroke.

“Urine infections are common but can be difficult to diagnose, particularly in elderly people, and can lead to significant illness and hospitalisation,” he said.

Anonymised health information about patients in Wales can be accessed by approved researchers via a databank based at Swansea University called SAIL, which stands for Secure Anonymised Information Linkage. The system is backed by Welsh Government, funded by Health and Care Research Wales, and operates in partnership with NHS Wales’ Digital Health and Care Wales.

Head of BHF Cymru, Adam Fletcher said:

“In Wales as many as 5,000 hospital admissions each year are for heart attacks, that’s 1 every 100 minutes.

We hope that by funding innovative research like Dr Ahmed’s, we will be able to identify those at risk of heart attack or stroke and prevent these life-threatening conditions before they happen.”

Dr Ahmed added:

“Researchers will use the excellent data science capabilities of the SAIL Databank in Wales to link data from GP records, hospital admissions, and NHS laboratories, to investigate the link between urine infections and heart attacks or strokes, in more detail than ever before.

“If a link is found, it will pave the way for further clinical trials of treatments to see if these serious events can be prevented.”
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 NI.

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.

In 2021, during the Covid-19 pandemic, the Marie Curie Research Centre at Cardiff University initiated a UK survey and, via Marie Curie commissioned a survey company, Opinium to collect data from a representative population of 8000+ respondents, with boosted numbers for Wales (n=2000). Members of the public were asked to give their views on a range of end of life issues including their fears, how they had planned for death and dying, their preferences around end of life care, their understanding of key terms, attitudes to survival versus quality of life, and more. The survey questions were based on those developed and delivered by MCRC in a 2018 Wales study. Both the 2018 and 2021 surveys had more than 2,000 respondents each across Wales, and all the responses in both surveys were analysed by MCRC with further support from the PRIME (Primary Care and Emergency Care) Centre Wales.

We now have two rich datasets that show us how the UK public understand and approach issues relating to death and dying, as well as their expectations for care and support at the end of life. These results have been published in national reports for Wales UK, and NI, 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). The bespoke Devolved Nation Reports have supported and will influence policy development around End of Life Care in Scotland, Wales and Northern Ireland.

In Wales, NI, and Scotland, the results of the survey are being used to inform discussions across the political spectrum and with the public on the national discourse on death and dying, with particular reference to advance care planning, death literacy, and compassionate communities.

We have delivered results via radio, television, social media, national conferences and clinical webinars to reach both public and professionals, to date.
Change of mindset’ needed to put clinical services at the forefront of community pharmacy work in Wales

A review published by PRIME Centre Wales colleagues based at Welsh Institute for Health and Social Care (WIHSC) identified that community pharmacies are well placed to deliver a range of extended clinical services in Wales, but a ‘change of mindset’ may be needed to bring this about.

The review was commissioned by the Welsh Government to analyse dispensing volumes in community pharmacies across Wales. The overall purpose of the study was to consider whether it is feasible to reduce prescription volume in primary care in Wales through practical changes to prescribing and dispensing arrangements, and whether such changes would release significant amounts of pharmacist time to provide direct care in the form of clinical services.

The study drew on a range of stakeholder viewpoints, data and the published literature to build an evidence base around dispensing volumes within community pharmacy. It concludes that a shift in emphasis is needed in order to put clinical services work first within the majority of community pharmacies.

At the moment, the mantra tends to be that the clinical services fit around the dispensing activity. The report provides useful evidence on how change could be made so that dispensing activity could more easily fit around the provision of clinical services, and what might be needed to move in that direction.

The report was submitted to Welsh Government in March 2021 but due to COVID priority work and the required engagement with external stakeholders, the publication of the report and subsequent Welsh Government response has been delayed until January 2022.

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.

NICE. Shared decision making. NICE Guideline 197, NICE, 2021. Available at: www.nice.org.uk/ng197

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.
Public involvement, engagement and collaboration

Widening the diversity and locations of public members

Overall, public involvement from diverse communities and locations has strengthened during this reporting period and contributors have enhanced their skills in virtual involvement. Remote working, established during the COVID pandemic lockdowns, has become routine practice for public contributors. It is an effective way for many individuals to be involved because it removes the need for travel although the opportunity for personal interaction and informal support is reduced.

The SUPER public involvement group (Service Users for Primary and Emergency care Research) held quarterly meetings and provided public and patient views on 15 research projects. Feedback from researchers presenting at the meetings shows how constructive they feel this interaction is. They reported that SUPER contributions met or exceeded presenters’ expectations.

The mix of feedback included: support for the research idea; need to clarify various aspects; advice about optimising public involvement; some very specific feedback e.g. relating to population, methods and communication.

Presenters said SUPER comments were shared with their research team and used to revise and update the research plan before funding submission. They said the process was supportive, SUPER members were friendly and the comprehensive meeting notes were very helpful.

This year, SUPER welcomed five new members. These individuals were selected to widen SUPER diversity; employed status, parents of school age children, different ethnic and cultural backgrounds.

SUPER members were actively involved in organising the PRIME Annual Meeting with two members on the organising sub-committee. Their proposal to include public involvement as a topic on the programme was accepted by other PRIME colleagues. The session, entitled ‘Implementing public involvement for Impact, included presentations by SUPER members, PRIME PPI Lead Bridie Evans and, from Canada, Carolyn Canfield Adjunct Professor & citizen-patient, University of British Columbia, spoke on How patient and caregiver roles in healthcare research are evolving in Canada and internationally. SUPER also submitted a poster (pictured opposite) presentation.

All PRIME-supported research across all work packages actively involves public contributors. As an example of the robust and embedded nature of that involvement, the GPs in EDs research team has co-authored a paper ‘Implementing public involvement throughout the research process – experience and learning from the GPs in EDs study’ currently under review with the Health Expectations journal. This paper describes how leadership and trust within a research team can support and extend public involvement beyond initial expectations.
Other examples of involvement and how this affects the research include: Lived Experience Advisory Panel (8 individuals) on the STRETCHED study advised on how to recruit and interview potentially vulnerable adults who had made many calls to 999 emergency ambulance services. Panel members highlighted the need to recruit through trusted intermediaries and ensure appropriate support was available when people discussed a topic with such emotional resonance.

Public contributors on the Trauma Care study evaluating the Welsh Ambulance Service Trust Trauma Desk helped code interview transcripts. Their personal experience of receiving care for trauma injuries gave insight into the responses by paramedics, including what was omitted.

**People from minority ethnic communities are involved in the BeSURE and HEAR2 studies**, both evaluating services for people with ethnically diverse backgrounds including refugees and asylum seekers. Their cultural and personal experiences provide invaluable insight to ensure the research is relevant, appropriate and deliverable. Both studies are recruiting and training peer researchers who will use their language skills, cultural understanding and local contacts to collect data from people in diverse communities.

