# Uned Ymchwil Arennol Cymru Wales Kidney Research Unit







2019-20 Annual Report

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F O R E W O R D

#### Hello!

It's a real pleasure to introduce this, our report of activity in 2019-2020. Inside you'll find out about the scale of the problem of kidney disease in Wales, and also about some of the many activities taking place within the WKRU to try and combat it. I hope you'll also get a sense of the wide variety of people that make up the membership of WKRU -researchers, patients and families, clinicians and service commissioners from across Wales. Its our members from these varied backgrounds working together that really helps to make a difference in combatting kidney disease.

The big story that you wont read about in this newsletter is Covid-19. While you might enjoy the chance to read about something else, if only for a short while, I'll just highlight that researchers in Wales are working hard on combatting the virus, and this extends to trials of new treatments, including in those with kidney disease. It's likely that we'll have more on this at our next annual meeting, and in our next report. Meanwhile, it is important too to acknowledge the huge impact that Covid-19 has had on kidney research in Wales, as on all other aspects of our lives. Many projects involving person to person contact, or access to laboratories, have been scaled down or put on

hold. Researchers have done their best to adjust, analysing data and teamworking from home, and some of the lessons from this will I think improve how we work effectively in teams across Wales once the current emergency is over -a silver lining to a very dark cloud, if you will. But we also have to recognise the very great impact of Covid-19 on those directly affected by kidney disease. Many kidney patients are having to shield themselves at present, and are bearing therefore a disproportionate impact from the measures that we all have to take to stay safe. And our thoughts in WKRU are especially with those who have been severely ill or lost their lives to the virus, or whose loved ones have been affected like this. We're considering at the moment how best to respond to this within WKRU. There may for example be a session dedicated to Covid-19 at our next annual meeting, and if you have other ideas or experiences on this, we'd love to hear from you. In the meantime, I hope you and those close to you stay safe through this, with very best wishes.

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WKRU Director, Professor Donald Fraser

Uned Ymchwil Arennol Cymru Wales Kidney Research Unit

N T R O D U C T I O N

#### The only Biomedical Research Unit in the UK funded to focus solely on Kidney Disease

450,000 people in Wales have Chronic Kidney Disease (CKD) Stages III-V (less than 50% of kidney function remaining) and that places them at a greatly increased risk of death and cardiovascular illness.

10,000 people are under follow up in renal secondary care, including 2,000 people dependent on Renal Replacement Therapy (RRT) to keep them alive. WKRU is built on internationally recognised research in each step of the translational pathway, from fundamental disease mechanisms and better diagnosis, to improved implementation and health outcomes,

WKRU research successes are informed by and involve patients, families and carers, service providers and service commissioners, as well as researchers. UNIT DIRECTOR Prof Donald Fraser



The membership of WKRU is based in three Centres around Wales: Bangor University, Cardiff University, Morriston Hospital/Swansea University.

WKRU SENIOR TEAM AND CORE STAFF

#### Our mission

#### Our strategic Objectives

-Improve the infrastructure supporting kidney research in Wales.

-Involve stakeholders (patients, families and carers, service commissioners, service providers, as well as researchers) in the key stages of research, namely, planning research, undertaking research, and dissemination of findings and subsequent improvements in practice.

-Build a portfolio of research funded by external awards at all stages of the pathway from basic research to healthcare delivery, leading to demonstrable improvements in practice (research with impact).

-Build a portfolio of industrial partnerships in research projects, leading to demonstrable changes in activity.

-Engage with the public to raise awareness of kidney disease, its clinical and social effects and share the findings of our research.

#### Administration Team

Kim Abberley Cheryl Ward

#### Bangor: Social Care Team

David Dallimore Leah McLaughlin Barbara Neukirchinger Jane Noyes

#### Swansea: Data Analysis Team

James Chess Gareth Davies Ashley Akbari

#### Cardiff: Laboratory and Clinical Research Team

Elijah Ablorsu Mohammad Alhadj Ali Argiris Asderakis Timothy Bowen Charlie Brown Rafael Chavez Kieran Donovan Matthias Eberl David Foxwell Sian Griffin Shivaram Hegde Jennifer Holmes Ian Humphreys Robert Jenkins Simon Jones Usman Khalid Mario Labeta Farah Latif Chia-Te Liao Soma Meran Glyn Morris Lucy Newbury Anne-Catherine Raby James Redman Steve Riley Dan Smith Kate Simpson Robert Steadman Michael Stevens Phillip Taylor Jerry Warden-Smith Aled Williams Alexa Wonnacott

### Other WKRU collaborators

John Geen David Glover Jamie Hugo-Macdonald Mick Kumwenda David Minton Gloria Owens Gareth Scholey Ben Thomas Janet Williams



**AERDY**IE

To bring benefit to the population of Wales and further afield, through delivery of collaborative, multi-disciplinary research that answers important renal health and social care problems. SUMMARY

#### Why a Wales Kidney Research Unit?

Kidney disease is common and often silent. Of the 1 in 10 of the population estimated to have significant kidney disease, half will not be aware of their diagnosis and so will not be taking measures to slow progression and avoid future morbidity. 15% of the UK population have Chronic Kidney Disease (CKD) and Renal Replacement Therapy consumes 2% of the NHS budget, or £120 Million p.a. in Wales. So the NHS in Wales needs to understand the service pressures and how best to meet them.

