



Canolfan PRIME Cymru PRIME Centre Wales



Ymchwil Iechyd
a Gofal **Cymru**
Health and Care
Research **Wales**



Ariennir gan
Lywodraeth Cymru
Funded by
Welsh Government

2020 - 2021 Annual report



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Foreword

Centre Director, Professor Adrian Edwards

I'm delighted to be welcoming you all again to read our 6th Annual Report. The new developments for [PRIME Centre Wales](#) particularly on the extra funding for the new Wales School for Social Prescribing Research, led by Prof Carolyn Wallace at University of South Wales – and of course what we are doing to provide high quality urgent research that addresses the COVID-19 pandemic.

It should not be overlooked that our range of internationally relevant 'other' research across the Workpackages also continues and develops from strength to strength despite the challenges of the last year.

Carolyn's work with the Wales School for Social Prescribing Research is described on page 3. It is wonderful to see this developing at pace, building rapidly since starting in PRIME last year, with grant applications, research in progress and evidence of impact.

The COVID-19 research also continues on several fronts. PRIME colleagues have been successful with several important UK research applications regarding COVID-19, and research and implementation work in progress.

[Prof Kate Brain's](#) study on early cancer diagnosis is described below, examining public attitudes to cancer symptom presentation, and how to minimise the

risk of late diagnosis caused by the COVID-19 impact (page 13).

[Profs Helen Snooks, Alan Watkins](#) and colleagues are working on the 'TRIM' study to evaluate the impact of altered 999 triage protocols – another key area of primary and emergency care that experienced significant changes at the height of the COVID-19 impact (page 11).

Helen and Alan are also working with [Andrew Carson-Stevens](#) and myself on the 'EVITE' study evaluating the effects – benefits, harms and costs – of shielding. [Prof Clare Wilkinson, Dr Marlise Poolman](#) at Bangor University, and [Prof Annmarie Nelson](#) at Cardiff University continue their work with Welsh Government to fast track the implementation of the CARIAD intervention for home-based palliative care (page 23).

[Prof Fiona Wood](#) and others at Cardiff University are working with our former PRIME colleague [Dr Rhiannon Phillips](#), now at Cardiff Met on a national survey of public experiences of the pandemic, including perceived risk, behavioural and lifestyle impact and patient safety implications (page 12).

Collectively PRIME is rising to several challenges in the primary and emergency care sector both COVID-19 related and existing ones that still need vital research.



Professor Adrian Edwards, Professor of General Practice, Division of Population Medicine, Cardiff University; Director, PRIME Centre Wales and Wales Covid-19 Evidence Centre

In January this year, we also wished Happy Retirement to our friend and long time co-researcher Professor Joyce Kenkre. Joyce retired from University of South Wales at the end of January and will be much missed by the colleagues there and of course all of us in PRIME in which she has been Associate Director, leading for USW, since our inception in 2015.

In fact Joyce's collaborations with us go back before that, in the previous Wales School of Primary Care Research. Her style, knowledge and wisdom will be a gap that we will find hard to fill. Joyce's networking was also unsurpassed, giving us numerous opportunities to collaborate, work with stakeholders and deliver the research and impact that we all strive for.

Finally, the [Wales COVID-19 Evidence Centre](#) has also been established since March 2021, hosted within PRIME Centre, and involving [Natalie Joseph-Williams, Alison Cooper, Ruth Lewis, Micaela Gal](#) and myself in the Core Team (page 5).



Professor Joyce Kenkre who retired this year 2

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



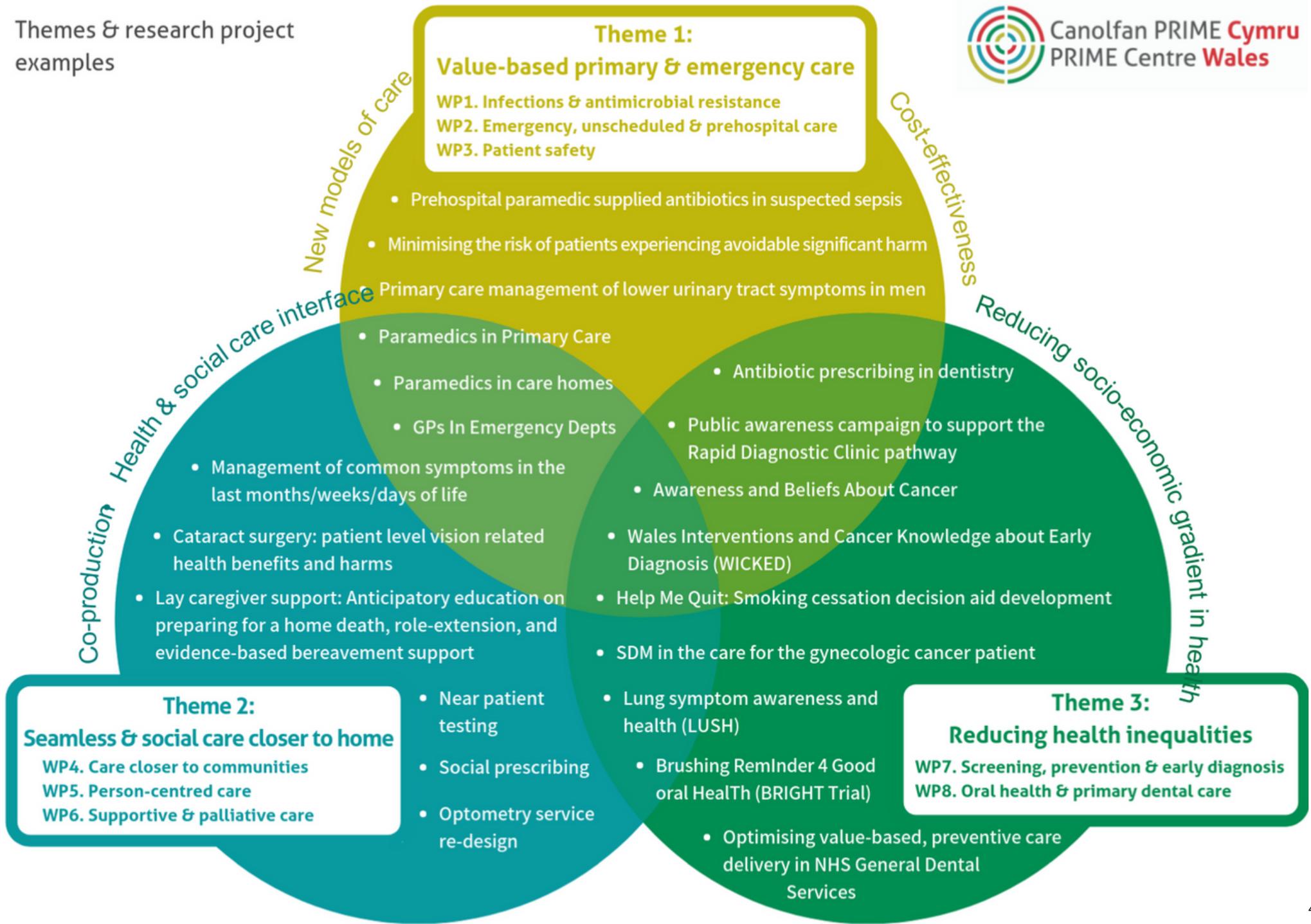
Theme 3:

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



PRIME Centre Wales became the home for the newly funded Wales School for Social Prescribing Research in 2020



Wales School for Social Prescribing Research (WSSPR)

WSSPR is a virtual all-Wales school which aims to develop a social prescribing evaluation methodology, building on the work previously completed by the Wales Social Prescribing Research Network (WSPRN).

The rapidly growing enthusiasm for social prescribing and its potential to influence delivery of services in primary care have exceeded expectation but the development of its evidence base and robust quality standards for evaluation have trailed.

Professor Carolyn Wallace, University of South Wales, leads WSSPR and it sits within PRIME Centre Wales under the theme 'Seamless Care Closer to Home', within the work package 'Care Closer to Communities'.