An example from the Cancer Screening & Early Diagnosis work package (WP7) includes the continual input and engagement with the public and participants for the COVID-19 Cancer Attitudes and Behaviours Study (CABS) successfully involved throughout the study, contributing at all stages of the study from inception through to analysis, dissemination and evidencing impact and is an extremely valuable member of our team. Ms Hepburn has been supported, where appropriate and comfortable to do so, to co-deliver CABS updates at public facing engagement events alongside our study PI (Prof Brain; Wales Cancer Alliance Webinar on ‘Public Awareness of Cancer During COVID’, December 2021), and has represented CABS at a Senedd cross-part meeting on public health research (December 2021).

Ms Hepburn has also played a crucial role in informing the development and roll-out of our public-facing end of study materials, including a infographic and video animation (both can be found here).

The infographic (opposite) and video have been sent to all study participants and have been rolled out on study, partner and stakeholder social media platforms and have received great engagement so far. Public involvement, engagement and public-facing dissemination are at heart of our work.

**PPI, engagement and public-facing dissemination are at heart of our work.**

The above examples would not be possible without the appropriate planning and review of public involvement throughout the study and as recognised in the national standards. It is also of upmost importance to the team to meet national standard requirements in relation to honorarium, offering a flexible and supportive approach to participation in study activities (e.g. offering flexibility in attending meetings virtually/in person, allowing flexibility in how feedback is provided on study papers and manuscripts (and training provided on the use of software such as Teams where wanted and appropriate), and offering the option to meet outside of study management meetings or working hours where needed or preferable).
The 2021 PRIME Centre Wales Annual Meeting was a virtual conference held on the 16th of November. Whilst restrictions meant that this was our second annual meeting to be held completely online, it meant we were able to offer a truly ‘international event,’ widening our audience reach, with over 130 people joining us live on the day from as far afield as Australia and the USA.

Being online also meant we are able to welcome esteemed international guest speakers from Melbourne and Canada, who braved the time difference to join us live on the day:

- **Professor Jon Emery** (centre top), Herman Professor of Primary Care Cancer Research, University of Melbourne, Australia
- Presentation title: Translating risk prediction models for cancer prevention, screening and early diagnosis in Australia.
- **Carolyn Canfield**, Adjunct Professor & citizen-patient, University of British Columbia, Canada
- How patient and caregiver roles in healthcare research are evolving in Canada and Internationally.

In addition, we were delighted to welcome guest speakers, who had their winning abstracts selected for presentations from an open call from our wider researcher community:

- **Dr Rebecca Bullingham**, Advanced Nurse Practitioner working in Oakfield Street Surgery in Ystrad Mynach/PhD graduate from Cardiff University
- ‘Clinical supervision for non-medical independent prescribers’

- **Dr Anwen Cope** (centre below), Senior Clinical Lecturer and Honorary Consultant in Dental Public Health, School of Dentistry, Cardiff University.
- The OPTIMISE study (Optimising value-based, preventive care delivery in NHS General Dental Services).

- Dr Darren Cousins, Consultant Sexual Health & HIV at the Cardiff Royal Infirmary, Cardiff & Vale NHS UHB
- ‘A pilot study to assess the feasibility of stimulating HIV home testing among people who use GP services’

Recordings of these presentations can be viewed using the links above.

The full agenda is available to [view here](#).
Work package key achievements over the past year

WP1. Infections & antimicrobial resistance
Leads: Dr Kathy Hughes & Dr Harry Ahmed

Antimicrobial resistance is one of the most serious health threats of our times. 75% of all antibiotic prescribing in the UK is in primary care. Our research aims to increase understanding of the epidemiology of infections and improve antibiotic prescribing.

Key activities/highlights over the past year:

1) Respiratory tract infection and serious bleeding – findings published in the BMJ

Harry Ahmed (WP co-lead) secured a NIHR Advanced Fellowship to investigate the impact of infection on oral anticoagulant users. Findings from the first study from this programme of work were published in the BMJ in December 2021 and found significant rates of major bleeding in oral anticoagulant users in the 0-14 days following a respiratory tract infection. Ahmed was lead author with colleagues from Cardiff University, University of Oxford, and the UK Health Security Agency.

Further studies are ongoing, and the programme of work will contribute to future clinical guidance and safety recommendations for oral anticoagulant users.

2) Helping women with recurrent UTI understand their treatment choices – prestigious NIHR Doctoral Fellowship for Leigh Sanyaolu (pictured above)

Leigh Sanyaolu, Clinical Research Fellow (pictured above) was awarded a National Institute for Health Research (NIHR) Doctoral Research Fellows for a programme of work on recurrent UTI in women. The work includes comprehensive evidence synthesis to quantify the benefits and harms of current treatment options, and understand stakeholder views of the various options available, complex data analytics to determine links between long-term antibiotic use and subsequent antibiotic resistant infections, and finally, development of a decision aid.

The work is supported by a PRIME team, across the workpages of infections and person centred-care, comprising of Adrian Edwards, Fiona Wood, and Harry Ahmed, and colleagues from the Centre for Trials Research (Rebecca Cannings-John) and the UK Health Security Agency.

3) Urinary tract infection and heart attacks and stroke

This British Heart Foundation funded study is using complex data-linkage to identify new mechanisms of acute cardiovascular events.

Dr Harry Ahmed is Chief Investigator on the MISSOURI study which started on 1st May 2021. The team comprises colleagues from the Centre for Trials Research, SAIL databank and the Specialist Antimicrobial Chemotherapy Unit and is linking GP, hospital admission, and microbiology data to better understand links between urine infections and heart attacks and strokes.

The research has received considerable publicity from the BHF and aligns with their policy to increase data science research in Wales.

Dr Ahmed said, “Researchers will use the excellent data science capabilities of the SAIL Databank in Wales to link data from GP records, hospital admissions, and NHS laboratories, to investigate the link between urine infections and heart attacks or strokes, in more detail than ever before. If a link is found, it will pave the way for further clinical trials of treatments to see if these serious events can be prevented.”

Head of BHF Cymru, Adam Fletcher, said, “In Wales as many as 5,000 hospital admissions each year are for heart attacks, that’s 1 every 100 minutes. The public’s generosity has funded BHF research that has turned ideas that once seemed like ‘science fiction’ into treatments and cures that save lives every day. But millions of people are still waiting for the next breakthrough.”
Key activities/highlights over the past year:

1) Evaluating policy responses to the COVID-19 pandemic
During this year, we have been working to deliver two major studies looking at the impact of COVID-19 on the delivery and experience of care. These projects are providing evidence on the impact of two aspects of the policy response to the pandemic: the shielding programme, and pandemic triage protocols in emergency ambulance services.

