NHS
National Institute for Health Research

APPLICATION DETAILS

Programme Name	Global Health Research
Funding Opportunity	Global Health Research - Groups
Call	Global Health Research 2016 - Groups

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Organisation	University of Bristol

RESEARCH DETAILS

Contract Start Date (DD/MM/YYYY)

01.04.2017

Name of proposed host institution

The University of Bristol

Global health research ambitions

To develop the existing South African Renal Registry (SARR) so that it can effectively and efficiently monitor equity of access to treatment and provide quality assurance at a national level for children and adults with all stages of kidney disease in the South Africa (SA).

To identify and interrogate routine healthcare databases in SA to inform heath service planning by estimating current unmet need for acute kidney injury (AKI), chronic kidney disease (CKD) and end-stage kidney disease (ESKD) requiring renal replacement therapy (RRT) and model future need.

To facilitate the training, career development and mentorship of clinician researchers and health services researchers in SA to use the registries and routine healthcare databases to support translational public health research that identifies local health needs, underpins comparative effectiveness research, monitors implementation of that evidence and demonstrates any resulting public health benefit.

To support the SARR in developing a platform for an African Renal Registry (ARR) for the African Association of Nephrology (AFRAN)/ African Paediatric Nephrology Association (APNA).

We are applying for £1,973,530.

Summary of the proposal in plain English

Acute kidney injury and chronic kidney disease occur more often in low and middle income countries, where they tend to affect younger people following infection, childbirth, trauma/ surgery, diabetes and hypertension. Simple interventions (rehydration, antibiotics and blood pressure control) will reduce

harm in these situations. When someone's kidneys stop working altogether in a high income country they can almost always be kept alive on dialysis or given a kidney transplant. The situation is different in South Africa – dialysis is generally only available to those suitable for kidney transplantation, an assessment that includes consideration of social circumstances, which disadvantages some young, fit groups. Indeed, South African Renal Registry data suggest that access to treatment is not equal between rich and poor, between provinces or for people with HIV and diabetes (www.sa-renalsociety.org/registry). This has motivated the Ministry of Health to hold a summit on the prevention and treatment of kidney disease. It has also convinced the African Association of Nephrology that the South African registry should be the platform for an African Renal Registry.

If it is to rise to this challenge, the South African Renal Registry's data collection, website and database need extensive development. The University of Bristol, with the UK Renal Registry, has the breadth of expertise to support this development and build the necessary academic links within South Africa. With this combination of "north-south" and "south-south" technical and methodological support, the South Africa Renal Registry could become the go-to organisation for efficient renal studies in Africa.

Translating data into health benefits for the population will initially focus on access to dialysis and transplant, but will evolve to focus on preventing the need for these expensive, life-restricting treatments. This will require hospital and laboratory databases to be brought together with the registry to form a fuller picture of kidney disease in South Africa. Researchers in South Africa are already identifying routine healthcare databases for infectious disease research, and these could be used to identify early kidney disease. Epidemiological, ethnographic, health economics and clinical trial researchers at the University of Bristol will work with colleagues at the University of Stellenbosch, University of Cape Town and other South African institutions to explore opportunities to use this data infrastructure to undertake efficient studies and trials in South Africa. The exact focus of these studies cannot be decided until the available data are fully understood. It will also be informed by research Priority Setting Partnership involving patients, the public, clinicians and policy makers. The possibility of a range of efficient "registry trial" designs will be explored in feasibility/ pilot studies.

The Group will also develop a sustainable funding model for the South African Renal Registry. The UK Renal Registry will apply its experience from working with the NHS and non-governmental organisations. Expertise from European, North American and global experts will be engaged through the steering committee. As the South African Renal Registry gains a reputation for efficient, high quality research, current core Ministry funding will be supplemented by public, charitable, industry and non-governmental organisation funding for special studies.

Groups: Strategic plan

a) Building on the strategic objectives of University of Bristol (UoB) and creating an environment for world-class global health research.

UoB has invested significantly in four interdisciplinary University research institutes (URIs) (£1m pa), with the health URI particularly pertinent to this work. These URIs are catalysts for interdisciplinary research, providing expertise and a hub for networking, dissemination, and public engagement and partnership working.

Promotion and encouragement of novel, strategic partnerships and international research agendas is important to UoB. The University's new strategy confirms our commitment to responsible globalisation, and to diversity and inclusivity as well as to building capacity. To enable development of novel partnerships and international research groupings, new "International Strategic Funds" have been made available via the University Research Committee. UoB is a member of the World University Network (WUN), which also includes the Universities of Cape Town, Ghana and Nairobi.

b) Why the institution is well-placed to be making this application.

UoB's research excellence is recognized by the Department of Health and Research Councils through its Research Excellence Framework success (in 2014, at least 80% of our researchers graded 3* or 4* in each of the four medical science categories, and 100% of the impact in both Clinical Medicine and Public Health rated as 4*), and the funding of major research facilities, including: two NIHR Biomedical Research Units, an NIHR biomedical research centre, an NIHR Collaboration for Leadership in Applied Health Research and Care, and the NIHR Health Protection Research Unit. Bristol academics play key roles in national initiatives such as 'Development and Evaluation of Complex Interventions for Public Health Improvement' (DECIPHer; a UK Clinical Research Collaboration Public Health Research Centre of Excellence) and the ConDuCT-II Hub (one of the eight MRC Hubs for Trials Methodology Research). See Additional Information section for details.

Recognising the strategic importance of this proposal, the UoB is providing the following in kind support:
•Senior academic time to travel to SA for workshops, courses and research projects.
•Lowered UoB estates/indirect costs.
•Access to the UoB Short Courses.
•Desk space for visiting researchers
•Access to funding for bolt-on projects through the WUN, the Research Development Fund, the Sustainability Fund, the Research Capability Fund and the Benjamin Meaker Visiting Professorship scheme.
For further details and values see Additional Information section.

c) Existing institutional partnerships, strategies and investments in the area, and building future capacity.

UoB has established links with UKRR, funding some of Dr Caskey's time. UoB researchers in the team are partly funded by UKRR for senior methodological advice, or collaborating with UKRR on NIHR grants.

UoB also has links with SARR through Dr Caskey (teaching at the African registries workshop in 2015 and co-authoring a paper with Profs Davids and Young on registries and research in Africa in 2016) and Prof May's work (teaching on statistics courses and exploring opportunities for collaboration with SARR in 2016).

UoB recently established a student exchange agreement with Stellenbosch University (SU), and supported Prof May to undertake teaching and research activities at the University of Cape Town (UCT) in October 2016, through the WUN and Newton Fund.

Plans for building future research capacity are covered below under "Research Capacity".

d) Proposed programme of activities

In months 1-6, activity will establish joint working and agree the initial priorities for investment and research. The needs of SARR will be assessed and investment in infrastructure and staffing agreed. UoB and UKRR staff will travel to SA to visit SARR and meet with key stakeholders. A first steering committee meeting and patient council will be held in SA. The specific objectives of group will be agreed, but in broad terms will entail:
•A Priority Setting Partnership exercise (commissioned from the James Lind Alliance) to systematically identify the kidney disease research priorities of key stakeholders (policy makers, health care professionals, patients, and the public).
•Analysis of SARR data to describe the epidemiology of treated ESKD in SA (with later extension to Africa), with particular focus on evidence of inequalities.