Aim: Develop a social prescribing evaluation methodology.
Objectives:

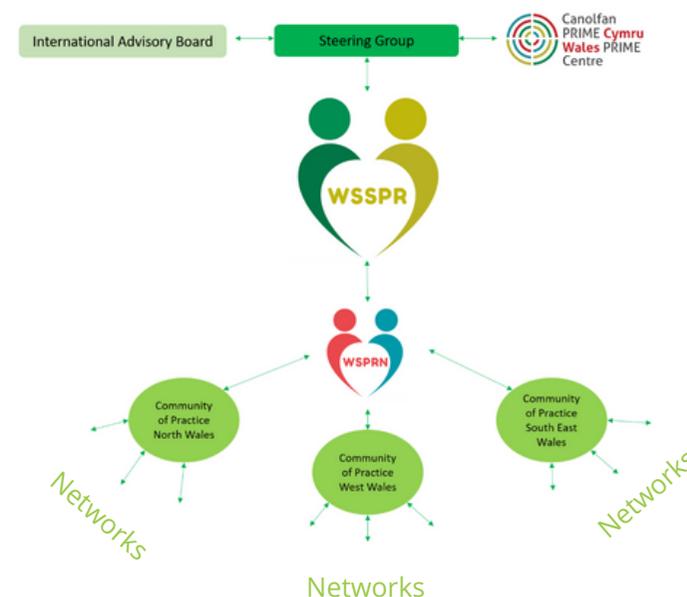
- Use a translational research model to describe, order and organise a multi-phase programme of applied research and evaluation.
- Increase research awareness and engagement with stakeholders, including citizens.
- Translate research findings into practice, policy and education.
- Build research capacity for social prescribing across higher education, third sector and workforce sectors.

We use mixed methods, including consensus methods, to develop an evaluation methodology framework for social prescribing, reporting standards for publication, an agreed glossary of terms and training resources for researchers.

The Wales School for Social Prescribing Research (WSSPR) is overseen by a steering group with representatives from academia, third sector, NHS and social care. The steering group is guided by an International Advisory Board who meet annually.

WSSPR is nested within PRIME Centre Wales, under Theme 2: 'Seamless Care Closer to Home' and within Work Package 4 'Care Closer to Communities'. Work conducted by WSSPR will feed into PRIME Centre Wales through regular operational group meetings. Within WSSPR is WSPRN, the Wales Social Prescribing Research Network. This is a network of researchers and practitioners in Wales who are interested in social prescribing research. The network currently has over 280 members.

Through the network, WSPRN, three Communities of Practice operate in North Wales, South East Wales and West Wales. These feed out to members of the public and the social prescribing community across Wales.



Further information is available at:
<http://www.wsspr.wales>



PRIME Centre Wales became the home for the newly funded Wales-19 Covid Research Centre in 2021

Wales COVID-19 Evidence Centre

Good questions, answered quickly

COVID-19 has dramatically changed the population health needs and the way healthcare is delivered to meet these needs. There has been a huge volume of research relating to epidemiology, characterisation of the condition, treatments, vaccination, and increasingly about the consequences of COVID-19 both for individuals and communities. The fundamental importance and value of research has been underlined by the COVID-19 pandemic, but policy-makers, public and clinicians know that the evidence base is not readily available to support practice, where and when it is needed, to the detriment of patients and clinicians.

Similarly, it is a continual challenging to ensure the evidence base is up-to-date, relevant to Wales and available to politicians, policy-makers and leaders and senior managers in NHS Wales, social care and third sector organisations to inform their decision-making. This is the driver for establishing the Centre and stands to improve the quality and safety of healthcare delivery in Wales.

Our Values Framework is built around social, economic and environmental justice; consistent with the generational focus of the [Well-being of Future Generations Act](#). We also seek to identify where most value can be created as much as the narrower goal of cost-effectiveness. We operate in a respectful, inclusive multi-disciplinary approach reaching across health, social and third sectors and with industry partners.

We need to use research and evidence in managing the pandemic.
We also need to understand the impact of the pandemic on the health and care delivery systems in Wales and how to ensure that we meet the health and wider needs of communities and people in Wales.

Operating practices – ensuring capacity and agility

The Centre integrates with worldwide efforts to synthesise and mobilise knowledge from research. Tertiary ('reviews of reviews'), secondary (reviews) and some primary (new) research may all be undertaken and have their contribution to managing the pandemic and in establishing the recovery and regeneration.

We operate with a core team, hosted in PRIME Centre Wales and led by Professor Adrian Edwards. The core team works closely with collaborating partners in [Health Technology Wales](#), [Wales Centre for Evidence-Based Care](#), [Specialist Unit for Review Evidence centre](#), [SAIL Databank](#), [Public Health Wales](#), [Bangor Institute for Medical & Health Research](#) in conjunction with [Health and Care Economics Cymru](#), and the [Public Health Wales Observatory](#). Together we aim to provide around 50 reviews per year, answering the priority questions for policy and practice in Wales as we meet the demands of the pandemic and its impacts.

The overarching priority is for research across these domains to be quickly, but rigorously undertaken, synthesised and made available and actionable to clinicians, the public, policy-makers and other stakeholders, summarised in the acronym 'Regenerate':

- **RE**search
 - **GENER**ation
 - **Ass**imilation
 - **T**ransfer
 - **E**mbedding
-

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).

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.

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.

The International Advisory Board provides independent advice, critical comment, international context; International experts in primary, unscheduled care research (collaborators from England, Belgium, Sweden, Canada, from primary care, public health, dental, community nursing, emergency care disciplines, and PPI contributors with international experience). Meets once per year.

The SUPER Group considers overall direction, patient and public priorities; Theme and project-specific proposals. 15-20 individuals recruited from Wales members of the public / general population.

The SUPER Group has met more than four times in the past year and conducted important business in correspondence.

All-Wales Steering Committee

Category	Name	Role	Institution
Directors	Adrian Edwards	Director, PRIME	Professor of Primary Care, Cardiff University
Directors	Joyce Kenkre	Associate Director, PRIME	Professor of Primary Care, University of South Wales
Directors	Helen Snooks	Associate Director, PRIME	Professor of Health Services Research, Swansea University
Directors	Clare Wilkinson	Associate Director, PRIME	Professor of General Practice, Bangor University
Work Package & strategy leads	Harry Ahmed	Infections & antimicrobial resistance	Director, GP Academic Fellows Scheme, Cardiff University
Work Package & strategy leads	Kate Brain	Screening, prevention & early diagnosis	Professor of Health Psychology, Cardiff University
Work Package & strategy leads	Andrew Carson-Stevens	Patient safety	Reader in Quality Improvement & Patient Safety, Cardiff University
Work Package & strategy leads	Ivor Chestnutt	Oral health & primary dental care	Professor & Hon. Consultant in Dental Public Health, Cardiff University
Work Package & strategy leads	Bridie Evans	Lay involvement & engagement	Research Associate, Swansea University
Work Package & strategy leads	Natalie Joseph-Williams	Patient-centred care	Lecturer, Cardiff University
Work Package & strategy leads	Ruth Lewis	Methodological innovation	Senior Lecturer in Health Sciences Research, Bangor University
Work Package & strategy leads	Anmarie Nelson	Supportive & palliative care	Maie Care Professor of Supportive and Palliative Care, Cardiff University
Work Package & strategy leads	Marlise Poolman	Supportive & palliative care	Senior Clinical Lecturer, Bangor University
Work Package & strategy leads	Alison Porter	Emergency, unscheduled and pre-hospital care	Associate Professor, Swansea University
Work Package & strategy leads	Emma Thomas-Jones	Clinical trials	Senior Trials Manager in Infections & devices, Cardiff University
Work Package & strategy leads	Carolyn Wallace	Social prescribing & third sector; Care closer to communities	Professor of Community Health & Care Sciences, University of South Wales
Work Package & strategy leads	Angela Watkins	Communications & operations	Cardiff University
Work Package & strategy leads	Fiona Wood	Patient-centred care	Reader, Cardiff University
Work Package & strategy leads	Gideon Calder	Social policy	Senior Lecturer, Public Health, Policy and Social Sciences, Swansea University
Multidisciplinary stakeholder leads & representatives	Joseph Carter	Third sector member	Head of British Lung Foundation, Wales
Multidisciplinary stakeholder leads & representatives	Antony Chuter	Lay member	Chair, Patient Liaison Committee, British Pain Society
Multidisciplinary stakeholder leads & representatives	Chris Jones	Welsh Government representative	Deputy Chief Medical Officer / Medical Director NHS Wales
Multidisciplinary stakeholder leads & representatives	Emma Lane	Community pharmacy	Senior Lecturer in Neuropharmacology, Cardiff University
Multidisciplinary stakeholder leads & representatives	Rachel North	Community optometry	Professor of Vision & Optometry Sciences, Cardiff University
Multidisciplinary stakeholder leads & representatives	Mark Llewellyn	Welsh Institute for Health & Social Care	Professor of Health & Care Policy, University of South Wales
Multidisciplinary stakeholder leads & representatives	Nigel Rees	Ambulance services	Head of Research & Innovation, Welsh Ambulance Services NHS Trust
Multidisciplinary stakeholder leads & representatives	Martin Rolph	Lay member & SUPER group representative	
Multidisciplinary stakeholder leads & representatives	Steve Smith	Social policy	Professor of Political Philosophy and Social Policy, University of South Wales
Multidisciplinary stakeholder leads & representatives	Marjorie Weiss	Community pharmacy	Professor of Pharmacy Practice, Cardiff University
Multidisciplinary stakeholder leads & representatives	Mark Williams	Industrial collaboration	Professor of Geropsychiatry Science, University of South Wales
Multidisciplinary stakeholder leads & representatives	John Wynn-Jones	Rural general practice	WONCA Working Party on Rural Practice