EVITE Immunity (funded through the National Core Studies Immunity Programme) is evaluating the impact of the shielding intervention, introduced during the pandemic to reduce the risk of harm to clinically extremely vulnerable people. Using routine data available through the SAIL databank and working with key stakeholders, we produced outputs from Phase 1: an exploration of the rationale for shielding; a profile of the 117,000 people shielding in Wales in terms of clinical conditions and demographic factors; estimated costs of the shielding programme; and an analysis which indicated higher rates of infection, death and health care utilisation in the shielding group compared with the general population.

We engaged with policy makers through presenting findings to the Welsh Government’s Technical Advisory Group (responsible for COVID-19 response in Wales) in July 2021. We also ran a panel discussion on ‘The pros and cons of shielding’ at the Health Services Research UK conference in July 2021, and have prepared four papers from Phase 1 for publication.

In the TRIM evaluation, we are working with emergency ambulance services around the UK to examine their response to COVID-19, including triage procedures tailored to the pandemic. The first paper from the study, on the demand across the UK for emergency ambulance care in the first wave of the pandemic, has been published in the Journal of American College of Emergency Physicians Open. We have also presented TRIM to the Welsh Government TAG group, and to the HSRUK conference in July 2021.

2) Addressing equity of access to emergency and urgent care
We have continued to work to build the evidence base on how access to emergency and urgent care can be made equitable to all. We were successful this year in securing funding of £729,227 from NIHR for BESURE, a 24-month study (from October 2021) of differences in how people from ethnic minority groups present to emergency ambulance services and Emergency Departments (EDs) with injuries, the care they receive and outcomes compared to White British people. Co-Chief Investigators are Professor Helen Snooks and Dr Ashra Khanom.

BESURE builds on our current HEAR study (Health and Care Research Wales RPPB funding, with Public Health Wales) examining the interpretation needs of asylum seekers and refugees when accessing emergency and unscheduled health care in Wales, and on the HEAR study of the health experiences of asylum seekers and refugees, a collaboration with Public Health Wales which reported in 2019. Output from the HEAR study is having evidenced impact, for example, the HEAR Technical Report has been added to the British Medical Association (BMA) Toolkit for supporting asylum seekers and refugees.
3) Building the evidence base on emergency admission risk prediction tools

We continued with our programme of work examining the use of emergency admission risk prediction tools in primary care. Welsh Government policy makers used findings from our completed PRISMATIC study to halt their rollout of risk prediction tools in primary care in Wales, and this year we ensured that PRISMATIC continued to achieve impact, in line with the Social Care Research and Development Strategy for Wales 2018-2023, by presenting findings to an NHS England Virtual Huddle of around 200 practitioners and policy makers.

We were awarded NIHR funding for a major follow-on study, PRISMATIC 2, which will assess effects, mechanisms, costs, and patient and healthcare professionals’ views related to the introduction of emergency admission predictive risk stratification tools in England. PRIME infrastructure funding directly supported development of this research proposal as part of a programme of work around risk prediction (including REF 2020 Impact Case Study, Mark Kingston’s PhD studies and dissemination of completed research to policy and research audiences). The work fulfils the higher level ambitions of the Bevan Commission, ensuring that health care is delivered prudently, without unnecessary activity, and targeting those at greatest need. The study also supported the Digital Health and Social Care Strategy for Wales, by providing evidence to inform an effective shift to digital tools in the delivery of health care.

4) Capacity building in an international context

During this year we consolidated our links with research partners in Morocco, Tunisia, the US, New Zealand and England, aimed at building international capacity and sharing knowledge on health and social care interventions. The IMPact study, funded through the UKRI Global Challenges Research Fund, addressed child welfare in southern Morocco, working with local families and stakeholders to develop safeguarding and fostering policies. We won further funds (RWIS Collaboration Booster Fund) to support international collaboration and knowledge exchange to increase the reach of real-life research evidence, by delivering workshops in Morocco and Tunisia. IMPact supported the research partner FAPE, a leading child protection civil society organisation in Morocco, to design service improvements.

Developing the literature review and identifying a useful methodology for the Moroccan context in IMPact has led to FAPE and the Moroccan Children’s Trust (MCT) drawing on the same systems approach to child protection in order to map the child protection system for the region of Souss Massa in a €400,000 two-year project funded by the European Union.

IMPact has contributed to a successful application for increased funding for the safeguarding centre, Centre Amane. MCT shared their engagement in the research project with their major funder Penny Appeal UK and used the preliminary findings of the qualitative study in order to secure a 50% increase in funding, to provide day care, staff and local training. IMPact fulfils the objectives of Public Health Wales International Health Division, in particular ‘strengthening Wales’s global health impact through sharing our assets and contributing to global health security and sustainable development.’ The Morocco-based researcher on IMPact, Dr Fadi Baghdadi, has now joined the Swansea PRIME Centre team, bringing additional Centre team, bringing additional research capacity, skills and experience.

See next page for the study team’s prize winning poster: ‘Improving child welfare in Southern Morocco: engaging with local families and stakeholders to develop safeguarding & fostering policies’
**IMPact**
Improving child welfare in Southern Morocco: engaging with local families and stakeholders to develop safeguarding and fostering policies

**A GROUNDED METHODOLOGY**

**A Systems Approach**

**BACKGROUND**
One in every thirty children in Morocco are currently in institutional settings. This is due to:
1. Illegality of sex outside marriage and an increase of women entering sex work and having unplanned births
2. Illegality of voluntary termination of pregnancy and the stigmatisation of children born outside wedlock
3. A lack of social services which means family breakdown and child abandonment is common

At its core, it is a lack of state-sponsored safeguarding and alternative care legislation and programmes that contribute to the high rates of children and young people entering institutional settings.

**VISION**
We envisage long-term sustainable effective change is possible by working collaboratively alongside researchers, professionals, and civil society from the Maghreb in a future large scale Participatory Action Research (PAR) project to identify, develop, and implement local social interventions in response to child abuse and neglect.