•Analysis of existing cohort studies and routine healthcare databases to describe rates, healthcare costs and outcomes of diagnosed AKI, CKD and untreated ESKD in SA.
•An economic evaluation using decision analysis to estimate the cost and cost-effectiveness of RRT in SA.
•Qualitative research will explore decision making and access to treatment, particularly for people from disadvantaged populations.
•Mixed-methods pilot work will explore the feasibility of developing an infrastructure for sentinel surveillance studies, efficient registry trials and cohorts linked to biobanks.

International collaborations and partnerships and capacity strengthening
The first phase has been designed to ensure that a strong and balanced partnership develops from this collaboration, with careful identification and involvement of key stakeholders, joint formulation of research questions and priorities, agreement of roles, responsibilities and dissemination plans, and integration of research teaching and training. We want to build:
•North-south collaborations between UoB/ UKRR and SARR/ SU.
•South-south collaborations between SARR and SU/ UCT/ other SA organisations and AFRAN/ APNA and ARR.
•Collaborations with other key global stakeholders: International Society of Nephrology, ERA-EDTA Registry, US registry and Dialysis Outcomes and Practice Patterns Study (DOPPS).
Plans for developing research skills in SA and Africa are set out below in the “Research Capacity” section.

Six-month delivery targets
To develop a strong, fair, effective research partnerships [1], we will:
•Identify key stakeholders and assess barriers and facilitators to their engagement
•Review existing hospital and laboratory databases for AKI and CKD
•Hold 1st visit by UKRR staff to SARR to assess technology needs
•Hold 1st visit by UoB staff to SU/ SARR to meet key stakeholders and jointly agree:
a)Initial research questions and priorities
b)Partners’ level of involvement in each activity and roles and responsibilities
c)Mechanisms for evaluating the effectiveness of the Group
d)Shared authorship and intellectual property policies
e)Plans for integration of research teaching and training
f)Plans for workshops
•Hold 1st meetings of the steering committee and patient council and agree terms of reference.

Aims for years 1-2 are to:
•Support SARR in developing its infrastructure to enable efficient, effective, secure data collection on treated ESKD from across SA and other African countries by investing in hardware, software and staff training.
•Establish the research priorities for kidney disease in SA and produce a detailed plan of research to tackle these.
•Strengthen the research capacity for registry-based renal epidemiology and health services research by developing a framework for planning, monitoring and evaluating research capacity in SA based on ESSENCE Framework.
•Obtain permission and link routine healthcare datasets from Western Cape to study rates of diagnosed AKI and CKD in the community.
•Analyse routine data on AKI, CKD and ESKD to identify the most important inequalities in diagnosis, treatment and outcomes.
•Hold workshops for clinician researchers and health services researchers in SA and Africa on how to use registries and routine healthcare databases to support translational public health research.
•Explore the cost-effectiveness of interventions to avoid harm from or provide treatment for kidney disease (CKD, AKI and ESKD) and use all available data in business cases for health policy discussions and service planning.

•Use mixed methods to explore the feasibility of using the registry infrastructure for
a)Registry randomised controlled trials [2].
b)Sentinel surveillance studies in a random sample of renal units to monitor health policy impact [3-6] and contribute to the global DOPPS [4, 7].
c)Cohort studies with biosamples (using the NHLS SU Biobank) and efficient follow-up through existing healthcare databases.

In the long term, we will focus on building capacity by looking for opportunities to secure funding for specific research projects that become possible and prove feasible. We will explore ways to incorporate local research institutions and programmes into national research environments and help strengthen these. Underpinning all this will be strong support, supervision and mentorship that will foster independent competitive researchers for the future.

e) Plans for commissioning further research

A Priority Setting Partnership will be set up and run by the Group using the planned workshops with support from the James Lind Alliance (www.jla.nihr.ac.uk). This will work with patients, carers and clinicians in SA to establish the research priorities for kidney disease in SA.

f) Sustainability plans

UKRR has negotiated a capitation fee-based funding model for its core work - providing the NHS with national quality assurance and activity data. Its CEO, Mr Cullen, has worked at the Department of Health and will lead discussions with counterparts in SA. With a more robust registry infrastructure and pilot data demonstrating the feasibility of various efficient study designs, SARR would be the go-to organisation in Africa for future grant applications to NIHR (efficient trials and instrumental variable analysis), MRC (a biosample facility embedded in a registry platform), WHO, non-governmental organisations and industry (efficient trials and cohorts with biosamples

Directors track record

Dr Caskey is Consultant Nephrologist and Medical Director of the UKR, the national audit and quality assurance organisation for people with kidney disease in the UK (www.renalreg.org). Since taking up this post in 2013 he has focussed on developing the research programme and reputation of the Registry by integrating a range of health services research expertise from the School of Social and Community Medicine at UoB. With this combination of a national efficient data collection infrastructure and internationally renowned expertise in health services research (including the UoB's own clinical trials unit – Bristol Randomised Trials Collaboration, BRTC), he has successfully secured funding for two challenging registry trials that could significantly change practice:
•PrepareME – a randomised controlled trial comparing quality-adjusted life years gained from preparing for conservative care versus preparing for dialysis (NIHR-HTA, £2.5m)
•H4RT – a randomised controlled trial comparing the relative effectiveness of high-volume haemodiafiltration compared with high-flux haemodialysis on non-cancer mortality and hospital admission due to a cardiovascular event or infection (NIHR HTA, £1.5m)
He has also led for the Registry as the measurement and analysis partner in two Health Foundation-funded stepped wedge cluster randomized controlled trials aimed at (1) reducing death with AKI in 5 hospital trusts and (2) reducing late presentation with ESKD in 20 renal units.

It will be important for this partnership to build links with other key global organisations. Dr Caskey sits on the committee of the European ERA-EDTA Registry committee and has worked closely with them on a number of registry collaborations and primary research studies. One of these is representing the ERA-EDTA in its collaboration with DOPPS, a global study of dialysis practice patterns and outcomes led by the US renal registry at Ann Arbor.

Dr Caskey was part of the ERA-EDTA faculty at the AFRAN registry workshop in Cape Town in April 2015. This was attended by approximately 30 clinicians and researchers from SA and 10 other African country representatives, with letters of support from their Ministries of Health to explore setting up national renal registries. This was where he met Prof Davids, who then visited Bristol and the UKRR during a trip to the UK in April 2016 to explore future potential for collaboration.

Team expertise, special interests and track record

UoB's Dr Caskey leads the group, with many years of health services research experience working with registries in the UK and Europe. Individual team members from the School of Social and Community Medicine bring a range of methods expertise that is a main strength of the proposal – Prof May (biostatistics and experience of collaborating with public health and statistical colleagues in SA), Prof Ben-Shlomo (clinical epidemiology), Prof Hollingworth (health economics), Dr MacNeill (complex clinical trials), Dr Rooshenas (applied qualitative research with intervention). The Group also includes clinician researchers Prof Coward (paediatric, diabetic nephropathy basic science) and early career researcher (ECR) Dr Bailey (NIHR academic clinical lecturer, epidemiology and qualitative methods).