Who's Who: Meet the team

Operational Group



International Advisory Board

- Dr Sibyl Anthierens**
Primary Health Care Sociologist,
University of Antwerp, Belgium
- Carolyn Canfield**
Independent Citizen-Patient & Adjunct Professor
University of British Columbia, Faculty of Medicine, Canada
- Professor David Conway**
Professor of Dental Public Health,
University of Glasgow, Scotland, UK
- Professor Jeremy Dale**
Professor of Primary Care,
University of Warwick, England, UK
- Professor Martin Dawes**
Royal Canadian Legion Professor,
University of British Columbia, Canada
- Dr France Légaré**
Research Axis of Population Health and Practice-Changing Research,
CHU de Québec - Université Laval, Canada
- Professor Michael Preston-Shoot**
Professor Emeritus (Social Work),
University of Bedfordshire, England, UK
- Professor Fiona Ross CBE**
Professor of Research, Centre for Health and Social Care Research
Kingston University, St George's University of London, England, UK
- Professor Niro Siriwardena (Chair)**
Professor of Primary & Prehospital Health Care,
University of Lincoln, England, UK
- Richard Stephens**
Consumer Lead, Chair Consumer Forum
National Cancer Research Institute, UK

Core Metrics

Reporting period: **2020/2021**



Health and Care Research Wales infrastructure award to the group



Jobs created through direct funding



Grants won during reporting period

Grants won	Led by group	Group collaborating
Number	16	8
Value	£5.2m	£2.5m
Funding to Wales	£3.2m	£0.5m
Funding to group	£2.9m	£0.1m
Additional jobs created for Wales	7	5
Additional jobs created for group	6	2



Number of publications



Number of public engagement events



Number of public involvement opportunities

Reporting period:
1 year, 1st April 2020 to 31st March 2021

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

Key achievements

Supporting the research response to Covid-19

Professor Adrian Edwards appointed to new Wales Covid-19 Evidence Centre

Health and Care Research Wales appointed Professor Adrian Edwards as the Director of the new [Wales COVID-19 Evidence Centre](#). The £3 million centre, announced in December, has been created on behalf of Welsh Government to make use of UK-wide and international research findings to answer key questions and support decision making in Wales.

This could include addressing the long-term effects of the pandemic and investigating challenges such as infection control and social distancing, the consequences of isolation and the health effects of the economic disruption.

The Centre will enable rapid access to key international research findings and evidence, so decisions can be made by Welsh Government and NHS Wales. It will also allow fast and focused research studies to be undertaken on a Welsh level, including into long COVID.

Professor Adrian Edwards said: "We need to use research and evidence in managing the pandemic. We also need to understand the impact of the pandemic on the health and care delivery systems across the country and how we ensure we meet the health and wider needs of communities and people in Wales.

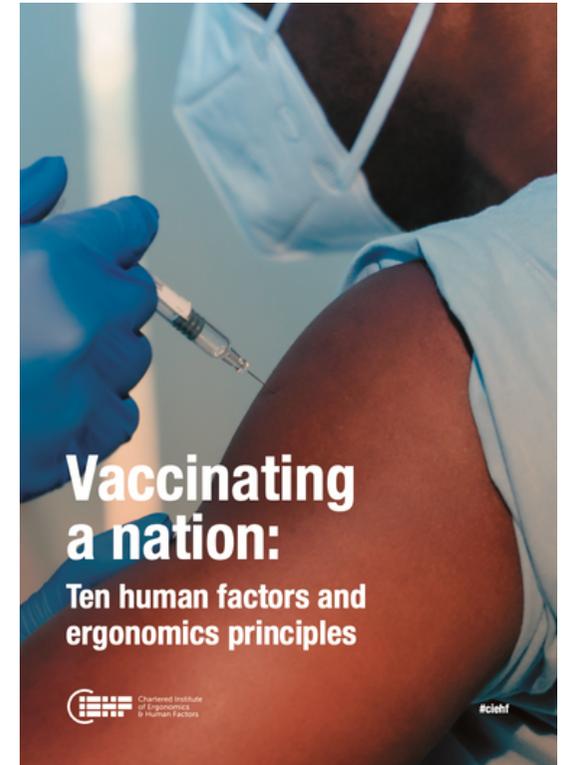
Visit the centre webpage for further information: <https://healthandcareresearchwales.org/about-research-community/wales-covid-19-evidence-centre>

Contributing to the expert guidance

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 safety, including:

- Vaccinating a nation: Ten human factors and ergonomic principles. <https://ergonomics.org.uk/common/uploaded%20files/publications/CIEHF-Covid-19-vaccination-programmes.pdf>
- Guidance to help design effective and usable work procedures for health and social care teams. <https://www.ergonomics.org.uk/common/Uploaded%20files/Publications/CIEHF-guidance-on-human-centred-design-of-work-procedures-document.pdf>

Dr 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, Dr 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.

Supporting the research response to Covid-19

What TRIage 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 TRIage model is safest and most effective for the Management of 999 callers with suspected Covid-19, was awarded funding of £358,400 in June through the UKRI-DHSC COVID-19 Rapid Response Rolling Call.

We are now working on the project with Welsh, 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.

Early findings from the TRIM study have been submitted for publication in the Journal of the American College of Emergency Physicians.

Also responding to COVID-19, the EVITE Immunity study, Effects of shielding for Vulnerable people during COVID-19 pandemic on health outcomes, costs and Immunity including those with cancer: quasi-experimental Evaluation, is examining the impact of the shielding programme.

Funded by the National Core Studies Immunity Programme, Phase 1 was completed during 2020-1 and examined the rationale for shielding and assessed the effects of shielding in general population and subgroups: deaths, hospitalisations, immunity status, safety, self-reported health and costs.

Subsequent phases will examine the immunological status of the shielded population, and use qualitative methods to explore the experience of being shielded, and the views of health care providers about the effects of shielding.

We have already published a Rapid Response about the EVITE study in the BMJ, as a topical response to an article on the House of Commons Public Accounts Committee report on shielding (<https://www.bmj.com/content/373/bmj.n1033/rr>).

Supporting the research response to Covid-19

COPE Cymru study

Understanding the impact of the COVID 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 will contribute to Welsh Government's strategic aims of preventing ill health with a focus on person-centred approaches to improving health and well-being in line with the [Wellbeing and Future Generations Act](#) and Welsh Governments 'A Healthier Wales: Our Plan for Health and Social Care 2019'.

The project also aligns 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](#) is a longitudinal cohort study which uses 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](#) and [Prof Fiona Wood](#).

Since setting the cohort up in Spring 2020, we have completed data collection for baseline, 3-month follow up and 12-month follow up.

Our analysis is ongoing. We have published a study protocol paper as an open access article on Figshare.