**RESEARCH OBJECTIVES**
1. Review existing safeguarding policies to identify gaps and recommend barriers to fostering
2. Provide barriers to foster carers and promote children to remain with their birth parents
3. Contribute to local safeguarding and foster care policies
4. Synthesise results to inform future research, to raise awareness of the general community and support vulnerable foster carers and foster children

"In our society, when an unmarried woman has children, people harbour feelings of hatred towards the small children"
*Single Mother of 4 children*

"There are those children who think of suicide because they are not offered much care from their parents and end up in the centre"
*14yr old woman in Residential Centre*

"The professionals work in isolation, the child protection system is fragmented, there’s no adequate sense of collaboration, boundaries or limits within their roles"
*Foster Care Manager*

**ODA Outcomes**
1. Research supported Moroccan NGO to improve and better target the impact of its services at the safeguarding centre, Centre Amarha
2. Literature review led to the methodology used by local NGO to map the child protection system for the region of Souss Massa, Morocco
3. Research contributed to UK NGOs’ successful application for a 50% increase in funding for the safeguarding centre, Centre Amarha
4. Diverse team has drawn on the strengths of UK academics and a paediatrician, US and Australian academics, and a Moroccan NGO to actively seek and apply for future research funding with additional researchers from the Maghreb
5. Planning papers for publication in internationally recognised high-impact peer reviewed journals

£5,000 will support the research partnership by sustaining 10 foster placements, generating data and understanding that is essential for intervention and proposal development as our collaborative research programme goes forward.

**Project Team**
Professor Helen Snooks
Dr. Fadi Baghdadi
Dr. Christopher Hands
Professor Ann John
Dr. Ashra Khanom
Mr. Abdelaziz Sfoussi
Dr. Mary Elizabeth Rautkis
Mr. Itaya Khili"f
Ms. Hajar Karda

Participants from a focus group with child protection professionals in Taroudant

Mapping out an issue tree with children in Residential Centre Tanwanou

Participants from a focus group with women in Ouled Terna

Drawing an issue tree with children at Residential Centre Ratfa
Key activities/highlights over the past year:

1) Development of a human factors and systems-based approach to understand patient safety concerns with patients and the public

PRIME funding has enabled collaborative working between Prof Andrew Carson-Stevens and Dr Natalie Joseph-Williams (WP5. Patient-centred healthcare) to develop a survey for identifying patient-reported safety concerns. The survey items have been embedded into the Sêr Cymru-funded COPE study and the National Core Studies Immunology-funded EVITE study. With the COPE study team, a mixed methods analysis of patient-reported safety concerns reported by survey 12-, 18- and 24-months, alongside follow-up key respondent interviews is ongoing.

This work was conducted by PRIME staff, Dr Anna Torrens-Burton and Ms Delyth Price, alongside Academic GP Fellow Dr Thomas Purchase, and safety report analysis led by HEIW Academic GP registrar, Dr Kate Davies and Clinical Lecturer, Dr Joy McFadzean. A policy briefing was prepared for Welsh Government in December 2021 inclusive of data and analyses to-date to advise on key priorities for safety improvement from a patient and public perspective.

Building on the PRIME and RCGP/Marie Curie funded research to understand how human factors design issues are influencing system performance in out-of-hours community palliative care (Yardley et al. 2022), the team has developed a novel human factors and systems-based approach to sensitively interview patients and the public.

Carson-Stevens and Joseph-Williams are currently planning collaborative work with the NHS Wales Delivery Unit to use our novel human factors and systems-based approach to explore patient- and family-experiences of healthcare resulting in nosocomial infection. The team are preparing a NIHR HS&DR proposal for Autumn 2022 to further develop and validate our novel methodological approach.

Papers:


2) Visualising the patient safety priorities for eye-health in Wales

PRIME has been a critical catalyst between Prof Andrew Carson-Stevens, Prof Rachel North and Dr Jen Acton for introducing a patient safety research agenda to the Ophthalmic Public Health Group in the School of Optometry and Vision Sciences (08/2018-), Cardiff University.

To-date, our collaboration has resulted in the co-development of grants, exchange of early career researchers, and in the past year conference presentations and academic papers to share our internationally novel and important contributions to advance eye health safety.

As a team, we have advised in the past year Welsh Risk Pool on the content and format of a 'Serious Incident Reporting Form' for optometry in Wales.

A KESS-2 funded PhD student (Ms Elinor Macfarlane) is currently analysing all patient safety incident reports describing eye-related healthcare-associated harm in Wales. We will share our findings and priority recommendations to improve the safety of eye health with policy colleagues in Welsh Government and industry partner Optometry Wales.

Conference presentations at Welsh Optometric Committee Research Symposium: Facilitating Practice Based Research in Optometry March 2022:
• The experiences of the optometry profession in the quality and safety of patient care in Wales. MacFarlane E, Carson-Stevens A, North R, Ryan B, Acton J.

Patient safety priorities for eye-health in Wales

Professor Rachel North,
Professor of Optometry, Cardiff University School of Optometry and Vision Sciences

Dr Jennifer Acton,
Senior Lecturer & Director of Recruitment and Admissions, Cardiff University School of Optometry and Vision Sciences
Key activities/highlights over the past year:

1) Addressing long-standing health inequalities in Wales through the Family Resilience Assessment Instrument and Tool (FRAIT)

Family resilience is key to supporting pre-school children’s health and development. In 2014, USW researchers developed an evidence-based assessment tool for health visitors (HV) to identify those families. Family Resilience Assessment Instrument and Tool (FRAIT) was incorporated into WG ‘Healthy Child Wales’ (2016) and mandated October 2017.

In 2022, PhD student Michelle Thomas successfully defended her thesis, supervised by Carolyn Wallace and David Pontin, PRIME Centre Wales, University of South Wales.

Researchers and Health Visitors co-productively explored family resilience as understood by HVs and developed FRAIT (available at www.frait.wales), which has changed every day HV practice. FRAIT consists of: FRAT (Assessment Tool), FRAI (Assessment Instrument), guidance document, training package and aide memoire (Keep-in-mind). An All-Wales HV FRAIT Community of Practice (COP) was established April 2017 with 20 members.

2) Evaluation Framework

Researchers (Wallace, Pontin, Llewellyn & Richards) developed an evaluation framework through an action research study for NHS Wales Urgent Primary Care Centre Pathfinders which includes an agreed core minimum dataset, development matrix, a patient satisfaction questionnaire and a literature review on the definition of urgent primary care. Wallace presented the findings to the Six goals for Urgent and Emergency Care Learning event. Publications are in draft development. The UPC Pathfinder Programme is part of the Strategic Programme for Primary Care, in an All-Wales collaborative approach between University Health Boards (UHBs) and Welsh Government to address the requirements of ‘A Healthier Wales’ (2018), ‘Social Services and Well-being (Wales) Act 2014’, and the ‘Well-being of Future Generations (Wales) Act 2015’. Welsh Government has made up to £4 million available to UHBs for 2020/21 and further recurring funding from 2021/22 onwards, to develop local urgent (same day) primary care centre pathfinders, to simplify the health provision, enable better management of demand, avoiding ‘hand offs’ and multiple entry points. The aim is to create a multidisciplinary primary care offer which will be geographically consistent 24 hours a day, 7 days a week across Wales.
The Violence Against Women Domestic Abuse and Sexual Violence (VAWDASV) Research Network Wales

The Violence Against Women Domestic Abuse and Sexual Violence (VAWDASV) Research Network Wales (co-founded and co-chaired by Dr Sarah Wallace) was launched in November 2021 via a USW Tomorrow Matters in person and to mark the International Day for the Elimination of Violence Against Women. VAWDASV is a major public health and social care problem, criminal justice and human rights issue, with a range of adverse consequences for health and wellbeing over the life course.