SU has supported SARR over the last five years through contributing to personnel costs, providing office space, and hosting a workshop for African delegates in 2015 which saw the launch of ARR. As well as Prof Davids (expertise in setting up and running a registry and using the data to inform high level policy decisions), senior SU personnel committed to the project include Prof Volmink (Dean and former Director of the SA Cochrane Centre), Prof Chikte (head of the newly-formed Department of Global Health), Prof Young (Director of the Centre for Evidence-based Healthcare) and Prof Sewram (head of the African Cancer Institute). Should the project involve the collection of biosamples, we have support from Prof Abayomi of the NHLS SU Biobank (initially part of the H3Africa initiative). Biostatistics support is available form Dr Esterhuizen. SU is also providing support to AFRAN by hosting the official journal of the Association, the African Journal of Nephrology on an open-access platform. Expertise in accessing routine healthcare databases in SA is provided by Prof Boulle at UCT's School of Public Health and Family Medicine.

UKRR brings IT systems and programming expertise (Mr Swinnerton) including from Kenya (Mr Whitlock), operations expertise (Dr Steenkamp) and ECR experience with epidemiological studies and cluster/ individual randomized controlled trials utilizing registry infrastructure (Dr Methven). The Registry's Chief Executive (Mr Cullen) has extensive leadership and change experience from working at the Department of Health.

SARR is a key project of the SA Renal Society and is run by co-chairs Prof Davids and Dr Julian Jacobs. Their team includes nephrologists Prof Paget (Head of Nephrology at University of Witwatersrand (UW) and President of the Society) and Dr Hariparshad (University of KwaZulu-Natal, regional SARR champion). Prof Davids links to AFRAN which has asked him to lead the establishment of ARR. Three countries are formally working with ARR during this pilot phase – Ghana, Zambia and Burundi.

Collaborations and partnerships

SU, UCT and other academic SA institutions: UoB's Prof May was funded by the WUN and Newton Fund for a 4 week research visit to SA in October 2016 during which she visited SARR at SU and met with Profs Davids, Chikte, Volmink and Young to discuss collaboration with UKRR and their new Masters in Biostatistics. She also met with UCT's Prof Boulle and discussed how Public Health datasets in Western Cape could be used for research in conjunction with SARR. Profs May and Boulle have collaborated for over 10 years on HIV projects linking clinical and public datasets.

UKRR: UoB funds 2 sessions of Dr Caskey's time for research development and UKRR funds 1 session of Profs Ben-Shlomo and May's time for senior methodological advice and 5 sessions of Dr

MacNeill's time for trials and biostatistical support. Two post-doctoral research fellows have been jointly funded (health economics and qualitative research). UoB's trials unit, BRTC, runs Dr Caskey's two recent NIHR HTA-funded trials (described in Director's Track Record).

SARR: Prof Davids hosted the AFRAN registry workshop in Cape Town in April 2015 which initiated collaboration with Dr Caskey and UKRR. He visited UKRR in April 2016 to discuss the opportunities for collaboration and external funding. Prof Davids has been tasked by AFRAN to establish a registry platform for other African countries.

Expert advisors on the steering committee will strengthen links with a network of global renal teams – the International Society of Nephrology, the ERA-EDTA and US registries and AFRAN/ APNA.

Involvement of collaborators and partners in prioritising research topics and themes.

Partners in SA have already been involved through:
•The April 2015 AFRAN workshop on establishing renal registries in Africa.
•The April 2016 visit by Prof Davids to Bristol.
•A 2016 review of registries and research in Africa written by Prof Davids, Dr Caskey and Prof Young (in press)
•The October 2016 visit by Prof May to SARR, SU and UCT.
They will continue to be involved through:
•Interviews and focus groups involving stakeholders and an initial steering committee aimed at establishing the priorities for the Group (months 1-6).
•A Priority Setting Partnership supported by the James Lind Alliance establishing research priorities relating to kidney disease in SA (months 7-24).
•Management group meetings, monthly by telephone or Skype.
•Steering committee meetings, six monthly alternating between face-to-face and telephone/ skype.

Involvement of users of the research.

Patients and carers will be key stakeholders in the initial work establishing priorities. The James Lind Alliance approach ensures that their views will be given the same consideration as those of clinicians. In addition:
•Patients will sit on the steering committee.
•An SARR patient council will be established, supported by Mrs Loud, chair of the UKRR Patient Council.

Structure and governance

The Director, Dr Caskey, will take overall responsibility for the Group. He will work closely with and be assisted in decision making by Prof Davids, who will take the role of Joint Lead and facilitate the delivery of the programme in SA. In day-to-day matters, Dr Caskey and Prof Davids will be supported by a project manager in Bristol and additional manager time at SARR.

The work of the Group will be overseen by a steering committee comprising:
•8 members of the team from the UK, ensuring full integration of the academic, technical and patient experts in the planning and oversight
•8 members of the team from SA, representing academic, technical, patient/carer and the policy making expertise
•4 permanent global members, one from each of AFRAN/ APNA, the ERA-EDTA Registry, US Renal Registry/ DOPPS and the International Society of Nephrology.
•1 observer global member, according to the needs of the Group at that time.
This committee will meet 6-monthy, alternating between face-to-face (in SA, coinciding with annual workshops in years 2 and 3) and telephone/ Skype.

Operationally the programme will be guided by a smaller management group comprising:
•The Director and Joint Lead
•The project manager and SARR manager
•Other members from the team according to the activities of the Group at that time.
This management group will meet monthly by telephone/ Skype.

Specific projects within the programme (e.g. the assessment of SARR development needs) will be managed through project-specific Task and Finish Groups. These will be populated with only the key people needed to deliver that project and will meet frequently until that task is complete, when they will disband.

Research capacity

a) Existing facilities, research posts and studentships

The Group will sit within the School of Social and Community Medicine at UoB and benefit from all its facilities, training opportunities and partnerships (outlined above in section b of the strategic plan and under additional information). Within the UoB team, Prof Coward is an MRC Senior Clinical Fellow and Dr Bailey is an NIHR academic clinical lecturer. Consistent with NIHR's definition of a Global Health Research Group, the Group does not have research posts or studentships at this stage.

b) Plans for training and capacity building

Training and capacity building will include Masters students, ECRs and senior academics.
•At SU and UCT, postgraduate students within the M Phil (Nephrology), MSc (Clinical Epidemiology), MSc (Public Health) and MSc (Biostatistics) programmes will take advantage of the Registry's data-rich platform for their research projects. Ten bursaries are funded by this grant to support this.
•Staff exchanges/visits between UoB and SU/ UCT will allow SU/ UCT ECRs to undertake a period of supervised research at UoB (up to 6 weeks) and undertake formal training through its internationally renowned Short Courses in areas not well covered in SU/ UCT (up to 3 per ECR).
•Senior SU/ UCT academics will be able to undertake short visits (up to 4 week) to UoB to develop research and methods ideas and attend up to 2 advanced courses.

Registry training workshops will also be run annually in SA, facilitated by UoB and UKRR staff. These will include delegates from SA and those who will be running ARR and will be run with a view to "train the trainers" so that attendees can return to their parent country and offer training to others involved in ARR. UoB is providing in kind support for its senior academics to travel to SA and deliver research methods training based on its Short Course programme. In addition, global experts attending the aligned steering committee meetings will share their extensive experience at these workshops.

ODA compliance statement

1.Which country/countries on the DAC list will directly benefit from this proposal?