WKRU is designed to help meet these challenges as it provides a core infrastructure enabling patients, families and carers, third sector organisations, service providers, service commissioners, industry partners, and researchers to answer important health and social care research questions related to kidney disease, and to develop state of the art services that benefit population needs.

#### Who benefits from the unit's work ?

#### Patients and carers

Advise and participate in research studies to improve outcomes for patients. Contribute to the wider service improvements of care in Wales and beyond.

#### Health and Social Care Professionals

Help direct research activity towards goals with impact beyond advancing knowledge.

#### **Researchers**

Connected to other stakeholders, ensuring that the research questions will improve the health and social care of kidney patients.

#### **Commissioners**

Connect with other stakeholders to advance a prudent healthcare agenda.



### Wales Kidney Research Unit 2015-20 in numbers

Over £9,500,000 of grants awarded to our group

Over 113 projects are currently lead or supported by WKRU



General Control of Con

99 Scientific articles published

9 Trials started in the last year with 9 getting laboratory support for sample processing

Tissue banking activities



Over 500 new patients were consented into the tissue bank 2026 Biological samples were collected and 2809 released to researchers for a total of 7037 samples held in the Wales Kidney Research Tissue Bank

#### Who is in the unit?

The Wales Kidney Research Unit has members from every Renal Unit in Wales.

Studies of population-scale health outcomes data have the potential to transform NHS services, and WKRU is working with the Swansea-based world-leading SAIL (Secure Anonymised Information Linkage) Databank to develop this capacity. In addition to laboratory and clinical research taking place in Cardiff, researchers in Bangor are focusing on social care aspects and wellbeing of renal patients.

#### Quotes from patients

"The Management team here do all things possible to ensure best use of resources. Indeed the Unit itself being established on an 'All Wales basis' ensures research is not duplicated and that collaboration is a top priority, sharing sharing of resources, data and best practice."









"We have noted the improved level of Public and Patient Involvement (PPI) at recent events such as the AGM, Open Days and meetings (eg. With KRUK), where attendance and participation has been increasing. This is most encouraging and offers quantitative evidence in terms of an outcome in fachieving specific WKRU objectives."

#### Get involved, get in touch

WKRU invites all patients, carers and members of the public to get involved with the design, delivery and dissemination of our research. In our quarterly *Involvement in Research Design* meetings we discuss grant ideas, each focusing on one aspect of kidney disease. The project is explained in detail in lay terms and a knowledge of science isn't necessary. We believe it is essential that patients and carers inform our research ideas. In Cardiff, we also regularly open our laboratory to the public.

#### More details at: http://kidneyresearchunit.wales/

You can also watch the <u>video</u> "WKRU: a day in the life" to see what we do.

More information on our activities can be found in our newsletter distributed to renal units all around Wales. To get involved in our research please email <u>colmontes@cf ac.uk</u> or <u>wkru@bangor ac.uk</u> c call 02921848469.

### Wales Kidney Research Unit 2015-20 at a glance

137 grant applications submitted for a total of 113 grants awarded and lead or supported by the Unit

Over £9,700,000 of grants awarded to our group



99 Scientific articles published



Over 1750 Members of the public participated in our events



2809 Samples released to researchers

7037 Samples held in the Wales Kidney Research Tissue Bank

Over 60 ongoing projects are currently lead or supported by WKRU **Lissue banking activitie** Biological Same Collegical Same

2026 Biological samples collected Over 500 New patients consented into the tissue bank

7 students are studying for a degree, including 4 clinicians with one PhD awarded and one submitted

49 People have been employed in the Unit 9 Trials started in the last year and 9 getting laboratory support for sample processing

### WORK PACKAGES

#### WKRU activity is organised into five work packages

#### Management

WKRU management is robust, democratic, efficient and responsive to opportunities and challenges. Activity is overseen by the grants management team at Health and Care Research Wales. WKRU reports to them on a quarterly basis with additional financial reporting mid-year, and a full annual progress report.

> Advice and input from three independent experts

Input and design from public and patients

WKRU director: responsible for activities including liaison with and reporting to the funder, day to day project management, financial management, resolution of any disputes arising, collecting important network information and making this available to all stakeholders.