Since the introduction of the VAWDASV (Wales) Act 2015, ending VAWDASV has become an increasing policy focus for WG, e.g., The Well-being of Future Generations (Wales) Act 2015 defines freedom from violence and abuse as a key component of wellbeing, Taking Wales Forward 2016-21, which pledged to build on the provisions of the VAWDASV Act, and The Social Services and Well-being (Wales) Act 2014.

The aim of the VAWDASV Research Network Wales is an inclusive research community for Wales that provides a safe, open forum to bring together those who are working towards an end to VAWDASV to set the future research agenda, foster collaboration and develop grant applications, undertake high quality research, and work towards the elimination of VAWDASV. The launch event included keynote speeches from Jane Hutt MS, the Minister for Social Justice, Martin Steggall, Pro Vice Chancellor for Research, University of South Wales, a panel discussion covering key topics in the area of VAWDASV, and a poetry recital performed by University of South Wales Faculty of Creative Industries MA Drama students.

See: Live broadcast (opposite).

Since its launch, we have a growing membership across Wales representing the sector, policy, and academia, increasing Twitter following, and regular bi-monthly meetings.

Professor Emily Underwood-Lee, co-chair of the event said:

“We aim to align all of our activities with the policy landscape of Wales, for example the landmark Violence against Women, Domestic Abuse and Sexual Violence Act (Wales) Act 2015, The Social Services and Well-being (Wales) Act 2014, and The Well-Being of Future Generations (Wales) Act 2015."

“By determining and understanding the research and practice priorities for Wales, we can share knowledge and expertise, ensuring that the network is accessible and inclusive, and develop future partnership working across the UK and internationally.”
4) Minority Ethnic Research Advisory Group (MERAG)

In Wales, the government has placed a strong emphasis on a ‘more inclusive and equal Wales’. Distinctive Welsh policies emphasise principles like inclusion, equality, rights independence, empowerment, control, and partnership (for instance, Social Services and Wellbeing (Wales) Act, 2014 and Wellbeing of Future Generations Act, 2015) to address inequalities (Improving Lives supports Prosperity for All, 2018a, p.1). From a research perspective, this means focusing specifically on such issues and conducting/developing more inclusive research (Race Equality Action Plan for Wales, 2021, Wellbeing of Future Generations (Wales) Act 2015).

Although there is little argument about the needs for such work; however, there may be several challenges in meeting these successfully. Firstly, researchers need to be more aware of inequality. At the same time, how people from Black and Minority Ethnic communities might be recruited into research studies may also be problematic. Recent experience conducting a Covid-19 study suggests a need to be proactive and creative in thinking about how this might be achieved from a research perspective.

One approach being developed at by PRIME colleagues at the University of South Wales, to respond to these challenges is by establishing a Minority Ethnic Research Advisory Group (MERAG). The MERAG initiative aims to proactively support efforts to make research culturally inclusive by establishing and working collaboratively with an advisory group of people from Black and Minority Ethnic (BAME) communities.

5) The coronavirus and people with learning disabilities study

The COVID pandemic has had an overwhelming and long-lasting impact on everyone. People with learning disabilities were more likely to experience an adverse outcome from a COVID infection. We know less about what it was like for people with learning disabilities to live through the pandemic.

This study was designed specially to consider the impact of the pandemic and is associated restrictions on adults with learning disabilities across the UK. It is the largest study involving adults with learning disabilities and family carers/paid support staff, to date, and was funded by UK Research and Innovation.

In Wales, the study was led by Professor Stuart Todd and Dr Edward Oloidi (University of South Wales) and Dr Stephen Beyer (Cardiff University). In each of the four countries of the UK the researchers worked in partnership with key learning disability organisations. In Wales, the researchers worked with All Wales People First, Learning Disability Wales and the All-Wales Forum of Parents and Carers.

The study found that people with learning disabilities in Wales engaged with public health advice for their own safety and for the safety of others. About 33% people across both groups reported that someone they knew well had died during the pandemic. People with learning disabilities experienced poor physical health and emotional wellbeing during lockdown. We also found that the social lives of people with learning disabilities were severely restricted during COVID and have yet to fully recover.

6) Health and Care Research Wales funded Optometry Study

Work continues on the sequential Realist Review and Evaluation constituting a work package within Hospital to Community (H2C Colab) – a Health and Care Research Wales funded study identifying the value of optometrists monitoring and managing chronic sight threatening eye disease in primary care. The Realist Review has now been completed, and the team are in the process of testing nascent programme theory within the Realist Evaluation phase through a series of focus groups and semi-structured interviews with community optometrists, hospital eye service, and third sector staff.

7) PARCHED study with Cwm Taf Morgannwg

Wallace and Davies are collaborating with Cwm Taf Morgannwg UHB on the PARCHED study - where we are completing a realist review and pilot evaluation exploring attitudes to hydration in a population at risk of frailty. The study will lead to the development of a refined programme theory articulating what hydration interventions work, for whom, to what degree, in what contexts, and how and why. Findings will have salience at individual, organisation, and system level in terms of patient and carer education, staff development, and wider service configuration, as well as aligning with the Welsh Government strategy for older people in Wales 2013-2023.
Key activities/highlights over the past year:

1) **WHO collaboration**
PRIME colleagues have been involved in a qualitative evidence synthesis on ‘what matters to families in the care of their preterm or low birthweight babies?’ commissioned by the World Health Organisation. An updated WHO guideline on the healthcare of preterm or low birthweight (LBW) infants is currently being developed. An understanding of families’ perspectives and values was required by WHO to inform the development of their guideline. The review is complete, submitted for publication and will also be presented at the International Conference on Communication in Healthcare, September 2022.

2) **Effectiveness of interventions for COVID-19 prevention in care homes**
We have developed a Core Outcome Set (COS) for trials assessing the effectiveness of interventions for COVID-19 prevention in care homes. A minimum set of outcomes, termed a core outcome set (COS), will ensure that the results of interventions can be compared and combined. PRIME funding enabled researcher Ishrat Islam to support the COS development process. A paper from this work relating to attitudes to the vaccine, health service use, and risk behaviours.