This programme will primarily benefit SA. In addition, by reinforcing and expanding the physical and methodological capabilities of SARR, the following African countries will also benefit through ARR:
•Zambia - Dr Kenneth Kapembwa (nephrologist)
•Kenya - Dr Jonathan Wala (nephrologist)
•Ghana - Dr Vincent Boima (nephrologist)

2.How is your proposal directly and primarily relevant to the development challenges of these countries?

Despite the relatively young age distribution of the African population, 1 person in 7 now has CKD [8]. Some of this will be due to increasing prevalence of non-communicable diseases (NCDs) – diabetes is already one of the commonest causes of ESKD requiring RRT [9] and the number of adults with diabetes in African is projected to increase from 19.8 million in 2013 to 41.5 million in 2035 [10, 11]. Other important risk factors for CKD in the African region include hypertension, environmental toxins and infection-related renal disease. The number of people with HIV in Africa exceeds 25 million [12] and this contributes greatly to CKD in this region [8]. In addition, high rates of AKI related to trauma, surgical complications and childbirth will also be contributing to CKD and ESKD and premature death [13, 14]. The significance of this is reflected in the agreement by the SA Ministry of Health to hold a summit on the optimal prevention and treatment of kidney disease in SA and the request by AFRAN that SARR provide the platform for a African dialysis and transplant registry.

3.How do you expect that the outcome of your proposed activities will promote the health needs of a country or countries on the DAC list?

This proposal will reinforce and expand an existing SARR human and IT platform to enable ongoing translational public health research in kidney disease relevant to SA and wider Africa through:
•Data infrastructure support and development
•Data collection and linkage to inform public health policy and planning
•Data analysis (biostatistics, epidemiology, ethnography and health economics) for research and to inform public health policy and planning
•Training and career development for health services researchers interested in addressing health inequalities in non-communicable diseases in SA and Africa.

The priorities for this work will be identified systematically by working with a full range of stake holders in SA (using the James Lind Alliance framework) and other participating countries. At this stage, however, tangible benefits for the countries are likely to be:
•An efficient robust registry platform capable of national quality assurance and annual public reporting in African countries that participate.
•Established research methods for identifying areas of inequity in access to treatment and outcomes on treatment that will inform health policy and planning. Lessons learned across the nine very different health provinces of SA will facilitate transfer of that learning to other African countries with varying healthcare infrastructure.
•Initial evidence of the cost-effectiveness of various treatment options to inform business cases and policy making, including low-cost, low-tech prevention of harm from AKI (hydration and antibiotics) and CKD (diabetes and blood pressure control). This will inform decisions about investing in health services to get maximal public health benefit.
•A north-south south-south network of health services researchers and registry experts for sustaining and expanding efficient AKI, CKD and ESKD research in Africa.
•Evidence from pilot work of the feasibility of various efficient study designs that can be used to support future applications for research funding to supplement core registry funding.

Pathways to impact

The Group aims to fundamentally change health policy and clinical practice in relation to kidney disease in SA and Africa through the following strategy:
•Support the IT development of the SARR
•Combine SARR and existing hospital and laboratory databases
•Facilitate the training, career development and mentorship of clinician and health services researchers capable of utilising the new databases to inform health service planning.
•Establish the capability and capacity to undertake efficient studies
•Develop a network of trained clinician researchers and health services researchers to support growth of renal registries in Africa

There will be stakeholders and beneficiaries at every level:
•National. Patients will benefit from more equitable access to and outcomes on treatment, driven by the public reporting of SARR data. The public will benefit from a focus on prevention of harm from AKI and CKD through low-cost, low-tech interventions that save lives and release scarce resources. Clinicians and policy makers will have the data they need to plan services and drive up standards of care. The SA Renal Society will have a registry that is sustainably funded and integrated throughout the service.
•Regional. AFRAN/ APNA gain an open access registry platform, provided within Africa and available to other countries in Africa to inform service planning, quality improvement and research. It will also benefit from the research skills and infrastructure that the Group will provide through the ARR network.
•Global. The International Society of Nephrology will benefit from data that can be used to lobby for kidney health in disadvantaged population, as well as from a framework for training clinicians and researchers. DOPPS will learn from efforts to embed its sentinel surveillance monitoring and research system into an LMIC registry.

We will develop a communications strategy tailoring the disseminated materials and products to the needs of these users and stake holders. We will learn from UKRR's "Think Kidneys" initiative (www.thinkkidneys.nhs.uk), which won the "NHS Publicity Campaign" award in 2016. Think Kidneys has developed animated infographic on "Almost everything you need to know about your kidneys" and posts regular patient-facing blogs on AKI and patient reported outcomes. With UKRR, it has 3.6k Twitter followers. With partners we will adapt these communication methods to the SA/ African setting.

A framework for planning, monitoring and evaluating the strengthening of research capacity will be developed in months 1-6 based on the ESSENCE guidance [15]. In short, the key areas of the programme will be agreed and the most appropriate indicators chosen. These might include numbers of Masters bursaries awarded, ECRs/ senior academics visiting UoB, peer-reviewed publications or African registries established. The optimal time points for the evaluation will be considered and ways of doing this qualitatively as well as quantitatively explored.

Exploitation of Intellectual Property

Foreground IP will be owned by UoB with appropriate licence to collaborating parties for research, training and teaching purposes. The foreground IP may be used in state-funded clinical care without cost to the state. A data sharing agreement will be set up with UKRR, SARR and any other routine clinical databases to allow access to data. A process will be developed with SARR to help it manage external requests for access to data. This process will be based on processes in place at UoB and UKRR, assessing risk of re-identification from data sharing and managing conflict with analyses already approved.

UoB will own the IP of any tools and data generated by UoB in the course of performing the QuniteT Recruitment Intervention (QRI) technique. In addition UoB will own any improvements to the QRI technique made during the course of the research.

We aim to publish in journals that allow us to retain copyright. Where not possible we will assign copyright to the journal and articles will be deposited in UKPubMed within 6 months of publication. All publications arising from the research will be made open access.

IP and dissemination will be an agenda item at each steering committee meeting to ensure that any issues are appropriately recognised, captured and protected, and to maximise potential uptake of the study findings. We will also submit to the national conferences of the Renal Association the British Renal Society and the South African Renal Society and international conferences: ERA-EDTA, AFRAN/ APNA, the American Society of Nephrology and the International Society of Nephrology, to

disseminate our work and engage our peers.

All dissemination activities and publicity regarding this study will be discussed with the NIHR communications team and sent for review prior and agreement prior to publication in line with the 28 day rule.

Justification of requested costs

a. How requested costs will be deployed

Recognising the importance of leadership to drive this group, significant costs have been allocated to the Director (Caskey, 40%, £158,847) and Joint Lead (Davids, 50%, £169,974).

7x UoB academics are funded at 10% (£176,738) with one partially funded by MRC and one fully funded by NIHR, so partially/ not costed*. The four SU/UCT/UW academics directly involved local research supervision are costed at 15% (x3) and 10% (x1) (£118,565).

At UKRR, 2 days/wk of project manager, 0.75 days/wk business support, 4 weeks/yr of operations, programming and ECR and 1 week/yr of CEO time (£187,501). At SARR: 1x 100% national and 1x 20% local SARR manager, 1x 50% statistician, 6x regional data capturers, 10% time for the co-chair (Jacobs) and 10% local champion time (Hariparshad) (£384,540). To develop the SARR database and host securely, £143,925. For local transportation and laptops/ dongles for data capturers (x6) and to run the SARR office, meetings, annual report and accounts, £42,340.