Director and unit manager review all activity and operational issues weekly. Senior management team (composed of leads from Cardiff, Bangor and Swansea and unit manager): monthly teleconference to assist the director

#### Research Infrastructure

Our researchers are based in Cardiff, Swansea and Bangor Universities, and the NHS.

WKRU underpins the Wales Kidney Research Tissue Bank, which includes samples from patients recruited locally, nationally and internationally.

We have integrated the all-Wales renal dataset into SAIL to allow us to undertake population-level studies.

We work closely with Kidney Research UK (KRUK), the principle UK funder of renal research. Donald Fraser is co-Chair of the KRUK Research Grants committee.

Siân Griffin is General Secretary of Transplantation Society and liaison with the KRUK Research Grants Committee. The senior team meets face to face annually at the unit general meeting, together with representatives of all stakeholder groups and the funder, and with the independent external experts of the unit.

### WORK PACKAGES

#### WKRU activity is organised into five work packages

#### Research Infrastructure

#### WALES KIDNEY RESEARCH TISSUE BANK

The purpose of The Wales Kidney Research Tissue Bank (WKRTB) is to serve as a repository of samples donated by patients and healthy volunteers for use in studies advancing the prevention, understanding and care of kidney diseases.

What is a tissue bank? This is an organisation that collects and stores biological samples (tissue, blood, urine etc...) and data. and makes them available to researchers to learn more about how diseases start, develop and how to treat them. The WKRTB collects such samples and supports research into kidney and related diseases by making anonymised samples available to scientists involved in such research.

How is it regulated? Access to tissue and any personal data that may be associated with it, is strictly controlled. A formal request to use WKRTB samples and the planned research must be reviewed and approved by the **Tissue Bank Governance** Committee. In order to do research with human tissue, researchers need to collect information from patients' medical records and record details of diagnosis tests. All personal information is kept confidential and anonymous.

bank? Before any work and collection of tissue can start, the tissue bank submits documentation for review by a Research Ethics Committee to ensure that all rules and regulations are followed, in particular Human Tissue Authority ones. All processes are reviewed and

Who reviews the tissue

### What type of research is conducted?

renewed every 5 years.

Many different types of research rely on the use of human tissues. They can be used to develop new tests to help diagnose diseases, or can be used to help develop new ways to treat or even cure diseases. Some of the research may lead to new medical products, such as diagnostic tests and drugs, or new procedures.

### What happens to the tissue?

Many people get involved to help recruit patients and collect samples, at Cardiff University and the NHS. Samples are collected during routine hospital visits and can either be processed and used immediately or stored at low temperature to be released to researchers later.













## Work packages

#### WKRU activity is organised into five work packages

#### Research Activity: A Snapshot

- Ongoing discussions with Brecon Group & refining an Information Governance Review Panel application to study CKD outcomes in Type 1 Diabetes. Clinical trainee undertaking a literature review specifically looking at outcomes in pregnancy
- SAIL project 'Wales Acute Kidney Injury (AKI) eAlert validation': the WKRU SAIL analyst worked through procedures to integrate various types of clinical data, with manual review of outputs followed by clinical expertise and implementation of manual corrections
- Process evaluation of implementing a new Specialist Requester nursing role, 'Seeking consent for organ donation: Process evaluation of implementing a new Specialist Requester nursing role'. Paper submitted January 2020 to Journal of advanced nursing
- We submitted an all Wales research priorities exercise in December 2019. 'Setting integrated health services and social care research priorities in kidney disease in Wales.' Submitted to British Medical Journal Open





### WKRU work has been presented in various conferences

- Poster presentations at UK Kidney Week; American Society of Nephrology annual conference with talks and poster presentations; Peritoneal Dialysis nurse National Forum
- SAIL work: Collaborate 2018, Administrative Data Research, Health Data Research UK
- Social Care research: Public Health Wales 2019 conference; Chief Nursing Officer conference presentation; Dialysis Options and Choices Key stakeholder meeting; Paul Popham Conference presentation; European Festival of Social Sciences and social prescribing; Meeting Kidney Research UK; HCRW Lets Talk Research Annual Involving People Conference. Transplant café – a service set up by Multi-Disciplinary Teams (MDT) and patients to hear stories and share with people who are having similar experiences
- British Transplant Society 2020; Presentation at National Home Therapies Group & National Health and Wellbeing Professionals Group

## Work packages

#### Training

Training in renal research is an important goal for the Unit to allow delivery of the research agenda but also increasing research skills and capacity. In addition WKRU makes every effort **to include all stakeholders' groups in activities** allowing a better understanding of research.

#### Mentoring trainee researchers

- Recent studies have revealed that synthesis and accumulation of the matrixpolysaccharide hyaluronan-(HA) is essential in driving scarring, and increased HA expression correlates with renal outcomes. One student is investigating the mechanisms involved in the potential anti-scarring role of a variant of the HA-receptor, CD44, as part of her professional training year project.
- The two former WKRU trainees who have now finished their role on the Clinical Research Facility have been awarded a 3-year WCAT (Wales Clinical Academic Track) fellowship.