3) **Supporting care home residents being engaged in research**
PRIME colleagues (Wood, Shepherd, Hood, Wallace) are delighted to have been successful in being awarded funding from Health and Care Research Wales for a Social Care PhD studentship. The studentship relates to supporting care home residents being engaged in research. Our student started in post in January 2022. The project addresses the priority area of equality, diversity and inclusion and is aligned with the wider Welsh Government policy in this area (Strategic Equality Plan, NIHR Include framework). The project also aligns with the new White Paper ‘Rebalancing care and support’ by recognising the importance of upholding people’s rights and promoting wellbeing and supports social care in Wales.

We continue to work on the qualitative and quantitative dataset generated by the COPE Cymru study (initially funded by Sêr Cymru). Our 2 year follow up data has just been completed representing over 3,000 respondents. We have a range of outputs from this work relating to attitudes to the vaccine, health service use, and risk behaviours.

4) **Health Board collaboration to widen provision of social prescribing**
Members of the Person-Centred Care team have recently been awarded funds to undertake innovation and engagement work in Cwm Taf Morgannwg UHB alongside a Health Board initiative to widen provision of social prescribing. Using co-production methods, our aim is to understand what people in Cwm Taf Morgannwg want and gain from social prescribing, and create resources which support the development of local services, and increase understanding of social prescribing in Wales.

5) **Patient-Reported Indicators Surveys (PaRIS)**
We have been leading for Wales the work associated with participation in the international OECD Patient Reported Indicator Surveys Programme. Prof Andrew Carson-Stevens, Dr Natalie Joseph-Williams and Dr Denitza Williams have been working with the international consortium as well as the Value in Health Team within NHS Wales to facilitate Welsh participation. The field trial participation (starting May/June 2022) will involve international and local collaborative efforts, working with the OECD consortium as well as Health Wise Wales and Welsh Shared Services, the field trial is being led by Cardiff University.
Key activities/highlights over the past year:

1) Lay carer administration of as-needed subcutaneous medication for common symptoms in the last days of life for those choosing to die at home – rapid implementation of research into practice

High quality palliative and end of life care research is needed in the UK, as such, it is an area of priority for the National Institute for Health Research (NIHR). The Bangor University (BU)-led, NIHR funded CARiAD feasibility randomised controlled trial (RCT) illuminated a pertinent element of care of the dying at home, that of the role lay/unpaid carers (family and friends) (henceforth referred to as carers) can play in administering needle-less injections to manage common breakthrough symptoms. Though legal, the intervention is new to most of the UK. This means that carers in most areas of the UK do not have the option to consider this type of care for a dying loved one at home.

In the UK, most people wish to be at home when they die. Timely symptom control is crucial. People in their last days of life are often unable to use oral medication; as-needed (top-up) injections for breakthrough symptoms require a healthcare professional (HCP) to travel to the home to administer. The wait between a symptom, like pain, developing and a HCP arriving can be distressing and often means that symptoms are not controlled in a timely way.

Carer-administration in this context is a transformative project aimed at reframing how care is delivered and supporting a sustainable shift away from the medicalisation of end of life.

The conclusion of the CARiAD feasibility RCT coincided with the start of the pandemic, and the CARiAD team, in partnership with Betsi Cadwaladr University Health Board (BCUHB, North Wales), led the development of national (all-Wales) policy for the intervention during March 2020. Supporting materials (document folders and injection training packs) were centrally prepared and then distributed, to support rapid implementation in the pandemic context.

The policy was made widely available, on Pallcare Wales, the Association for Palliative Medicine for Great Britain and Northern Ireland website and the carer-facing website of the Helix Centre (Imperial College London). It was cited in a number of COVID-related palliative care publications, both professional and public-facing. Clinical implementation in North Wales commenced in April 2020.

Clinical implementation in BCUHB gained pace in the past year, and the intervention is now active across North Wales. The intervention is also active in Powys.

Carer-administration in this context is a transformative project aimed at reframing how care is delivered and supporting a sustainable shift away from the medicalisation of end of life.

A joint Bangor University/BCUHB study aimed at understanding the cost-effectiveness of the intervention in North Wales is underway. We have obtained Bangor University Impact funding to accelerate the impact of the intervention, and a research proposal for a realist evaluation targeting Health and Social care Delivery Research funding is in development.

The CARiAD policy and package has been presented at several clinical workshops across the UK as well as keynote/conference presentations.

Clinical implementation of the package is due to be the topic of a BBC Inside Health discussion (summer 2022) and the team has been invited to discuss the inclusion of the CARiAD package in the Science Museum Group’s collection.

Marlise Poolman is collaborating with the Helix Centre in their development of a smartphone-based app to support the intervention, as well as towards the setting up of a national carer support group.

In the two years until March 2022, the ‘CARiAD package’ has been used to train more than 100 carers across North Wales, making North Wales UK-leading in this regard. Clinical outcomes continue to be very positive.

Carer-administration is increasingly becoming more embedded as usual practice across North Wales. Our work has also positively impacted the pace of spread of the practice across the UK.
2) The experiences of bereavement during Covid-19

Millions of people across the UK (including Wales) have faced bereavement during the COVID-19 pandemic, at a time of unprecedented restrictions to usual end of life and mourning practices, and the support and other coping resources available to them. We designed the study to develop understanding of these experiences and identify real-time implications for improving end of life care and the support available to people during bereavement.

‘Bereavement during COVID-19’ is a national study conducted by researchers from the Marie Curie Palliative Care Research Centre, Cardiff University, and University of Bristol, that is investigating the experiences and needs of people bereaved during the pandemic (via longitudinal survey and interviews), and the response of the voluntary bereavement sector to these challenges (via cross-sectional survey and case-study interviews). The study was funded by the UKRI/ESRC rapid covid funding stream. It opened in August 2020 and closed in February 2022, with additional funding from Marie Curie recently awarded to conduct a fourth survey (2 years post-bereavement) with our participant cohort (closing January 2023).

Publication of four peer reviewed journal articles (Harrop et al 2021; Selman et al. 2021; Torrens-Burton et al. 2022; Harrop & Selman 2022).

In May 2021, we published a report in collaboration with the Marie Curie Policy team in Northern Ireland on end of life and bereavement experiences in Northern Ireland during the pandemic.

The results were presented at the launch of the UK Commission on Bereavement (June 2021), with considerable media attention following this and the second study publication (e.g. see Covid 'bereavement crisis' as thousands endure loneliness and social isolation, ITV News London).

The coverage of the first paper/commission launch included a public statement by the then Minister for Mental Health, Nadine Dorries MP, committing to address the gaps and challenges identified in the study (Government committed to plugging gaps in support for grieving families, Evening Standard). Emily Harrop sits on the steering group of the UK Commission and the Core Oversight/Steering group for the National Bereavement Framework for Wales and attends regular meetings with the bereavement team at the DHSC, enabling real-time consideration of research results at Welsh and UK policy levels.