There are a number of other papers in draft format or submitted for publication. Papers led by PRIME colleagues include: vaccine hesitancy and patient safety in primary care and experiences of using NHS services during lockdown.

PRIME staff members have also been invited to give presentations at the Society of Academic Primary Care meeting on i) patient reported safety concerns during the pandemic and ii) public attitudes towards the COVID-19 vaccine.

The COPE Cymru team have provided Welsh Government and Public Health Wales with study updates and briefings. These will be extended as our analysis progresses.

For example, our work on vaccination hesitancy is identify key reasons for vaccine refusal and could help to improve communication around the vaccine to improve uptake.

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

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.

An online survey was carried out by Cancer Research UK and HealthWise Wales with over 7,500 participants, asking about help-seeking following symptoms, cancer screening and health behaviours during the first UK lockdown period (March- August 2020). Qualitative interviews were also carried out with 30 participants to explore their attitudes and behaviours towards help-seeking during this time.

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.

Interview participants described putting health concerns on hold to avoid burdening the NHS. They expressed fear about attending primary care services – and bigger fears around attending secondary care relating to catching or passing on the virus. However, those who did attend face-to-face consultations described feeling “safe” and “secure” when doing so.

Our policy briefing paper and press release in February this year 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.

We received extensive media coverage including an interview with Prof Kate Brain, the study lead, on ITV's Good Morning Britain. The findings were highlighted by prominent social media influencer [Deborah Jones \(@bowelbabe\)](#) and were featured in [The Express](#), [The Guardian](#), [The Telegraph](#), [The Times Online](#), [BBC online](#), [The Sun](#), [The Daily Mail](#), [ITV Wales](#), [Metro](#), [Evening Standard](#), and Sky News. CABS researchers have also been invited to present at leading national and international conferences, including

Cancer Research UK's Early Diagnosis Virtual Series, the Cancer and Primary Care International Network and Society of Academic Primary Care.

Principal investigator Professor Kate Brain said: "The CABS team is proud to have delivered the first study outputs for public release within six months of study onset, and to see them rapidly translated into national campaigns and initiatives encouraging people to come forward to their GP with potential cancer symptoms.

This prestigious grant funding was enabled by our internationally recognised track record of excellence in cancer Screening, Prevention and Early Diagnosis research, as well as the infrastructure afforded by the Health and Care Research Wales-funded PRIME Centre, Centre for Trials Research and HealthWise Wales."



Os ydych chi'n credu bod rhywbeth o'i le, galwch eich meddyg teulu.
Peidiwch ag aros. Peidiwch â phoeni. Gwiriwch ef.

If you feel something isn't right, call your GP – they want to hear from you.
Don't put it off. Don't worry. Get checked.

NIH Eusan Gofrestrdy / Registered Charity No: 107290

CANCER RESEARCH WALES
YNCHWIL CANCER CYMRU



COVID-19 Cancer Awareness and Behaviour Study (CABS) media coverage

Sky News @SkyNews

"I actually feel very safe in my hospital."

Columnist and podcaster, Deborah James urges people with potential symptoms of cancer to seek medical help, even if they have concerns about visiting hospital due to #COVID19 fears.

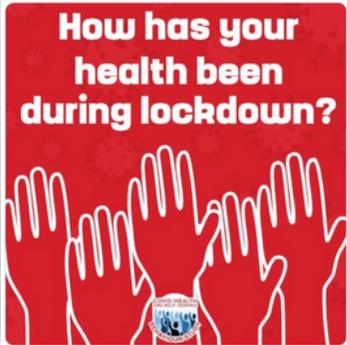
#Coronavirus updates: trib.al/zs8w6NX



Visit news.sky.com

HealthWiseWales @HealthWiseWales

'@CTRCardiffUni, @CR_UK & @CABSCovid19 have created an online survey asking people about their health during #lockdown. Data suggests that people from #BAME backgrounds have been the most affected. Take part and help researchers discover why bufile.ly/39WYHQQ



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Health

Covid: Half with cancer signs didn't contact GP in first wave

By Rachel Schraer
Health reporter

25 February | Comments

Coronavirus pandemic

Cancer

This article is more than 5 months old

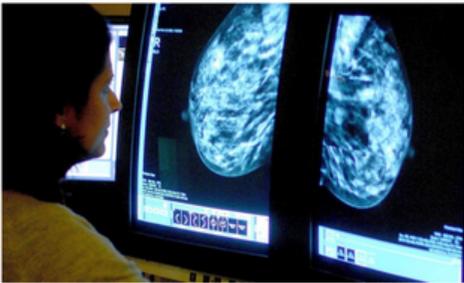
Nearly half with cancer symptoms in the UK did not see GP in first wave of pandemic

People avoided seeking medical help during first lockdown because they did not want to burden NHS

- Coronavirus - latest updates
- See all our coronavirus coverage

Denis Campbell Health policy editor

Thu 25 Feb 2021 07:01 GMT



The survey of 7,543 adults across the UK found 3,025 developed at least one possible sign of cancer between March and August last year. However, 1,355 of them did not contact their GP. Photograph: Rui Vieira/PA

Almost half of those who had a potential symptom of cancer during the pandemic's first wave did not see a GP, even when they coughed up blood or developed a lump, a new study shows.

People held off seeking medical help because they did not want to waste health professionals' time, add to the pressure on the NHS or go to hospital in case they caught Covid-19.

Many people's behaviour was influenced by the government's message during the first lockdown last spring to "stay home, protect the NHS, save lives", researchers found.

Western Mail

Date: 25 February 2021
Page: 5

Stay-at-home advice sent message that cancer can wait - expert

THE stay-at-home messaging employed by the governments during the coronavirus crisis could have "sent a strong message to the public that cancer can wait", a Cardiff University expert has warned.

The comments come after a new study found that a significant number of people with potential symptoms of cancer did not seek medical help during the first six months of the pandemic.

Some did not even seek care for worrying signs like coughing up blood or an unexplained lump or bump.

Experts called for a concerted effort to remind the public that NHS services are open safely.

The NHS has already been running campaigns encouraging people to seek help for potential cancer symptoms.

It has raised particular concerns about a dip in the number of people being treated for lung cancer, warning that thousands are being treated than would be expected.

A UK-wide survey found that nearly half of people who experienced possible cancer symptoms between March and August last year did not contact their GP.

Researchers from Cardiff University and Cancer Research UK examined the experiences of 7,543 people.

A total of 40.1% of participants say they had experienced one potential symptom.

And among this group, 44.8% of people did not contact their GP.

Three in 10 of those who were coughing up blood did not seek help, nor did 41% with an unex-

plained lump or bump or swelling.

And 58.6% of those who noticed the change in appearance of a mole - a key sign of skin cancer - did not seek help.

Worry about wasting health-care professionals' time, concern about putting extra strain on the NHS, not wanting to be seen as someone who makes a fuss, difficulty with access to healthcare services and worry about catching Covid-19 were reported as barriers to seeking medical help among the participants.

A policy paper from the university and Cancer Research UK highlights how there were 19% fewer urgent cancer referrals - around 350,000 - between March and November in 2020 compared with the previous year.

Principal investigator Professor Kate Brain, a health psychologist from Cardiff University's School of Medicine, said people had "put their health concerns on hold to protect the NHS".

"This suggests the government's message to 'stay home, protect the NHS, save lives' - which was intended to control the spread of Covid-19 - also sent a strong message to the public that cancer can wait," she said.



GETTY IMAGES

Almost half of people with potential cancer symptoms did not contact their GP during the first wave of the pandemic, a survey suggests.

Symptoms left unchecked included coughing up blood, lumps and changes to the appearance of moles.

NHS figures showed a fall in referrals to cancer services last spring.

But this study, of almost 8,000 people, captures the fall in people contacting their GP in the first place.

The team that carried out the study, from Cardiff University and Cancer Research UK, said this raised concerns that people could be diagnosed later - and so be less likely to be treated successfully and recover.

Bereavement during COVID-19: A national study of bereaved people's experiences and the impact on bereavement services

The first UK-wide survey exploring bereavement experiences and support was carried out in 2020 by researchers at Cardiff University and the University of Bristol, to look at the people's experience of bereavement during the COVID-19 pandemic.