3x 3-day workshops in SA, £118,000. 10x ECRs and 10x senior academics visiting Bristol and 10x Masters bursaries, £198,100. National (x2 in years 2-3) and international conferences (x2 in years 1-3) and open access publications (x5), £44,000 & £15,000.

Working visits to SA (3x 3 people/yr), £54,000. Monthly management meetings and 6-monthly steering committee meetings (alternating face-to-face/ telephone), £102,000.

Commissioned Priority Setting Partnership work (James Lind Alliance), £60,000.

b. How the requested costs represent value for money

With this investment, NIHR will be establishing a self-sustaining human and IT platform for delivering translational public health renal research in SA and across the continent of Africa. The current infrastructural and political readiness make now the right time for this investment. The money is entirely focused on building capacity that will remain in SA and serve Africa. Once established, the platform will provide evidence to drive improvements in public health in an efficient way that quickly covers the initial investment. With dialysis likely to cost £25,000 per year [16], avoiding just 80 person years on dialysis (i.e. reducing treatment rates by less than 1% [9]) would itself pay for the grant.

c. Financial and other contributions from the lead university

•Senior academic time to travel to SA for workshops, courses and research projects (6 people at 5% = £67,976 plus the value of the courses delivered).
•Lowered UoB estates/indirect costs (£90,465).
•Access to the UoB Short Courses (3 for each of 10 ECRs and 2 for each of 10 senior academics = £25,000).
•Desk space for researchers visiting UoB (£12,500).
•Access to funding for bolt-on projects through WUN, the Research Development Fund, the Sustainability Fund, the Research Capability Fund and the Benjamin Meaker Visiting Professorship scheme.

UoB's cover letter provides details.

* Coward funded by MRC until 31st July 2019 and Bailey.

Additional Information

Abbreviations:

AKI=acute kidney injury, ARR = African Renal Registry, AFRAN = African Association of Nephrology, APNA = African Paediatric Nephrology Association, BRTC = Bristol Randomised Trials Collaboration, CKD = chronic kidney disease, DOPPS = Dialysis Outcomes and Practice Patterns Study, ECR = early career researcher, ERA-EDTA = European Renal Association – European Dialysis and Transplant Association, ESKD = end-stage kidney disease, RRT = renal replacement therapy, SA = South Africa, SARR = South African Renal Registry, SU = Stellenbosch University, UCT = University of Cape Town, UKRR = UK Renal Registry, UoB = University of Bristol, UW = University of Witwatersrand, WUN = Worldwide Universities Network.

Other additional background information

Details of the UoB in-kind contribution, including value.

In addition to the 10% of University of Bristol academic time that has been costed into the grant to fund teaching, mentorship or research involving visiting colleagues from South Africa, the University will provide 5% of their time to travel to South Africa for workshops and research projects. This includes Prof Margaret May, Prof Yoav Ben-Shlomo, Prof Will Hollingworth, Dr Leila Rooshenas, Dr Stephanie MacNeill and Prof Richard Coward. This equates to £67,976 in-kind contribution.

This will also allow us to deliver a suite of Short Courses in research methods in South Africa, which would cost £440-1,100 in the UK.

The University has agreed to lower the Estates/Indirect costs associated with this project. This equates to £90,465 in-kind contribution

Visiting researchers from South Africa will have access to the University of Bristol Short Courses at a reduced rate for training in applied research methods. Assuming up to 3 courses for the each of the 10 early career researcher and 2 for each of the 10 senior researchers, this equates to £25,000 in-kind contribution.
•Visiting researchers from South Africa will be given desk space for the duration of their stay (up to 6 weeks). This equates to £12,500 in-kind contribution.
•We will support early career researchers (in Bristol and Cape Town) to apply for funding to support research mobility through the Worldwide Universities Network, of which University of Bristol and University of Cape Town are both members. Funding for bolt-on projects can also be sought internally through the Research Development Fund, the Sustainability Fund or the new Research Capability Fund.
•Through the University's Institute of Advanced Studies, senior academics will have access to the Benjamin Meaker Visiting Professorship scheme. This funds visits of up to three months and covers travel, accommodation and subsistence up to £800 per month.

Further institutional research infrastructure at the UoB

In addition to the infrastructure outlined in response to question b of the Strategy section, the UoB, with the Wellcome Trust, has established the Elizabeth Blackwell Institute for Health Research which plays a central role in developing the University-wide health research strategy, particularly in driving innovative interdisciplinary research. Its core objectives are to nurture talented clinical and non-clinical health researchers from inside and outside Bristol, ensuring that research is grounded in clinical, social and public health needs. The Institute works closely with Bristol Health Partners, an academic health partnership between the city's NHS trusts, Clinical Commissioning Groups, Universities and City Council. The CKD Health Integration Team, led by Dr Caskey, was one of the first streams of work to be supported by the Bristol Health Partners.

The University has also prioritised expansion of data science research through the Bristol Jean Golding Institute.

National Institute for Health Research

UPLOADS

The following pages contain the following uploads:

Upload Name
Director CV
Finance Plan
Host Organisation Authorised Signatory
Organogram
Letters of Support
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Letters of Support
Director Cover Letter
Joint Lead CV
References
Supporting Diagrams
Project Contact List

CURRICULUM VITAE

Dr Fergus John Caskey

Degrees and qualifications

- MBChB (Glasgow) 1993
- MSc in Health Services and Public Health Research (Aberdeen) 1999
- MD with commendation (Aberdeen) 2003
- FRCP (London) 2009

Current positions held

- 2005-present: Consultant Nephrologist, North Bristol NHS Trust
  - 0.15 WTE, funded by the NHS
- 2009-present: Honorary Clinical Senior Lecturer, University of Bristol
  - 0.20 WTE, funded University of Bristol
- 2013-present: Medical Director, UK Renal Registry
  - 0.65 WTE, funded by the UK Renal Registry (charity)

Previous positions held

- 2004-2005: Clinical Research Fellow, German Renal Registry, Berlin
- 2000-2004: Specialist Registrar, South West England (Bristol/ Gloucester)
- 1997-2000: Clinical Research Fellow, University of Aberdeen

My main duties as Medical Director of the UK Renal Registry are to provide clinical leadership on the development of the strategic direction of the Registry with a particular focus on building its research capability. The Registry now collects data on all patients in the UK with end-stage kidney disease (on dialysis or with a kidney transplant) and follows them automatically through electronic data capture. In recent years its remit has been broadened to cover:

(1) Acute kidney injury occurring in primary or secondary care
(2) Pre-dialysis chronic kidney disease managed in secondary care
(3) Dialysis for acute kidney injury
(4) Patient-reported outcomes.

We are also currently working with HQIP to take over the National CKD Audit, which monitors quality of CKD management in primary care. For more information about the work of the Registry, please visit www.renalreg.org.