- A new PhD project is starting using SAIL data funded via Cardiff University Pharmacy Department, with the aim of doing an All Wales study into management of renal anaemia.
- In 2019-20, one nephrologist has completed his PhD studying the role of a molecule in several aspects of renal disease and titled
   "The Involvement of Hyaluronan Matrix in Regulating Peritoneal Infection, Inflammation & Fibrosis".
- Another nephrologist has completed her PhD on "MicroRNA Regulation of Podocyte Insulin Sensitivity "and is awaiting her viva.
- A trainee transplant surgeon also completed her PhD project studying "The Role of Hyaluronan and its Receptors in the Acute Kidney Injury to Chronic Kidney Disease Continuum".



WKRU is a hub of activity for people at all stages of their careers in research. We recently hosted a year 12 student, Ms Tanya Enoch from Cathedral Sixth Form College in Cardiff for a short placement. She was interested in basic science and educating people about kidney disease. Tanya produced two information leaflets and a poster designed to educate people on risk factors and ways to stay healthy with kidney disease. We have shared her work with our charity partners who are interested in working further with Tanya to develop this project.





## Work packages

#### WKRU activity is organised into five work packages

#### Training





Awarded a PhD studentship in partnership with Kidney Wales

We were awarded a Knowledge Economy Skills Scholarship to appoint a PhD student to **look into, 'Why do people say "no" to a** kidney transplant? Understanding patient **decision making and choice'. Supervised by** Professor Jane Noyes, Professor of Health and Social Service, School of Health Sciences, Bangor University and Dr Kate Shakespeare, Clinical Psychologist; Ysbyty Glad Clwyd Renal and Diabetes Centre and in partnership with Kidney Wales and members of the Multi Disciplinary teams in Betsi Cadwaladr University Health Board the aims of this three year study are:

#### Aims

- 1. To understand the reasons why potentially eligible patients, decline a kidney transplant or disengage from the transplant work up process.
- 2. To develop a person centered model **that encapsulates patients' decision**making processes when considering transplantation as a treatment choice.

#### Secondary Aim

To use the findings to inform the future development of a decisionmaking toolkit to facilitate shared understanding between patients and providers about kidney transplantation choices.

We look forward to working with these key stakeholders on this important work.



### MEETING THE PUBLIC

#### WKRU activity is organised into five work packages

#### A flavour of WKRU activities

Communication is key to WKRU delivering on its aims. Outreach and engagement between its members and other stakeholders allow us to disseminate the results of WKRU research widely and maximise their impact.

Over the past year we have created and taken opportunities to talk about WKRU to patients and **the public. We attended the 'Renal Roadshows'** with the Welsh Renal Clinical Network in Newport and Bangor. We met people with kidney disease who were in the process of deciding about dialysis, on dialysis and transplant recipients. **We had an opportunity to listen to people's views** and thoughts about future and ongoing research, as well as recruiting people with kidney disease and family members into the research.









We presented a TED style talk at this year's Health and Care Research Wales annual involving people event. This year it took the form of a festival in Cardiff's National Museum and a duplicate event held in Bangor. People were invited to come and hear about all of the research across health and social care in Wales in an informal way.

Some of our latest research has been featured in the latest issue of Kidney Matters – a patient led magazine produced by Kidney Care UK. You can read more about this on page 18.

We were selected to present at the Public Health Wales Research Showcase Event: Bringing Together Health and Social Care Research: A Revolution in Transformation. The event saw speakers from Welsh Government: Ifan Evans - Director of Technology & Transformation 'A Healthier Wales: Coordinated Research, Innovation and Improvement', as well as breakout sessions on big data and social prescribing. We attended a research event 'Co-producing research: How do we share power?' organised by INVOLVE: Centre for Public Engagement Kingston University & St Georges UCL Centre for Coproduction in Health Research. We listened to a variety of stories and presentations about successful co-productive research and learned to think about some of the questions that might illustrate success.

### MEETING THE PUBLIC

#### WKRU activity is organised into five work packages

#### TRANSPLANT GAMES IN NEWPORT - JULY 2019

We attended the fantastic British Transplant Games held in Newport and organised by health and social care professionals, charities and third sector organisations across Wales. We had an opportunity to meet individuals who had received deceased organ donations, and live organ donors and recipients.

Taking place in different host cities every Summer, the games see teams from hospitals across the UK come together to compete in a medley of sports. The 4-day event attracts around 1000 transplant athletes and more than 1500 supporters.







Kidney Health for Everyone Everywhere – from Prevention to Detection and Equitable Access to Care

We partnered with the World Kidney Day Campaign adding their logo 'Kidney Health for Everybody' to all our social media Channels.