The researchers, including a team from the [Marie Curie Palliative Care Research Centre](#), are conducting the research to give voice to the experiences of people bereaved in the UK of any cause since 16 March.

On June 15th 2021 a UK Commission on Bereavement was launched to identify recommendations for improving support for bereaved people.

The event coincided with the release of the first pre-print publication from the Bereavement during Covid-19 study, with key findings presented at the launch by the study Co-PIs [Dr Emily Harrop](#), Cardiff University and Dr Lucy Selman, University of Bristol, followed by a key note response to these results from Nadine Dorries MP, Minister for Bereavement.

The mixed-methods research study, funded by the UKRI/ESRC, is investigating the grief experiences and support needs of people bereaved during the pandemic. It has had considerable media attention

following the release of interim results in November 2020 and the first pre-print publication reporting baseline survey findings released in June 2021 (see <https://www.covidbereavement.com/media-coverage>).

This included coverage of a public statement by the Minister committing to meet the gaps in support identified in the published research ('[Government committed to plugging gaps in support for grieving families](#)', Evening Standard)

Going forwards the Commission, chaired by Right Reverend Dame Sarah Mullally, the Bishop of London, will be considering emergent findings from the study, along with stakeholder evidence submissions.

[Emily Harrop](#) sits on the steering group of the UK Commission and the Core Oversight group for the [National Bereavement Framework for Wales](#) and attends monthly meetings with the bereavement team at the DHSC, enabling real-time consideration of emerging research results at Welsh and UK policy levels.

Early study findings on end of life and bereavement experience have also been widely disseminated to practitioner audiences, including invited presentations at [National Bereavement Alliance](#) Monthly webinars, the first All Wales CPD session for palliative care professionals and a National Palliative and End of Life Care monthly Webinar

Dr Emily Harrop, from the Marie Curie Palliative Care Research Centre based at Cardiff University and a research associate in the School of Medicine, said:



Video above of news coverage of this study on ITV News At Ten (26 November 2020). Please also click [here](#) for an article from the ITV news website.

"The survey results so far show the exceptional challenges of pandemic bereavement in terms of difficult experiences at the end of life, restricted funerals and social isolation.

"Alongside these difficulties and relatively high levels of needs, bereaved people also report problems accessing support from friends and family and bereavement services."



[Guardian article](#), 26 November 2020

Key achievements

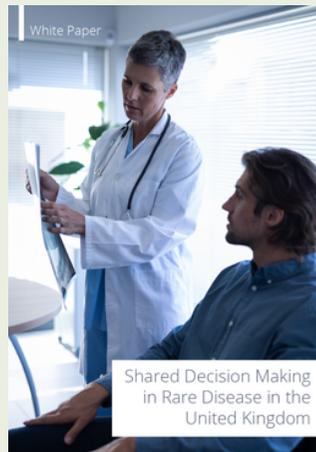
Making an impact

Shared decision making in rare disease in the United Kingdom

A PRIME Centre Wales led [White Paper](#) has been published (Jan 2021) to address shared decision making for patients with rare disease.

There are many benefits of shared decision making (SDM) for patients. With greater knowledge of the options available to them and the support to consider these based on their own preferences, patients feel better informed. Their confidence to participate also increases and they are clearer about what matters to them. Patients have more accurate expectations of the benefits and risks of treatments and, by increasing involvement in their care, adherence to treatment could be improved.

In the context of rare diseases, SDM is even more important as there is often not a gold-standard treatment or care option available. Clinician experience and patient knowledge may be limited, but patients certainly have invaluable experience of what it means to live with the condition, which should guide decision making. NICE is publishing its [Guideline on SDM](#) in June (and to which Adrian Edwards has contributed as academic committee member) but there is currently no specific guidance for clinicians and people living with rare diseases on why, when and how this model should be used and the strategies they could use to implement it.



Dr Natalie Joseph-Williams, Senior Lecturer in Improving Patient Care, PRIME Centre Wales, School of Medicine, Cardiff University, comments:

"Over the last few months, I have chaired a Working Group whose aim is to shine a light on the important subject of SDM in rare disease. Our collaboration has led to this white paper, which we hope presents a clear picture of the current barriers and needs within SDM in rare disease in the UK and opportunities for its implementation going forward.

"We hope this paper delivers a call to action for stakeholders in rare disease communities to facilitate the implementation of SDM. Ultimately, we want every patient with a rare disease to be able to say: "this is what matters most to me right now", and for them to receive care and support that is tailored to their own goals and preferences – care that values patients' lived experiences."

Towards eliminating avoidable harm in health care

On May 29th 2021, the 74th World Health Assembly at the World Health Organization adopted the first ever Global Patient Safety Action Plan 2021-2030, which envisions "a world in which no one is harmed in health care, and every patient receives safe and respectful care, every time, everywhere".

Dr Andrew Carson-Stevens was a member of the WHO Task Force that created the 10-year road map which contains actions that all income countries can make to improve patient safety.

In response to the [WHO Patient Safety 2021-2030 agenda](#) to integrate human factors into the planning, management, and improvement of healthcare systems over the next decade, the Patient Safety WP have been working across PRIME Centre to embed key human factors principles and concepts into research funding bids.

Alongside Dr Natalie Joseph-Williams, co-lead of Patient-centred Healthcare (WP5), the Patient Safety WP team has developed a human factors-driven approach to survey and interview patients about safety concerns to understand where and how the healthcare system can be improved driven by their experiences.



This novel methodological approach is also being used to understand safety concerns reported by shielding members of the public as part of the National Core Studies / UKRI funded research led by Prof Helen Snooks in WP2 (Emergency, Unscheduled & Pre-hospital Care).

Making an impact

Evaluation of the neighbourhood district nursing pilots in Wales

In November 2020 PRIME and Welsh Institute for Health and Social Care researchers based at the University of South Wales published a report summarising the evaluation of three Neighbourhood District Nursing (NDN) Pilots at Cwm Taf Morgannwg University Health Board, Powys Teaching Health Board and Aneurin Bevan University Health Board.

These pilots were funded by Welsh Government in 2017 to test Neighbourhood District Nursing in Rural, Valley and Urban locations.

The pilot NDN teams provide home-based nursing care to people living within a defined geographical area linked to named primary care teams. NDN teams typically consist of Registered Nurses (RNs) who have completed a specialist professional qualification in community nursing (SPQ) – these are usually team leaders, RNs, health care support workers and administrative staff.

Staff will have completed additional training to support individuals and their families at home e.g., some RNs will be independent prescribers, others will have been trained in using specific equipment e.g., Doppler imagers to monitor blood flow in lower limbs. Referrals for NDN services can come from GPs, other allied health professionals e.g., Occupational Therapists, statutory public services and individuals/families may refer themselves.

As part of the NHS in Wales, NDN teams incorporate the principles of the Welsh Government Prudent Healthcare initiative. NDN staff encourage people to look after and be responsible for their own health and well-being with support from the health service, statutory public teams and voluntary teams.

NDN is free at the point of need and supports all citizens in Wales. NDN teams provide quality assurance information to senior nurse managers who are accountable to NHS Wales colleagues and ultimately Welsh Government.

In addition to providing nursing care, NDN teams support the public to lead healthier lifestyles and prevent ill health at an individual or population level.

They put people at the centre of decisions about their own health and promote the co-production of decisions about the right type of care they need and ensure they can access the right information and advice at the right time.

The teams encourage people to consider what care they need, including whether they can look after themselves (self-care), and to use the most appropriate service to meet their clinical need.

Further information is available at: <https://wihsc.southwales.ac.uk/prime-usw/prime-usw-research-portfolio/evaluation-neighbourhood-district-nursing-pilots-wales/>



The recommendations

1. Embed a person-centred holistic approach to care that promotes reablement and independence.
2. Develop a NDN workforce with a range of skills and career progression to meets the needs of the local population.
3. Encourage NDN teams to use local authority population assessments and local GP data to identify sustainable generalist and specialist nursing skill sets and training needs for their practice.
4. Review the team leader role to better implement the Wales District Nursing Principles in a local context whilst also supporting change management.
5. Harness community resources to benefit patients, their families and the NDN service.
6. Provide a coaching and mentoring role to support individuals and service development.
7. Develop an all-Wales NDN community of practice (COP) to share knowledge, learning and good practice.
8. Embed information technology and a longitudinal core dataset into Neighbourhood District Nursing service delivery across Wales.