Since my appointment, links with the School of Social and Community Medicine at the University of Bristol have been formalised and regular meetings with senior epidemiologists and statisticians held. Resulting from this has been the Registry's Research Methods Study Group, which is attended predominantly by methodology experts in statistics and epidemiology from around the UK, with additional specific expertise invited according to the topics for discussion. This new group aims to advise on research strategy, resolve methodological issues identified by the clinical study groups and identify potential grant applications and high impact publications. My role also involves:

- Leading on research collaborations with other groups in grant applications involving Registry data or utilising Registry infrastructure. (See list of successful grant applications)
- Supervising academic clinical fellows, doctoral and post-doctoral candidates, including:
  - Dr Lucy Plumb, Dr Barnaby Hole and Dr Jemima Scott, renal trainees and/or academic clinical fellows in nephrology developing PhD fellowship applications
  - Dr Ani Rao, a UK Renal Registry-funded University of Bristol PhD candidate studying the issues of recruitment to chronic kidney disease studies in the elderly using mixed methods.
  - Dr Alexander Hamilton, a British Kidney Patient Association-funded University of Bristol PhD candidate studying the psychosocial impact of end-stage renal disease in young adults.
  - Dr Shona Methven, an NIHR clinical lecturer developing a post-doctoral fellowship application that will utilise large dataset to determine the optimal management of diabetic nephropathy
  - Dr Paul Mitchell, a UK Renal Registry and CLAHRC-West-funded health economist developing a post-doctoral fellowship application to explore ways to attach patient values to various health states in people with kidney disease.

- Advising and supporting researchers from outside the Registry to analyse UKRR data:
    - Dr Kate Birnie, NIHR post-doctoral fellow at the University of Bristol, who will be using new data feeds and novel statistical methods (marginal structural modelling) to look at EPO, anaemia and outcomes
    - Dr Amanda Owen-Smith, NIHR post-doctoral fellow at the University of Bristol, who is undertaking qualitative research to explore reasons behind variation in access kidney transplantation
- Strengthening international collaborations, including the ERA-EDTA Registry and the USRDS Registry.
- Arranging educational and promotional meetings, including:
    - Co-lead for a CME session with international speakers on Statistical Approaches to Analysing Observational Data at the 2015 ERA-EDTA Congress
    - Faculty for a Workshop in Setting up a Pan-African Renal Registry at the 2015 World Congress of Nephrology.
    - Lead for the ERA-EDTA funded consensus meeting for European renal registries on collecting quality of life and experience data in Bristol in June 2014.
    - Lead for the Registry's journal club
- Acting as a member of the UK Renal Registry Senior Management Team

My University of Bristol sessions are primarily to deliver research output in line with my UK Renal Registry activity. Clinically I remain active, with a weekly kidney transplant clinic and related patient administration.

Research grants held

Relevant current grants

1. NIHR HTA 15/80/52: The High-volume Haemodiafiltration vs High-flux Haemodialysis Registry Trial (H4RT). Chief investigator. £1,500,276 (2017-2021)
2. NIHR HTA 15/57/39: Prepare Multimorbid frail older people for End-stage kidney disease – the PrepareME trial. Chief investigator. £2,538, 968 (2017-2021)
3. NIHR HTA: Bioimpedance Spectroscopy to maintain renal output: BISTRO. Co-applicant. £1,288,508 (2016-19)
4. NIHR HTA: Survival Improvement with Cholecalciferol in Patients on Dialysis – the SIMPLIFIED registry trial. Co-applicant. £1,341,913 (2015-23)
5. NIHR HTA: Risks and benefits of bisphosphonate use in patients with chronic kidney disease: a population-based cohort study. Co-applicant. £513,819 (2015-18)
6. NIHR SBRI Devices for Dignity: Care.Know.Do. Development and evaluation of a tailored, online & telephone support programme for patients with CKD, phase II. Co-applicant (with Atlantis Healthcare). £160,000 (2015-18)
7. Health Foundation: Tacking acute kidney injury: a multi-centre quality improvement project. Co-applicant. £500,000 (2015-18)
8. NIHR HS&DR: Risk modelling for quality improvement in the critically ill: making best use of routinely available data. Co-applicant. £255, 248 (2015-17)
9. NIHR RfPB: Optimising early dialysis catheter function – the UK Peritoneal Dialysis Outcomes and Practice Patterns Study. Co-applicant. £371,877 (2014-17)

References (** = Caskey F.J. last author)*

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2.* Udayaraj UP, Ben-Shlomo Y, Roderick P, Casula A, Ansell D, Tomson CR, et al. Socio-economic status, ethnicity and geographical variations in acceptance rates for renal replacement therapy in England and Wales: an ecological study. Journal of epidemiology and community health. 2010 Jun;64(6):535-41.

3. Caskey FJ, Kramer A, Elliott RF, Stel VS, Covic A, Cusumano A, et al. Global variation in renal replacement therapy for end-stage renal disease. Nephrology Dialysis Transplantation. 2011;26(8):2604-10.

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8.* Udayaraj U, Ben-Shlomo Y, Roderick P, Casula A, Dudley C, Collett D, et al. Social deprivation, ethnicity and uptake of living kidney donor transplantation in the United Kingdon. Transplantation. 2012;93(6):610-6.

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Global Health Research - Detailed Budget Template

HEI Name: University of Bristol

Application Ref: 16/137/18

Priority Area: Golbal Health Research

Expenditure Category	Total Annual Cost				
	2017/18	2018/19	2019/20	2020/21	Overall Total
Direct Salary Costs	153,437.50	157,537.00	171,326.00	0.00	482,300.50
Other Direct Research Costs	178,368.00	192,366.00	155,366.00	0.00	526,100.00
Overseas Partner Costs	319,822.00	311,485.00	293,037.00	0.00	924,344.00
Indirect Costs	12,299.70	12,802.80	15,683.40	0.00	40,785.90
Total Funding requested from NIHR	**663,927.20**	**674,190.80**	**635,412.40**	**0.00**	**1,973,530.40**

DETAILED BUDGET
Application Ref: 16/137/18

Posts and Salaries – Details

Details of posts and salaries	Role	Salary	Weighting	Other Allowances	Superann. and NI	Current Annual Costs
Research staff						
Dr Fergus Caskey	Lead applicant	91,166.00	0.00	11,944.00	27,854.00	130,964.00
Professor Yoav Ben-Shlomo	Co-Applicant	96,819.00	0.00	0.00	29,669.00	126,488.00
Professor Richard Coward	Co-Applicant	102,465.00	0.00	0.00	27,360.00	129,825.00
Professor Will Hollingworth	Co-Applicant	66,603.00	0.00	0.00	20,537.00	87,140.00
Professor Margaret May	Co-Applicant	62,107.00	0.00	0.00	19,380.00	81,487.00
Dr Leila Rooshenas	Co-Applicant	41,709.00	0.00	0.00	12,375.00	54,084.00
Dr Stephanie MacNeill	Co-Applicant	44,239.00	0.00	0.00	12,984.00	57,223.00
						0.00
						0.00
						0.00
						0.00
						0.00
Research support staff						
Project Manager TBC	Project Manager	47,976.00	0.00	0.00	12,474.00	60,450.00
Business Support 1 TBC	Business Support	38,513.00	0.00	0.00	10,238.00	48,751.00
Business Support 2 TBC	Business Support	47,976.00	0.00	0.00	12,474.00	60,450.00
Reetha Steenkamp		71,429.00	0.00	0.00	18,571.00	90,000.00
George Swinnerton/Tim Whitlock		61,905.00	0.00	0.00	16,095.00	78,000.00
Ron Cullen		151,786.00	0.00	0.00	39,464.00	191,250.00
Shona Methven		91,667.00	0.00	0.00	23,833.00	115,500.00
						0.00
						0.00
						0.00
						0.00
						0.00