WKRU Annual General Meeting (AGM) took place with a mixed audience of researchers, clinicians and patients, all of whom presented their work and ongoing relationship with the unit.

Owain Brooks, pharmacist in Morriston Hospital in Swansea was the poster prize winner at this year WKRU AGM (see his study p21).

We produced a video of one of our patient representatives live kidney donor journey and shared this with Kidney charities and partners over World Kidney Day. The video is available for download here.

http://www.youtube.com/watch?v=kXiNmNweaSg &t=683s



### MEETING THE RESEARCHER

#### FOCUSING ON FIBROSIS

Nephrology specialist, Dr Soma Meran and her team are looking for ways to tackle kidney fibrosis, or scarring – where excess scar tissue forms. The scar tissue prevents the kidney working properly and is an important factor in chronic kidney disease development.

In collaboration with the University of Exeter and the Cleveland Clinic Lerner Research Institute, the research involves altering the cells responsible for wound healing and tissue repair and could lead to treatments that would prevent and even reverse kidney fibrosis.

Dr Meran said: "We were amazed to discover that a protein called hyaluronidase-2 can bind to RNA (long chains of information, similar to DNA) in a cell and alter its activity. We could potentially use this technique to stop the cells responsible for fibrosis and scar formation from producing scar tissue. This opens up exciting **new research avenues in the study of fibrosis.**"



Growing up in a war-torn country, separated from her parents in London, Dr Meran says her childhood memories of the Iraq war will always shape her.

Dr Meran featured in the Kidney Research UK <u>Update magazine of Autumn 2019</u>: "From war child to leading the fight against kidney **disease**"





Normal healthy cells on the left. Enlarged, scar-forming cells with stress-fibres shown in bright green on the right. These fibres contract to pull the scar together.

### INVOLVEMENT IN RESEARCH DESIGN

#### CASE STUDY

We have an upcoming study, pregnancy choices with kidney disease, due to open in September 2020. Below we describe how we involve the multiple key stakeholders in setting up new research.

Involving patients, the public and key stakeholders in the research design.

The original intellectual ideas for this research emerged from consultations with women with CKD who as individuals, partners, mothers and carers said that they faced complex decision making about pregnancy and their personal health and wellbeing. This grant was developed in partnership with three women living with CKD who provided direct input into the shaping of the application, advised on methods of data collection, dissemination, engagement with the Multi-Disciplinary Teams and the overall focus of the research.

Designing Involvement and participation throughout the study

We have designed the study to encourage participation throughout such as creating a multi-disciplinary steering committee with patient representatives, invitations to attend data analysis meetings across Wales, presentations at patient group meetings, and opportunities to co-present research and co-write academic articles.

Designing dissemination of research for the people who matter the most

We will work closely with patient representatives from the five renal centres in Cardiff, Swansea, Bangor, Glan Clwyd and Wrexham and encourage patients to share findings through their social networks, renal unit visits, clinic visits and informal contact with other patients. We will produce a webpage and social media presence on Facebook, Twitter and relevant wider groups such as 'MumsNet'. We intend to recruit through these channels as well as disseminate outcomes through them. We will produce a mailing list which we will update regularly and deliver updates via newsletters and important announcements. We intend to utilise a variety of media such as text, podcasts, video diaries (vlogs), visual graphics and co-presented PowerPoint presentations with patients to ensure that the findings are presented accessibly, in a way that is suitable, easy to understand and immediately useful for patients.

pregnancy choices with kidney disease

> We will connect with Welsh renal charities and present findings at their meetings, such as Paul Popham Patient led events and Kidney Wales events. Our main academic paper from the study will be published as an open access article so that patients can access the full text without encountering a paywall. We will produce a press release and celebration style 'study launch' event so that people can keep track as the study progresses. The study is due to open on the 01.09.20 and you can follow it here.

www.kidneyresearchunit.wales/i mpact-case-studies.htm?id=34

Funded by the British Renal Society and Kidney Care UK. This study is a partnership with Bangor University, Cardiff University, Cardiff Met, Cardiff and Vale, Swansea Bay and Betsi Cadwaladr University Health Boards. We are supported by the Welsh Renal Clinical Network, Paul Popham Renal Fund and Kidney Wales.















## DIALYSIS OPTIONS AND CHOICES





Funded by Health and Care Research Wales part of the Research for Patient and Public Benefit Scheme in October 2018 this 2 year pan Wales coproductive study has been learning about the key factors **influencing patients' pre** dialysis decision making. The team are working to complete the final stages of analysis and dissemination and will report in full in autumn 2020.

Highlights to date include: Thanks to working with the multi-disciplinary teams across Wales we recruited a varied sample of people with kidney disease and their family members across Wales. We mapped out service pathways focussing on home therapies, drawing together all of the work with renal professionals and the renal community over the past two years.