Making an impact

A whole-team approach to optimising general dental practice

Studies across the health service reveal benefits of teamwork and barriers to its optimal use. Drawing upon the established Maturity Matrix Dentistry method, the Skills Optimisation Self-Evaluation Toolkit (SOSET) was developed to enable the whole dental team to critically review how they address skill-mix in delivery of patient-centred oral healthcare in their practice.

This year, colleagues from PRIME's [oral health and primary dental care](#) research work package was [published in the British Dentistry Journal](#), outlining the development of the SOSET and explores its usefulness to general dental practice teams.

Eighty-four papers were coded and 38 dental team members were interviewed across six sites. The SOSET matrix was developed containing nine domains reflecting the use of skill-mix, each containing six development-level criteria.

The domains addressed factors such as team beliefs on skill-mix and knowledge of team members' scope of practice, patient demand, the business case, staffing and training, and the practice premises.

The process was piloted in 11 practices across South Wales, and feedback was received from 92 staff members.

Results showed that the SOSET process was straightforward, that the whole team could contribute to discussion and that it would be used to improve practice.

Following piloting, four domains were merged into two new domains, and the number of criteria within all domains was reduced and the wording simplified (seven domains, with four criteria each). We used a systematic and rigorous process to develop the SOSET to support dental teams to progress their teamwork practices.

Its usefulness was demonstrated in the pilot. The SOSET is now being offered to general dental practices across Wales.

Further information is available at: <http://www.primecentre.wales/optimising-skill-mix-in-dentistry.php>

Publication:
Barnes E, Bullock A, Chestnutt IG, Cowpe J, Moons K, Warren W. 2020. Dental Therapists in General Dental Practice. [A literature review and case study analysis to determine what works, why, how and in what circumstances](#). European Journal of Dental Education 24 (1) , pp. 109-120. 10.1111/eje.12474.



Public involvement, engagement & collaboration

Service Users for Primary and Emergency care Research

PRIME has policies and processes to enable and promote successful public involvement and engagement across research activities.

This ensures public perspectives and patient experiences are integrated throughout research development, implementation and dissemination and in managing and delivering PRIME strategy. Researchers and public contributors have committed to collaborations, developed knowledge and skills and sustained relationships.

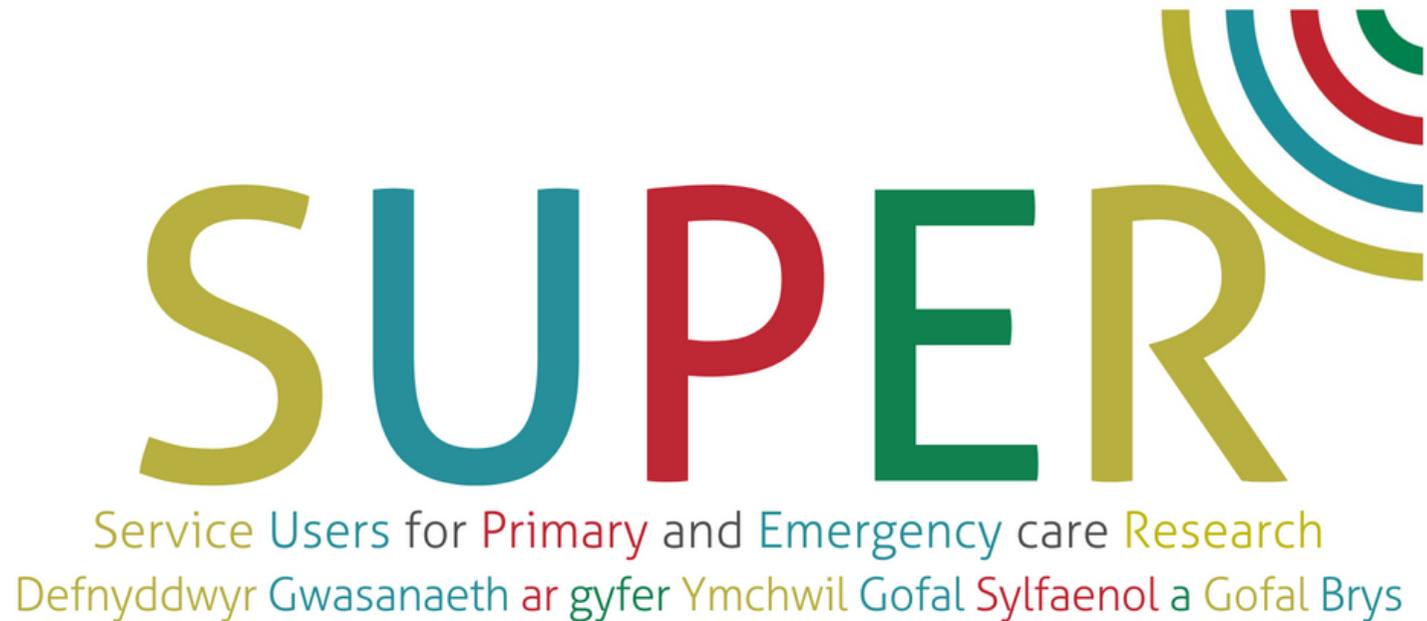
Effective approaches incorporate values and actions which, when operating together, strengthen processes and outcomes of public involvement and engagement. We have [published a paper](#) describing the comprehensive and coordinated way we undertake public involvement, which is central to the objectives and workstreams ([Evans et al, 2020](#)).

PRIME supports the SUPER public patient group. During the pandemic, the group has adapted to online working, holding six meetings, and remains able to effectively contribute public and patient perspectives to developing and delivering PRIME research. Over the year, members have been involved in proposals linked to COVID-19 (for example Person-Centred Care and Patient-Reported Safety Concerns during the pandemic).

They have also supported other research (for example exploring take-up of flu vaccines among care home staff, several

related to early cancer diagnosis, dental care and emergency care).

Also, SUPER is working with the Wales COVID-19 Evidence Centre about research priorities. They were actively involved in planning the PRIME Annual Meeting and also presented 'Public involvement across PRIME Centre Wales: striving for excellence' where SUPER Chair Mari James and PRIME PPI Lead Bridie Evans considered collaboration through the research cycle.



SUPER has recruited five new members. Members designed and implemented a multi-step process to enable new members to understand and experience a SUPER meeting and to match skills and gaps. New members widen SUPER diversity, coming from a younger demographic, employed and from different ethnic backgrounds.

PRIME Researchers Fiona Wood, Adrian Edwards and Freya Davies are involved in the development and delivery of two award winning research programmes – both programmes received a 'highly

commended' Patient and Public Involvement Award at the Health and Care Research Wales Annual Conference (2020).

The [LEAP-MS study](#) (Wood, Edwards, Davies) – this study aims to develop an intervention to support people living with progressive Multiple Sclerosis (MS) to be physically active. The focus of the study is based on research priorities set by people with multiple sclerosis, PPI representatives have been integral to the development of the funding bid and project management, and co-production

events have been held with people with MS, their families and health care professionals.

The DOMINO-HD study (Wood) – this study aims to identify the key environmental factors that may be responsive in targeted interventions with a view towards optimising disease management for individuals with Huntington Disease (HD). All this work is underpinned by public and patient involvement.

The initial study concept was supported by input from a number of stakeholder events and PPI activities focusing on lifestyle and physical activity of people with HD; in partnership with the HD involving people group and BRAIN Involve. In long term studies of people with challenging conditions, particularly when asking participants to engage with unfamiliar technologies, successful delivery of the study is dependent on participant centric design, therefore this was a key focus from the outset.

Patient Advisory Groups have been effective forums for widening the number and range of public views into many PRIME studies. These groups are chaired by public members who are study coapplicants. In the TRIM study about triaging patients with suspected COVID-19 who call the 999 emergency ambulance service, the group has discussed terminology to help identify non-judgemental language.

In the EVITE Immunity study about shielding during the pandemic, public contributors piloted a participant questionnaire and reviewed other materials to be included in the application for ethical approval.