Annual Costs of Posts and Salaries

Annual costs of posts	%FTE	Total months at Unit	2017/18	2018/19	2019/20	2020/21	Total
Research staff							
Dr Fergus Caskey	40	12	52,386.00	0.00	0.00	0.00	52,386.00
Dr Fergus Caskey	25	24	0.00	52,386.00	54,075.00	0.00	106,461.00
Professor Yoav Ben-Shlomo	10	36	12,650.00	13,393.00	13,393.00	0.00	39,436.00
Professor Richard Coward	10	36	0.00	0.00	8,655.00	0.00	8,655.00
Professor Will Hollingworth	10	36	8,864.00	9,160.00	9,457.00	0.00	27,481.00
Professor Margaret May	10	36	8,271.00	8,567.00	8,864.00	0.00	25,702.00
Dr Leila Rooshenas	10	36	5,481.00	5,648.00	5,821.00	0.00	16,950.00
Dr Stephanie MacNeill	10	36	5,733.00	5,908.00	6,088.00	0.00	17,729.00
							0.00
							0.00
							0.00
							0.00
Research support staff							
Project Manager TBC	40	36	24,180.00	24,960.00	25,740.00	0.00	74,880.00
Business Support 1 TBC	10	36	4,875.00	5,070.00	5,265.00	0.00	15,210.00
Business Support 2 TBC	5	36	3,022.50	3,120.00	3,218.00	0.00	9,360.50
Reetha Steenkamp	7.5	36	6,750.00	7,050.00	7,350.00	0.00	21,150.00
George Swinnerton/Tim Whitlock	7.5	36	5,850.00	6,150.00	6,450.00	0.00	18,450.00
Ron Cullen	2	36	3,825.00	4,125.00	4,500.00	0.00	12,450.00
Shona Methven	10	36	11,550.00	12,000.00	12,450.00	0.00	36,000.00
							0.00
							0.00
							0.00
							0.00
							0.00
Total			**153,437.50**	**157,537.00**	**171,326.00**	**0.00**	**482,300.50**

DETAILED BUDGET

Application Ref: 16/137/18

Travel and Subsistence

Description	2017/18	2018/19	2019/20	2020/21	Total
Working Visits (3 UK staff travel each year)	18,000.00	18,000.00	18,000.00	0.00	54,000.00
Training Workshops (in South Africa)	50,000.00	34,000.00	34,000.00	0.00	118,000.00
Visiting Fellowships (SA staff travel to UK)	25,934.00	25,933.00	25,933.00	0.00	77,800.00
Advanced Fellowships (Senior SA staff travel to UK)	18,434.00	18,433.00	18,433.00	0.00	55,300.00
Annual Steering Committee	32,800.00	32,800.00	32,800.00	0.00	98,400.00
					0.00
					0.00
					0.00
					0.00
Total	**145,168.00**	**129,166.00**	**129,166.00**	**0.00**	**403,500.00**

Conference Fees

Description	2017/18	2018/19	2019/20	2020/21	Total
National Conference Attendance (*8)	0.00	4,000.00	4,000.00	0.00	8,000.00
Inteernational Conference Attendance (*12)	12,000.00	12,000.00	12,000.00	0.00	36,000.00
					0.00
					0.00
					0.00
					0.00
					0.00
					0.00
					0.00
Total	**12,000.00**	**16,000.00**	**16,000.00**	**0.00**	**44,000.00**

Equipment

Description	2017/18	2018/19	2019/20	2020/21	Total
					0.00
					0.00
					0.00
					0.00
					0.00
					0.00
					0.00
					0.00
					0.00
					0.00
Total	**0.00**	**0.00**	**0.00**	**0.00**	**0.00**

Consumables

Description	2017/18	2018/19	2019/20	2020/21	Total
					0.00
					0.00
					0.00
					0.00
					0.00
					0.00
					0.00
					0.00
					0.00
Total	**0.00**	**0.00**	**0.00**	**0.00**	**0.00**

Dissemination costs

Description	2017/18	2018/19	2019/20	2020/21	Total
Open Access Publications (*5)	0.00	6,000.00	9,000.00	0.00	15,000.00
					0.00
					0.00
					0.00
					0.00
					0.00
					0.00
Total	**0.00**	**6,000.00**	**9,000.00**	**0.00**	**15,000.00**

Other direct costs

Description	2017/18	2018/19	2019/20	2020/21	Total
Management group – monthly telephone calls	1,200.00	1,200.00	1,200.00	0.00	3,600.00
James Lind Alliance - Commissioned work	20,000.00	40,000.00	0.00	0.00	60,000.00
					0.00
					0.00
					0.00
					0.00
					0.00
Total	**21,200.00**	**41,200.00**	**1,200.00**	**0.00**	**63,600.00**

Direct Costs Total	**178,368.00**	**192,366.00**	**155,366.00**	**0.00**	**526,100.00**

Balance check 0

DETAILED BUDGET

Application Ref: 16/137/18

Overseas Partner costs

Description	2017/18	2018/19	2019/20	2020/21	Total
South African Renal Registry	186,895.00	182,305.00	163,855.00	0.00	533,055.00
University of Stellenbosch	110,543.00	106,794.00	106,796.00	0.00	324,133.00
University of Cape Town	11,578.00	11,579.00	11,579.00	0.00	34,736.00
University of the Witwatersrand	10,806.00	10,807.00	10,807.00	0.00	32,420.00
					0.00
					0.00
					0.00
					0.00
Total	**319,822.00**	**311,485.00**	**293,037.00**	**0.00**	**924,344.00**

DETAILED BUDGET

Application Ref: 16/137/18

Indirect Costs

Description	2017/18	2018/19	2019/20	2020/21	Total
University of Bristol	12,299.70	12,802.80	15,683.40	0.00	40,785.90
					0.00
					0.00
					0.00
					0.00
					0.00
Total	**12,299.70**	**12,802.80**	**15,683.40**	**0.00**	**40,785.90**

Host Organisation Authorised Signatory Agreement

Authorised signatory signature against declaration

In **signing this letter**, you as an **authorised signatory** for the Host Organisation confirm that they fully endorse the application for an NIHR Global Health Research Centre or Unit award and assert that appropriate support will be provided should the application for funding be successful.

Signing and uploading this document constitutes an electronic signature of the supporting role with regard to this application.

Authorised Signatory Full Name: Mrs. Margie Smith

Authorised Signatory Signature: 

Date: 24/01/2017

University of Bristol, Dr. Fergus Caskey NIHR Global Health Research Group application

The PROTEA Global Health Research Group

A Partnership for Renal registry Opportunities in
Translational public health research and Efficient studies in Africa

Professor Nishan Canagarajah
Pro Vice-Chancellor (Research and Enterprise)
Vice-Chancellor's Office
Senate House
Tyndall Avenue
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25th January 2017

Ref: CNC/CS/sd

Dear NIHR Global Health Research Panel

The PROTEA Global Health Research Group: Partnership for Renal registry Opportunities in Translational public health research and Efficient studies in Africa

I am delighted to write this letter expressing the University of Bristol's strongest support for Dr. Caskey's application to the NIHR Global Health Research Group scheme. Bristol's research strategy in this area is overseen by our Global Challenges Steering group, which I Chair, and draws its membership from the University Research Committee, research institutes and academics experienced in working with ODA partners. The University ran an internal selection process for this call with an internal review panel which included the PVC Health and Dean of Health Sciences who are both fully supportive of Dr. Caskey's application. The University has invested significantly in four interdisciplinary University Research Institutes (URIs) (£1m p.a) two of which (those focussed on environment and health) are particularly pertinent to Global Challenges research.