Study results are directly cited in the National framework for the delivery of bereavement care, GOV.WALES and UK Commission on Bereavement (bereavementcommission.org.uk). In her role in the evidence sub-group for the Commission, Emily Harrop has helped design and oversee the commission call for evidence, as well as submitting written and oral evidence drawing on relevant findings from across our portfolio of bereavement studies. The impact and significance of this work for policy and practice in the UK was recognised in the UK Medical Schools Report and in the Medical Charities report: Making a difference: Impact Report 2021 Association of Medical Research Charities.

We presented results to a wide range of policy and practitioner audiences, including the National Bereavement Alliance, ECHO Knowledge Network and the National Palliative and End of Life Care Webinar series, the Welsh Bereavement and Funerals Cross Party Group, as well as educational sessions for palliative care professionals, medical examiners, psychotherapists, psychiatrists and volunteer bereavement support workers. We gave invited talks at the National Education for Scotland Bereavement Conference, the second international bereavement conference (November 2021), a national symposium on bereavement support (May 2021), and the Marie Curie Research Conference (February 2022). We also presented at the Palliative Care Congress (March 2022) and the EAPC conference (October 2021).

Results demonstrated the exceptionally difficult sets of experiences associated with bereavement during the pandemic, with acute disruption to end of life, death and mourning practices, as well as social support networks. We found high levels of vulnerability in grief and needs for emotional support, but also that the majority of participants had not tried to access bereavement services, for reasons such as lack of appropriate support, discomfort in asking for help and uncertainty about how to access services. We have been raising awareness of these challenges and making recommendations for improving the support provided to relatives at the time of death and during bereavement.
Key activities/highlights over the past year:

1) Dissemination and impact of results and recommendations from the COVID-19 Cancer Attitudes and Behaviours Study on cancer screening

The coronavirus pandemic created widespread disruption for the national cancer screening programmes, with national lockdowns and prioritisation of COVID-19 causing screening to be paused between March and June 2020. This led to an estimated 3 million fewer people screened between March and September 2020 (Cancer Intelligence Team, 2021). As recognised in the strategic priorities of the Welsh Government Quality Statement for Cancer, NHS Long Term Plan, A Healthier Wales and Cancer Research UK’s Early Diagnosis Roadmap, diagnosing cancer sooner and decreasing cancer inequalities are mainstays to improving cancer outcomes.

Understanding the effect of the pandemic on attitudes and behaviours among the screening-eligible population is essential for mitigating long-term adverse effects on screening participation and to inform Wales/UK policy and practice regarding informed and equitable screening participation. Recognising the need for rapid knowledge of the effects of the pandemic on cancer symptom help-seeking, screening and preventive behaviours, Prof Brain (PI) supported by Dr Quinn-Scoggins (co-app) successfully led a bid to the UKRI ESRC COVID-19 Rapid Response funding call in May 2020 (£689,000 over 18 months). The COVID-19 Cancer Attitudes and Behaviour Study (CABS) is a mixed-methods population cohort study that was rapidly set up in June/July 2020. The CABS team utilised existing network links through the PRIME WP7 SPED team with co-applicants from Health and Care Research Wales funded centres infrastructure and external partners.

Participants were English-speaking adults and recruited online via CRUK’s online panel, the HealthWise Wales database and targeted social media advertising (Quinn-Scoggins et al., 2021).

The headline finding from the CABS survey and interviews was that 1 in 5 UK adults were less likely to engage in cancer screening than before the pandemic due to barriers such as fear of COVID-19 infection and uncertainty about screening procedures, particularly for cervical screening.

Published outputs include:


2. Peer-reviewed open access publication. Title ‘Intention to participate in cervical and colorectal cancer screening during the COVID-19 pandemic: A mixed-methods study’ (Wilson et al., 2021; senior author - Prof Brain, second author – Dr Quinn-Scoggins)

The policy briefing report was shared with 54 key stakeholders including local and national governments, charities, and public health organisations.

Stakeholder meetings were held to share key study insights and provide recommendations for cancer screening policy and practice including:

Presentation to Cancer Research UK’s senior strategic advisory group; and a collaborative discussion meeting chaired by Dr Quinn-Scoggins with Public Health Wales’ Screening Engagement team to advise on a public communications strategy for resuming cancer screening services.

We created a public-facing infographic and short video animation (above) which provide a high-level overview of the study methods and key results, shared widely on social media and with the study participants themselves.
The impact, effectiveness, and feasibility of the WICKED and ThinkCancer! Studies

The WICKED programme (2016-2019) (with PRIME researchers Clare Wilkinson, Kate Brain, Julia Hiscock, Ruth 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), which has now been completed. The feasibility study was rolled out at the start of the COVID 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. A protocol for a randomised controlled phase III trial of a novel behavioural intervention for primary care teams to promote the earlier diagnosis of cancer (ThinkCancer!) has been written and a grant application submitted. The phase II RCT will aim 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).

Think Cancer! Has been shortlisted for a Moondance Cancer Award, the Innovation in early detection and diagnosis award within the ‘Pioneering Innovation’ category Dissemination of WICKED/ThinkCancer!

**Publications**

- 2018 – WICKED Protocol paper – BJGP Open

Wicked study team meetings, 2021
Key activities/highlights over the past year:

1) Developing a decision aid to support shared decision making regarding risk-based recall intervals in general dental practice

Clinical guidelines recommend that dental recall intervals should be personalised for each patient based on their risk of disease. Despite this, most patients attend their dentist every six months. As a result, a substantial proportion of NHS dental resources are spent providing check-ups to dentally-fit individuals who are at low risk of disease. Dental policy makers want to encourage greater use of risk-based recall intervals in general dental practice. It is argued that increased use of risk-based recall would free up clinical resources which could be used to provide care for more patients with active dental disease, many of whom have not accessed dental care in a long time.

However, it is important that patients are supported by healthcare professionals to make informed decisions about their care. This will involve discussions between dentists and patients regarding the risks and benefits of risk-based recall in order to arrive at a shared decision.

This process can be supported by decision aids which build upon patients' existing capabilities to help them arrive at a deliberated decision which aligns with their values. This study, funded by Health and Care Research Wales Research for Patient and Public Benefit (RfPPB) Wales scheme, aims to develop a decision aid to support shared decision making between patients and dentists regarding risk-based dental recall intervals and to understand the practical and logistic considerations of running a randomised trial of a decision aid for dental recall intervals in general dental practice.