The SUPER Group in-person meetings moved to web-based and continued through the year

Work package updates

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 over the past year:

- [RCGP Research Paper of the Year for the PACE study](#) (CRP testing reduced antibiotic prescribing in patients with COPD)
- NIHR Advanced Fellowship awarded to [Harry Ahmed](#) to investigate relationships between infection, antibiotic use and serious bleeding in anticoagulant medication users.
- Ser Cymru Grant awarded for the '[COPE](#)' study in collaboration with Cardiff Metropolitan University: a longitudinal mixed methods study of attitudes, beliefs and behaviour in response to the coronavirus pandemic.
- [Leigh Sanyaolu](#) (Academic Fellow) awarded an NIHR Doctoral Research Fellowship aimed at generating new knowledge around the benefits and harms of prophylactic antibiotics for recurrent UTIs.

- MISSOURI: Team led by [Harry Ahmed](#) with colleagues from [CTR](#) and Swansea awarded £220,000 from the BHF to investigate the relationship between UTI and acute cardiovascular events using linked health data.
- Rapid evaluations of primary care diagnostic and treatment pathways for common infections, for example, the pharmacy-led sore throat test and treat service.
- Missing link study – studying immune markers and the urinary microbiome in patients with urinary tract infection

Current focus and plans for forthcoming year:

- Increasing our portfolio of work and generate new and novel insights into the epidemiology of infections, building on collaborations with Oxford, PHE, and the [SAIL databank](#).
- To successfully secure major external funding for trials and observational studies that lead to significant practice change in our approach to antibiotic prescribing.
- To increase our critical mass and support early career researchers to develop into independent researchers in infections.

WP2. Emergency, unscheduled & pre-hospital care

Leads: Professor Helen Snooks & Dr Alison Porter



We deliver research in collaboration with NHS organisations and academic partners from Wales and across the UK.

Our core interests:

- Clinical and cost effectiveness of:
- Alternative care pathways to reduce ambulance conveyance to the Emergency Department
- Risk prediction tools in primary care
- New treatments in the prehospital care context
- Adoption and implementation of new technology and working practices in pre-hospital care
- Including patients and service users in planning and delivering research
- Use of anonymised linked routine data in research

Key activities/highlights this year:

- Secured funding for an evaluation of the shielding programme for people at high clinical risk from COVID-19, EVITE Immunity (National Core Studies Immunity Programme), completing Phase 1 in March 2021, with Phase 2 planned for the coming year.
- Secured funding for definitive trial of paramedic administered anaesthetic block on scene for suspected hip fracture [RAPID2 \(HTA\)](#).

- Gained funding and started TRIM, an evaluation of 999 999 Triage models for COVID19 (UKRI Rolling Call)

Current focus and plans for forthcoming year is to deliver our active programme of research on:

- How best to respond to 999 callers with sustained high needs, through the [STRETCHED](#) and [INFORM](#) studies
- Impact of paramedics working in primary and community care settings, through the [ARRIVE](#) and PARE studies
- Feasibility of undertaking a definitive trial of [Take Home Naloxone in emergency settings \(TIME\)](#)
- Use and impact of the Pre-Hospital 12-lead electrocardiogram (PHECG2)
- Triage of COVID-19 patients in ambulance services ([TRIM](#))
- Effectiveness of interpretation services for asylum seekers and refugees ([HEAR2](#))
- Costs and effects of pre-hospital analgesia for suspected hip fracture ([RAPID2](#))

WP3. Patient safety

Lead: Dr Andrew Carson-Stevens



We investigate the frequency and avoidability of healthcare-associated harm, identify priority areas for safety improvement, and develop and implement interventions to minimise harm to patients in health and social care settings.

Since lockdown, we have sought to be resourceful and collaborate and synergistically exchange expertise with a diverse range of collaborators (nationally and internationally) to launch multiple patient safety studies. We have closely collaborated with healthcare organisations and embedded researchers into clinical teams tackling COVID-19 to identify essential learning at a critical pace.

Key activities over the past year:

- Development and implementation of a patient safety incident reporting approach for optometry in Wales (with colleagues from [School of Optometry and Vision Studies, Cardiff University](#)).
- Development of a national incident reporting system for primary care in France alongside researchers at the Université de Nantes. The system was developed and launched during the height of the first wave of the COVID-19 pandemic. We have investigated the nature of unsafe primary care during lockdown using the [PISA](#) methods.
- Advised the UK Ministry of Defence on strategies for maximising learning from patient safety incidents occurring in their healthcare facilities.

- Supported Cardiff and Vale UHB to generate actionable learning from patient safety incidents that occurred between March and July 2020 during the COVID-19 pandemic. The work was funded by a Wellcome Trust funded studentship. We identified patient safety priorities in terms of where and how the Health Board can strengthen its existing care delivery processes and mitigate avoidable unsafe care to future patients during subsequent waves.
- [Dr Carson-Stevens](#) is collaborating with the University Health Network in Toronto, Canada, to examine the change in the nature of safety incidents resulting in healthcare-acquired infections during the pandemic.

Current focus and plans for forthcoming year:

- [Organisation for Economic Cooperation and Development \(OECD\) Patient-reported Safety Indicator Survey](#) project
- Epidemiology of avoidable healthcare-associated harm in prisons
- Development and implementation of human factors-driven approaches to explore patient-reported safety concerns and application in [COPE](#) and [EVITE Immunity](#) studies

WP4. Care closer to communities

Lead: Professor Carolyn Wallace



We investigate how communities, organisations (statutory, nonstatutory, 3rd sector), and practitioners can work together with people to coproduce seamless care that can be accessed in the right place, at the right time, and in the right way.

Key activities over the past year:

- Continued development and implementation of the [Family Resilience Assessment Instrument and Tool](#) with all health visitors across Wales, using the FRAIT Community of Practice and looking forward to identifying innovative ways of furthering this research programme using digital technology, as well as the potential to expand this work internationally, e.g. with colleagues in India.
- Implementation and development of the [Community Nursing Research Strategy](#).
- Final reports on the Social Prescribing Services provided by [Mind Cymru](#) and the [British Red Cross](#); and ongoing [evaluation of the Social Services and Well-being \(Wales\) Act 2014](#).
- Using consensus methodologies including on studies including identifying learning needs of social prescribers, mapping to explore the complexities of managing children's care, research priorities for social

prescribers, mapping to explore the complexities of managing children's care, research priorities for social prescribing, quality indicators for health visiting practice and factors for multi-agency working.

- Ongoing capacity building including [KESS studentships](#), building research capacity in the third sector and supporting primary care

Current focus and plans for forthcoming year:

- Investigate ways to improve equity of access to health and social care, and health education e.g. in rural settings, location of services, removing barriers, vulnerable groups such as people with learning disabilities, and tackling health inequalities
- Tackle workforce development so that efficient, effective, timely care can be available that is good value for money. This may involve examining the redistribution of tasks to the most appropriate providers, with associated factors such as up-skilling/training, supervision, remuneration, workload, safety, and a work culture of feeling valued.
- Continue to implement and develop the Community Nursing and Social Care Research Strategies for Primary Care in Wales.

WP5. Person-centred healthcare

Leads: Professor Fiona Wood & Dr Natalie Joseph-Williams



People should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. Treatment and care should take into account individual needs and preferences.

Key activities over the past year:

- Integrating shared decision making into the [Value Based Healthcare Agenda](#) in Wales. We work closely with Public Health Wales, Improvement Cymru, HEIW, and Welsh Government colleagues to develop and deliver shared decision making training to NHS clinicians across Wales.
- Improving delivery of person-centred healthcare through research
 - Working with [Patient Safety WP](#) to explore patients' experiences of healthcare during the COVID-19 pandemic and patient-reported safety incidents,
 - Working with the [Infections WP](#) to develop research on uptake of influenza vaccine amongst care home staff, uptake of a potential COVID-19 vaccine amongst members of the public, and shared decision aids for women with recurrent urinary tract infections.
- Ongoing research in relation to development and validation of diagnostic and [decision making aid for men with lower urinary tract](#)

symptoms, exercise self-management support for people with multiple sclerosis, and lifestyle support for people with Huntington's Disease.