We are supporting the renal transformational fund working to improve digital renal

services and the redesign of the educational programme. We have produced two webinars 1. 'What does good look like – what do sustainable renal service look like from the multiple perspectives' and 2. 'There is no place like home – redesigning training areas to support transitioning to home therapies'.

You can find these webinars on the Wales Kidney Research Unit YouTube channel here https://www.youtube.com/cha nnel/UCuMnTURP10rWTuKw9Y \_eu-A? view\_as=subscriber.

We encourage you to share these webinars with people living with kidney disease and contribute to them yourselves. This is especially important now as we look towards a service post COVID 19. We have real opportunities to produce more sustainable services. Selected presentations include:

- European Festival of Social Sciences Social Prescribing Network Event, Bangor University.
- Health and Care Research Wales annual conference – Collaboration and Partnerships.
- The Chief Nursing Officer annual Conference 2019. 1000 Lives Improvement Event.
- Kidney Care UK's magazine
  'Kidney Matters' (p. 26-27).
  https://www.yumpu.com/en
  /document/read/63056765/k
  idney-matters-issue-8 spring-2020

For further information, to follow the study progress and to share your views, and read our updated newsletter reports see our website here <u>http://kidneyresearchunit.wales</u> /dialysis-options--choices



# WKRU WORK IN SALL

#### Defining Acute Kidney Injury Episodes

Research team: Dr Gareth Davies, Dr Tim Scale, Dr Ashley Akbari, Dr James Chess, Professor Ronan Lyons from Morriston Hospital and the University of Swansea





#### Background and Aims

Acute Kidney Injury (AKI) is a common, serious condition affecting up to 20% of all hospital admissions in the UK. AKI has an agreed definition for its recognition, however there is no consensus for the duration of an AKI episode. We aim to describe four different potential definitions of an AKI episode.

#### Method

We identified AKI using an algorithm (an implementation of the NHS England eAlert algorithm) applied to serum creatinine (SCr) results from a South Wales population of ~518,000 people, held in the Secure Anonymised Information Linkage (SAIL) Databank. Using a **person's index AKI case, we applied four** different rules to define an episode of AKI. These definitions are: ALERTS - until they no longer trigger an AKI eAlert, 90 DAYS - until 90 days post first AKI test and <1.2/<1.5 until the SCr

recovers to <1.2 or 1.5 times their baseline creatinine.

#### Results

There were 1,832,122 SCr tests in 340,908 people between 2011-2013, of which 93,843 were alerts (5.12%). This fell to 81,948 alerts in 21,979 patients when dialysis and transplant patients were excluded. Of these patients with AKI 7,792 (35.5%) were dead at 1 year after their first episode. There were 31,505, 33,759, 26,657, 34,904 episodes in patients by <1.2, <1.5, 90 Days and ALERTS definitions respectively.

#### Conclusion

AKI episodes can be created in SAIL and by adjusting the definition we see a variation in the number of episodes that a patient experiences. Once described, this cohort can be used to define a gold standard for AKI in future analysis.

#### Ongoing SAIL projects

- Which factors determine treatment choices in patients with advanced kidney failure: Co-productive study with patients and key stakeholders
- Acute Kidney Injury Alerts and Outcomes in Wales



# KEPT - A CASE STUDY

#### Knowledge and Experiences of Peritoneal Dialysis-Associated Peritonitis

Research team: Dr Jessica Baillie, Dr Paul Gill, Professor Molly Courtenay from the School of Healthcare Sciences, Cardiff University

Funded by \*rcbcwoler



#### Background

Peritonitis (infection of the peritoneum) is the most common complication of Peritoneal Dialysis (PD) and

can result in: PD failure, antibiotic treatment,

hospitalisation, morbidity and mortality. It is crucial that patients know how to prevent peritonitis, monitor for it and are able to promptly seek help if they suspect they have the infection. This study aimed to examine **patients'** and **families'** knowledge, understanding and experience of peritoneal dialysis (PD)-associated peritonitis.

#### Methods

statistics.

This study used a mixedmethod approach.

Phase 1 - A telephone questionnaire for patients and family members (n=75) using PD, from six hospital sites across Wales and England. We **examined participants'** knowledge of peritonitis and their experiences if peritonitis was diagnosed. Data was

Phase 2 - A purposive sample

analysed using descriptive

of participants (n=30) from phase one took part in telephone or face-to-face semistructured interviews, exploring in-**depth participants'** understanding of and their experiences of peritonitis. Data was analysed thematically. Study registered on Welsh and English research portfolios with Ethics and governance approvals.