This year, we published the findings from part 1 of the project: a qualitative study which will describe how decisions regarding dental recall interval are currently made, and explore the barriers and facilitators to the implementation of risk-based recall intervals in general dental practice. 20 general dental practitioners (GDPs) and 20 patients will participate in semi-structured telephone interviews.

We are using the data to map the capability, opportunity, motivation-behaviour (COM-B) model to the Behaviour Change Wheel. This will identify behaviours for change which to be prioritised in the design and testing of the decision aid. The findings will also include a list of ‘frequently asked questions’ will inform the domains of the decision aid.

Part 2 of the study will involve the development of a decision aid to support shared decision regarding dental recall interval. The development process will follow published guidelines and involve substantial user engagement. The planned output is a paper-based decision aid to support co-production of dental recall interval suitable for chairside use in general dental practice.

Part 3 is a mixed-method feasibility study examining the practical and logistical considerations of running a randomised trial of a chairside decision aid for dental recall interval in general dental practice. A quantitative before-and-after study with a stepped wedge design will be used to explore potential recruitment rates, and to test a prototype Decisional Quality Measure. 100 dental patients will be recruited to take part in this study. This will be supported by qualitative interviews with GDPs (n=10) and patients (n=20) which will be undertaken after they have used the decision aid. The findings will be synthesised to assess the appropriateness, acceptability and utility the aid, and to inform the design of a larger pilot study ahead of a full randomised trial of the aid in general dental practice.


Professor Ivor Chestnutt, Professor and Hon. Consultant in Dental Public Health, Director Postgraduate Studies, and Clinical Director of University Dental Hospital

Dr Anwen Cope, Senior Clinical Lecturer and Honorary Consultant in Dental Public Health
2) Development of a secondary school-based digital behaviour change intervention to improve tooth brushing - publication of the BRIGHT trial findings

BRIGHT Trial: Brushing Reminder 4 Good oral HealTh: the clinical and cost-effectiveness of a Short Messaging Service behaviour change programme to improve the oral health of young people living in deprived areas. Funded by NIHR Health Technology Assessment.

Tooth decay is very common affecting one-third of young people aged 12-15 years, increasing to nearly one-half in young people living in deprived areas. Young people with tooth decay often have toothache, loss of sleep, problems eating and need to take time off school.

However, tooth decay can be prevented and one of the most effective ways is regular tooth brushing with fluoride toothpaste. In New Zealand, a study found that sending unemployed young adults a short message service (SMS, also known as text message) on their mobile phone every week increased how often they brushed their teeth. However, the researchers recommended further testing over a longer period and with some modifications.

This project called BRIGHT tested whether a classroom-based lesson about dental health followed by a series of text messages, delivered through schools to young people aged 11-13 years at recruitment, reduces tooth decay, increases how often (and how well) they brush their teeth and would be of enough benefit to ensure it was worth the cost of running it.

The project was run in schools where there are a high proportion of young people eligible for free school meals (as an indicator of areas of deprivation) in England, Scotland and Wales. We carried out a pilot trial first to check whether it is possible to run the main trial. The pilot aimed to involve 10 schools and 1200 young people. In each school, one year group received a classroom-based lesson about looking after teeth and a series of text messages to their phones if they agreed to take part. Another year group in each school did not have a talk or text messages. The pilot let us check that the classroom-based lesson works with the schools' curriculum and helped ensure we have the best way to work with the schools to collect the information we need from young people. The pilot trial showed the main trial was possible so it went ahead.

This larger trial involved 42 schools and 5,040 young people in total. Focus groups were conducted with 50 pupils, from six secondary schools across the UK, who had received the intervention. Semi-structured interviews were conducted with 12 members of staff.

We found that overall, both participant groups found the intervention to be acceptable and pupils described the text messages as useful reminders for brushing. The findings of this study demonstrate that pupils described the pupils described the text messages as useful reminders for brushing.

Teaching staff recognised the value of the lesson and reported that in general the content was suitable for their pupils.

Future interventions should consider having a more varied SMS schedule piloting the texts with a youth forum for a longer period of time, and delivering the lesson plan to a class of pupils rather than an assembly. The findings of this study also have implications for policy change in that they support the incorporation of oral health into the curriculum throughout primary and secondary education.

Reflections & forward look

I hope you have enjoyed reading of our activities, our successes and impacts in PRIME Centre Wales. The 7th Annual Report seeks to describe the range of research and impact achieved through PRIME. Our work tackles many important aspects around COVID-19 that affect primary and emergency care, and the recovery period now.

Of course, we continue to tackle the ongoing major challenges for primary and emergency care where 90% of healthcare encounters take place.

These are the issues known to all of us concerning long term conditions, infections, dental, patient safety, palliative care, care in the community and the interface with social care and third sectors.

Inclusivity and efforts to reduce inequalities in health and care drive our research, as do motivations to develop early career researchers and build capacity for this work in the future.

I certainly want to acknowledge and thank all those involved with PRIME Centre Wales, especially those members of the Swansea, Bangor, South Wales and Cardiff university teams. Congratulations to all the team in research and our research partners.

I especially want to thank and acknowledge the administration and professional support service staff members – Angela, Anne, Richard, Natasha, Jane, Ffion, Neil across our four partner universities. The professional support and academic staff come together so creatively and enthusiastically to make PRIME successful and develop the way it has been and will do. Without you all the whole enterprise would be impossible and we all express our appreciation.

Fundamental to our successes in achieving these goals is our values framework – based on collaborative research, exemplar working with patients, public and other stakeholders, and being respectful of multi-disciplinary input across our partner universities.

We also thank our public, patient, NHS and social care and other academic contributors for this wonderful collaboration tackling the highest priority research challenges that are fundamental to an effective and high value health service for the people of Wales.

The benefits of the infrastructure funding to be able to do this quickly and effectively are clear.

This was shown during COVID, with urgent applications for important research made possible (e.g. CABS, EVITE, TRIM, LISTEN studies among others as well as setting up and conducting the research rapidly (e.g. also COPE study of public attitudes and experiences during the pandemic).

The capacity of the infrastructure to support rapid bids and set-up has also been demonstrated gain and beyond the COVID context in the SERENITY palliative care study with European partners. Once again, we thank our funders and our public, national and international advisors for their support and direction.

We look forward to next year and further, conducting current studies, establishing new ones across COVID topics, the COVID recovery and our continuing key themes and workpackages and taking these through to knowledge mobilisation and impact stages.

We aim to develop and build wider collaborations with others across UK and internationally, to strengthen our teams, enhance the research and widen its impact.

Networking again at ‘live’ conferences and research meetings will be important for this, and we also look forward to meeting again in person for PRIME’s 8th Annual conference in October 2022 in Swansea. We hope to see you there!
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