- PhD Successes: [Dr Amber Jordan](#) has recently successfully defended her PhD in viva. Her PhD was on supporting adolescents to become more involved in shared decision making regarding their health.
- Policy & International Collaborations: [Natalie Joseph-Williams](#) has led an [international group to develop guidelines for the implementation of Patient Decision Aids in routine clinical practice](#), and is Chair of the [SDM in Rare Diseases White Paper](#) Group. [Adrian Edwards](#) is academic lead on the [NICE SDM Guideline](#) committee.

Current focus and plans for forthcoming year:

- Collaborate with the Patient Safety Work Package, led by [Dr Andrew Carson-Stevens](#), to explore the nature of patient-reported safety concerns experienced in healthcare settings during the coronavirus pandemic
- Deliver and embed Shared Decision Making training to healthcare professionals across Wales as part of the NHS Value Based Healthcare programme.
- Understand and evaluate the role of [Patient Reported Outcome Measures \(PROMs\)](#) in informing and measuring shared decision making in routine clinical practice.

WP6. Supportive & palliative care

Leads: Professor Annmarie Nelson & Dr Marlise Poolman



An estimated 23,000 people in Wales require palliative care at any one time¹⁴. Non-palliative care specialists (GPs, community nurses, and paramedics) play an important role in supporting families and delivering end-of-life care to patients.

Key activities over the past year:

Care in the last days for those wishing at home when they die

- Completion of the NIHR-funded [CARIAD feasibility RCT](#) on the intervention of teaching unpaid carers to give as-needed subcutaneous medication for breakthrough symptoms in people wishing to be at home when they die. As part of the COVID-19 pandemic response, the Welsh Government End of Life Board requested our team to draft policy for the CARIAD package to be implemented rapidly.
- The [NIHR fast-tracked publication](#) in support of this work, and WG approved the new all-Wales policy in March 2020. Implementation is progressing at pace. Many groups in England also expressed interest.

Bereavement

- In 2019, we were commissioned to look at the scope of provision of all bereavement services in Wales using NICE guidelines. A key consideration from the results is the development of a national framework for bereavement care, to facilitate increased prioritisation of bereavement support at organisational and regional level, and equity and access across Wales. As a result of this work £1m extra

funding to support bereavement services has been agreed by Welsh Government and the draft framework is close to completion following recent consultation exercise.

Current focus and plans for forthcoming year:

- Ongoing dissemination of results from [Bereavement during Covid-19 study](#), including regular engagement with the UK Bereavement Commission, Welsh Government Bereavement Framework Core Group, DHSC bereavement team and other policy, practitioner and academic audiences. [Emily Harrop](#) sits on the steering group for the [UK Bereavement Commission](#) and the Welsh Core Group, alongside [Anthony Byrne](#). Their involvement with the Welsh group will continue over the next year to finalise and implement the new National Framework and associated funding commitments.
- [Public Attitudes to Death and Dying](#) - we are aiming to produce papers and reports offering comparisons with the Wales (2018) data, and the Northern Ireland (2029) data, post pandemic. Additionally, we will explore the association between personal characteristics and people's attitudes to death and dying.



WP7. Screening, prevention & early diagnosis

Leads: Professor Kate Brain & Professor Clare Wilkinson



Screening, prevention & early diagnosis (SPED) has continued to build on its strengths in cancer and other health priorities. Focus has been aimed at developing strategies to prevent obesity related disease and reduce harm from tobacco, increasing public awareness, and improve equitable uptake of cancer screening.

Key activities over the past year:

- Developing and evaluating community-based strategies for encouraging earlier cancer diagnosis and integrated prevention across tumour sites.
- Addressing the (adverse) social gradient in cancer, including completion of the [ABACus3 trial](#) of a targeted cancer awareness intervention for adults living in deprived communities
- Increased national and international collaborations seeking to accelerate early diagnosis for cancer
- With our sister centre, the [Wales Cancer Research Centre](#), we have been developing our international collaborations in Vietnam, Australia and the US through an NIH grant and associated work
- The [WICKED study team](#) created and began delivering workshops to General Practice staff across Wales to expedite cancer diagnosis to improve cancer outcomes as part of

the ThinkCancer! Feasibility Study Recruitment in the NIHR funded [Cancer: Life Affirming Survivorship support in Primary care \(CLASP\)](#) Programme hit its target of 2,500 patients recruited throughout England and Wales.

Current focus and plans for forthcoming year:

- Involve patients, health professionals, and members of the public in developing, evaluating and implementing person-centred interventions that address health inequality in cancer screening, prevention and early diagnosis
- Develop and test new measures and tools to improve cancer screening, prevention, and early diagnosis behaviour across a range of cancer types
- Underpin our research with state-of-the-art behavioural science and sociological theory and methods
- Deliver these aims whilst ensuring all our programmes of work are completed on time, and new grant applications in this field are in the pipeline



WP8. Oral health & primary dental care

Lead: Professor Ivor Chestnutt



Poor oral health is closely linked with social and economic disadvantage. In the UK, 49% of children have developed dental caries by age five, and dental extractions under general anaesthetic are a leading cause of hospital admission in children aged 5-9 years. A programme of major reform in how dental services are commissioned in Wales is underway.

Key activities over the past year:

- Exploring how technology can be employed to improve oral health in disadvantaged adolescents.
- We have received funding to provide evidence to support the current reforms to how primary dental care is commissioned in Wales.
- The international applicability of our work has been recognised by the award of a prize from the International Association for Dental Research.
- The PRIDA study - working with Public Health Wales and the office of the Chief Dental Officer we are exploring how a shared decision aid can be used to agree an appropriate interval to attend the dentist.
- With colleagues in the Cardiff University School of Mathematics, we have won funding from Health and Care Research Wales to determine how a more efficient and cost effective preventive approach can be adopted in primary dental care in Wales – the [OPTIMISE study](#).

- The NIHR funded [BRIGHT clinical trial](#) (in collaboration with the Universities of Dundee, Leeds, Sheffield and York) has completed all baseline examinations, and year two examinations in the schools recruited in 2017/18 are underway. The objective of this work is to determine the clinical and cost effectiveness of SMS messages in encouraging behaviours conducive to good oral health in adolescents living in disadvantaged communities.

Current focus and plans for forthcoming year:

- Developing, evaluating, and implementing value-based models of preventing dental decay including the use of operational research
- Co-production in the delivery of dental services – shared decision making in relation to the appropriate use of dental services
- School based clinical trial to determine the potential of SMS messaging to improve oral hygiene and prevent dental caries
- An epidemiological study to ascertain the impact of oral health improvement programmes and the oral health of young adults in Wales.

Conclusion

The 6th 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 ongoing major challenges around long term conditions, infections, dental, patient safety, palliative care, care in the community and the interface with social care and third sectors.

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. 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.

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.

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.

The benefits of the infrastructure funding to be able to do this quickly and effectively are clear. Once again, we thank our funders and our public, national and international advisors for their support and direction.

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.

Forward look

Rapid changes in health and social care have occurred over the past year. We are evaluating many of these such as the TRIM study of 999 triage protocols or the CARIAD programme of delivering palliative care procedures in the community. As we move towards a period more of recovery and regeneration after the second wave of the pandemic in UK, much of our research will play a vital part.

Primary and emergency care still accounts for over 90% of all healthcare encounters in Wales. We also now face particular pressures from ‘backlogs’ of cancer care, long term condition management and much else.

Studies like CABS (cancer behaviours) and COPE (public experiences in the pandemic) will vitally inform service adaptations. Other studies in the Patient-Centred Care and Patient Safety fields look at innovative ways of using patient experiences and outcomes to determine what value is really delivered by services, potentially as a vital tool in managing both the ‘backlogs’ and ongoing need.

Establishing both the Wales School for Social Prescribing Research and the Wales COVID-19 Evidence Centre within PRIME are testaments to the quality and impact of PRIME's research. It also shows the value of our ‘applied’ and ‘translational’ research. That is, we work at the end of the spectrum which is concerned with real life solutions and putting things widely into practice.

It is vital that we have a strong evidence base to inform policy and practice in primary and emergency care. PRIME Centre aims to deliver that and to increase our capacity to do so in the future.



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PRIME Centre Wales Annual Report 2019-20:

<http://www.primecentre.wales/annual-report-2019-20.php>



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