#### Interim Findings

Key findings relate to seeking help when peritonitis was suspected. Most respondents (97%, n=73) reported they would contact the clinical team if they suspected peritonitis. Of the 37% (n=28) of participants with experience of peritonitis, 64% (n=18) stated they contacted the clinical team immediately on suspicion of peritonitis. However, participants struggled to identify peritonitis when symptoms started, leading to delays in seeking help, until they felt more certain. Subsequently, some participants seeking help from renal or generic out-of-hours

were misadvised or misdiagnosed. Delays led to individuals presenting with severe peritonitis, requiring lengthy hospitalisation and, in some cases, transfer to haemodialysis. Participants felt shame and blame when they were diagnosed with peritonitis.

#### Conclusions

This study revealed differences between participants' helpseeking intentions and actions when peritonitis was suspected. To safely use a home therapy, it is imperative that individuals know when to seek help and are appropriately supported when they do so – further work is thus needed to promote this.



### Collaborations

#### A hyperkalaemia educational animation for people with kidney disease: An acceptability study

Research team: Pharmacist Owain Brooks and colleagues from Morriston Hospital and School of Pharmacy and Pharmaceutical Sciences, Cardiff University study

#### Background and Aims

Hyperkalaemia is a potentially life-threatening emergency and a common complication in patients with renal impairment. Patients are inundated with a variety of information from renal healthcare professionals. The magnitude and multiplicity of medication often prescribed in renal disease can also be confusing for patients.

We have created a hyperkalaemia patient education animation and have explored the views of renal patients to refine the animation before making it widely available.

#### Method

Opinions were gathered from a focus group of representatives from the Paul Popham renal support charity. This informed the development of a data collection tool, to be used during oneto-one interviews with haemodialysis (HD) patients. Interviews were transcribed verbatim and thematically analysed.

#### Results

The animation was shown to 12 HD patients. 50:50 male:female. Four main themes were identified: the requirement for patient education, the utility of the animation, ways of **learning and the animation's impact on the** patient.

MUSCLE CRAMPS MUSCLE WEAKNESS HEART PALPITATIONS CHEST PAIN





KIDNEY CARTENS:

#### Discussion

Multimedia interventions have been shown to positively impact on learning. Our focus group and one-to-one interviews identified a need for hyperkalaemia education for renal patients. The animation was well received by all patients, including its design, simplicity and narration. Subsequent versions of the animation were created following patient feedback and will soon be available in English and Welsh to renal patients in South West Wales, before being rolled-out across Wales. A paper-**based 'comic book' version of the animation will also be** created.

#### Conclusion

The animation was well received by patients. Valuable feedback was obtained and will continue to be requested. We believe that this, and subsequent animations (including **'understanding dialysis', 'blood pressure and fluid balance' and 'CKD**-mineral and bone **disorder') will improve patient understanding of** kidney disease and positively impact on patient health and wellbeing.

#### Kidney cartoons: High potassium



### COLLABORATIONS

In January 2020 WKRU researcher Dan Smith took part in 5 primary school visits on behalf of Anita Shaw of STEM powered learning and the Royal Society of Engineering. These visits consisted of him giving a 20-30-minute assembly to the school where he talked about all the different forms of science and engineering that exist outside of school, enthusing the students to pursue science and engineering in later life as an interesting and exciting career path. He showed the students some equipment that he uses including a pipette and glassware, and then ran a demonstration where the students got to see how pH paper works and they performed their own version of the "elephants' toothpaste" experiment.

After the assembly Dan took part in a year 6 class of up to 2 hours where the students were given an experiment to perform. They had various fruits and vegetables which they were to cut up and crush in water in order to extract their vitamin C content. The relative vitamin C content of each fruit or

WKRU is currently working with all renal charities across Wales (Kidney Wales, Paul Popham Fund and Kidney Care UK) and the Welsh Renal Clinical Network to deliver information about COVID 19





vegetable was then determined using simple cornflour and iodine colour change chemistry, with the vitamin C presence requiring more iodine to be added before the solution turns blue. The students worked in groups of 2 or 3 to do this test with multiple samples and a vitamin C tab of known concentration. They also documented their findings so that they could compare this result with those obtained when the younger classes undertook the experiment later in the year.

The schools that took part are: Deighton Primary Antysgallog Primary St. Illtyds Primary St. Marys Primary Willowtown Primary



and available support services to people living with kidney disease. You can view the updates on our website here. <u>http://www.kidneyresearchunit</u> .wales/news?id=94







Super scientists in Year 6 investigating the vitamin C content in different fruit &vegetables! Feeling inspired after a visit from @DrDanChemyMan @STEMpwdLearning #handsonlearning



St. Illtyd's Primary

A big thank you to Dr. Dan Smi (STEM ambassador) for delivering a fantastic interactive assembly and for working with our Year 6 pupils. @EduRAEng @STEMpwdLearning @DrDanChemyMan @TheWKRU #WVEP #BEST



A fascinating assembly with @DrDanChemyMan this morning showing us how fun science can be.





### CONFERENCES AND AWARDS

Dr Mohammad Alhadj Ali, WKRU Clinical Research Fellow received the prestigious "Future Leaders for Clinical Diabetologists" Award from the European Foundation for the Study of Diabetes in Barcelona in September 2019.

Dr Alhadj Ali has worked on Immunotherapy for Type 1 Diabetes for 10 years and been principal investigator and co-investigator for several trials run by the Diabetes Research Group. He is coinvestigator in a recent world-first <u>clinical trial</u> at Cardiff with a drug aimed at helping the regrowth **of insulin making 'beta' cells of the pancreas,** which are lost in patients living with the disease.

Mohammad Alhadj Ali did his PhD in the field of immunotherapy for Type 1 Diabetes at the University of Bristol. He was awarded the Donell Etzwiler International Scholar Award from International Diabetes Centre in Minnesota, USA in 2015, Innovators in Diabetes (IDia) fellowship from Diabetes UK in 2017, W T Edward Medal from Cardiff Medical Society 2018 and the prestigious training award from Association of British Clinical Diabetologists 2018. He explained: **"Patients in Wales have now become the first in** the world to test a drug which could treat Type 1 Diabetes. This is an area that attracted me, because we need new therapies as insulin on its own is not sufficient to achieve the best

Dr Farah Latif, WKRU Clinical Research Fellow won the poster prize at the Cardiff and Vale UHB annual Research & Development conference. She has now been awarded a WCAT (Wales Clinical Academic Track) fellowship to do a three year PhD.



management of Type 1 Diabetes. Diabetes is a growing concern and a heavy burden on healthcare services nationally and globally. Immunotherapy applied here is very innovative and creative work. We are looking into halting the immune attack, to protect cells that still secrete insulin, so we can reduce dependency on insulin, and prevent the disease in patients that have a genetic predisposition to developing the **disease".** 

Dr Alhadj Ali is currently developing a research project combining diabetes and kidney disease research as those pathologies are often associated.



### CONFERENCES AND AWARDS

Chronic-kidney-disease affects 15% of the UK population and increasing numbers of people worldwide. There is no cure for CKD and it is a relentlessly progressive disease. For many years one of our groups, based in the WKRU laboratories in Cardiff University School of Medicine, has focused on investigating the mechanisms controlling the scarring characteristic of CKD progression.

We have identified a molecular chain made up of linked sugar molecules as a central driver of scarring.

This chain is called Hyaluronan and over 20 years we have built an international reputation worldwide as a major centre of Hyaluronan research. This led to us being asked to host the 12th International Conference on Hyaluronan in 2019.

The event was held between June 9<sup>th</sup> and 13<sup>th</sup> at the Hilton



Hotel, Cardiff and was sponsored by the International Society of Hyaluronan Sciences.

The main Conference consisted of 3 Keynote presentations, covering the current state of the art in Hyaluronan research and there were 10 scientific and 3 poster sessions with more than 150 presentations. The Conference Dinner was held at Caldicot Castle. Delegates were welcomed by a fanfare from medieval heralds before trying their skills at archery, skittles and country dancing. The meeting of 250 clinicians and basic scientists was hugely enjoyable and a great success.



Urinomics is a conference focussing on urine and its potential in various healthcare applications. Dr Dan Smith, WKRU post-doc won the poster prize at Urinomics 2019 excellent poster presentation and CITER Annual Scientific Meeting: best oral presentation.

### CONCLUSION

I hope you've enjoyed reading about the great work that WKRU members are doing to improve the outlook for people affected by kidney disease in Wales. I'll finish by thanking all contributors, and particular thanks go to Chantal Colmont, the driving force behind this review (and so much else at WKRU!). This report has had to be selective, in telling just a few of our stories you can find more on our website, and also at our regular engagement activities and other events, you'll find notices about these on our website. If this inspires you to get involved, or if you have questions or would like to find out more about our programme of activities please get in touch.

#### We'd love to hear from you!

Professor Donald Fraser

Thank you to you our Welsh Kidney Family for Staying Home, Protecting the NHS and Saving Lives!

Diolch i chi ein Teulu Arennau Cymru am Aros Gartref, Amddiffyn y GIG ac Arbed Bywydau!







"The efforts of WKRU should be commended to improve public awareness of kidney health and social care. Since its inception, the WKRU has staged several successful events such as those on World Kidney Day, Techniquest, the National at Eisteddfod and participating in school visits, to engage with the public in raising awareness of renal health."

### OUR CLINICAL PARTNERS

























CARDIFF TRANSPLANT UNIT Uned Trawsblaniadau Caerdydd





### Wider Partnership



# Uned Ymchwil Arennol Cymru Wales Kidney Research Unit