Building on recent successful registry-based collaborations fostering innovative research with colleagues at the University of Bristol, Dr. Caskey has brought together this extremely strong international team to deliver translation public health renal research in Africa. We welcome this new partnership with Professor David of Stellenbosch University, who has demonstrated his ability and perseverance in re-establishing the South African Renal Registry for dialysis and transplant. It is also a great commendation that he has been given a mandate from the African Association of Nephrology to use this as the platform for other African countries.

While there is a clear need to ensure equity of access to and outcomes on dialysis and transplant treatments in South Africa, preventing the need for these expensive, life-changing treatments must be the ultimate goal. The UK Renal Registry and University of Bristol will exchange knowledge relating to the interrogation of hospital and laboratory databases to identify acute kidney injury and early stages of chronic kidney disease with partners already doing similar work for infectious diseases in South Africa. Ways of embedding these new data in the South African Renal Registry will be explored. University of Bristol health economists and complex clinical trials experts will then help build the capability to develop a cost-effective evidence base for interventions that reduce harm and expenditure across the full spectrum of kidney disease in Africa.

This NIHR funding thus provides the opportunity to introduce and embed South African health services researchers, with huge experience and expertise predominantly in infectious diseases, into a recently reborn and still vulnerable South African Renal Registry. With this infrastructure and local expertise, supported by the experience from the University of Bristol, the South African Renal Registry should be able to establish itself as the go-to organisation for translational renal public

health research in Africa – a sustainable combination of “north-south” and “south-south” collaboration that will benefit all.

The programme of work is fully aligned with the University of Bristol’s current and future research strategy, in particular all of our URIs are catalysts for interdisciplinary research, providing expertise and a hub for networking, dissemination, and public engagement and partnership working.

Our promotion and encouragement of novel, strategic partnerships and international research agendas is important to this University. The University’s new strategy confirms our commitment to responsible globalisation, and to diversity and inclusivity as well as to building capacity. To enable development of novel partnerships and international research groupings, new funds have been made available via the University Research Committee for this purpose, as well as investment in potentially transformative new research ideas.

More specifically the University is very happy to provide the following support in-kind:

- In addition to the 10% of University of Bristol academic time that has been costed into the grant to fund teaching, mentorship or research involving visiting colleagues from South Africa, the University will provide 5% of their time in-kind to travel to South Africa for workshops and research projects. This includes Prof Margaret May, Prof Yoav Ben-Shlomo, Prof Will Hollingworth, Dr Leila Rooshenas, Dr Stephanie MacNeill and Prof Richard Coward. This equates to £67,976 in-kind contribution. This will also allow us to deliver a suite of Short Courses in research methods in South Africa, which would cost £440-1,100 in the UK.
- Visiting researchers from South Africa will also have access to the University of Bristol Short Courses at a reduced rate for training in applied research methods. We have costed three courses for the each of the 10 visiting early career researchers and two for each of the 10 senior researchers, this equates to £25,000 in-kind contribution.
- The University has agreed to lower the Estates/Indirect costs associated with this project. This equates to £90,465 in-kind contribution.
- Visiting researchers from South Africa will be given desk space for the duration of their stay (up to 6 weeks). This equates to £12,500 in-kind contribution.
- We will support early career researchers (in Bristol and Cape Town) to apply for funding to support research mobility through the Worldwide Universities Network, of which University of Bristol and University of Cape Town are both members. Funding for bolt-on projects can also be sought internally through the Research Development Fund, the Sustainability Fund or the new Research Capability Fund.
- Through the University’s Institute of Advanced Studies, senior academics will have access to the Benjamin Meaker Visiting Professorship scheme. This funds visits of up to three months and covers travel, accommodation and subsistence up to £800 per month.

This demonstrates the firm commitment of the University of Bristol to this bid and to the team led by Dr. Caskey who have our full and enthusiastic support.

Yours sincerely

Professor Nishan Canagarajah
Pro Vice-Chancellor (Research and Enterprise)

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20 January 2017

The UK National Institute for Health Research
Evaluation, Trials and Studies Coordinating Centre
University of Southampton, Southampton
SO16 7NS

Letter of support: Funding application for an NIHR Global Health Research Group

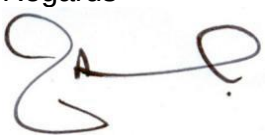
Dear Colleagues

On behalf of the Faculty of Medicine and Health Sciences of Stellenbosch University I wish to express our strong support for this funding application for further development and research around the newly-established South African and African renal registries. This collaboration between the SA Renal Registry and the UK Renal Registry, and the two universities supporting/hosting these registries (Stellenbosch University and the University of Bristol) has great potential for generating critical data on renal disease and its treatment in South Africa and the African continent, and will serve as a valuable, data-rich platform for training a new generation of African scientists.

Stellenbosch University is a research-focused university with a strong African footprint. Particular strengths within our Faculty, which would be of relevance for these registry initiatives, include a strong Centre for Evidence-based Healthcare (running our MSc in Clinical Epidemiology), our Biostatistics Unit and a newly-formed Department of Global Health. We also have good links with colleagues at the South African Cochrane Centre (I have previously served as Director) and colleagues like Debbie Bradshaw at the MRC's Burden of Disease Research Unit. These institutions are just across the road from our Faculty.

We have been very happy to provide some support to Prof Davids and his registry initiatives over the past few years. We partially funded the salary of one of the previous registry managers, provided some office space and hosted the AFRAN Registry Workshop in 2015. Should this funding application be successful the registry staff and activities would be expected to increase substantially. The Faculty is willing to house the registry and provide support in the form of adequate office space, including basic utilities such as telephone and internet access. We would release staff to visit the UK Renal Registry at the University of Bristol for visits or training, and receive UoB staff/students on their visits to the registry here in Cape Town. The existing MOU between Stellenbosch University and the University of Bristol should facilitate such exchanges. Finally, as an epidemiologist, I am also willing to serve as an advisor for the overall project and also serve as a mentor to more junior colleagues/students on specific sub-projects.

Regards



Prof Jimmy Volmink
DEAN

Prof Jimmy Volmink
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17th January 2017

To Whom It May Concern at NIHR

International Society of Nephrology
www.theisn.org

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Dear Sir

Proposal to establish an NIHR Global Health Research Group:

UK Renal Registry/University of Bristol & South African Renal Registry/Universities of Stellenbosch & Cape Town

The International Society of Nephrology (ISN) gives its strong support to this proposal to establish a Global Health Research Group based on a partnership between renal registries in the UK and South Africa.

The ISN, the global organisation representing 10,000 nephrologists from 130 countries, has a major commitment to the development of sustainably capacity building in the developing world, and has a thirty year record of support in Africa, which is bearing fruit in this proposal: Dr. Razeen Davids, lead investigator in South Africa, is himself a past ISN Fellow, and other ISN Fellows who have recently completed their training with him will in turn be playing a key role supporting the establishment of new renal registries in their own countries based on the South African Renal Registry platform.

Establishing registries for kidney disease is of proven benefit in developed world settings – providing information to focus health planning, and establishing platforms to support clinical trials and translational public health research. The ISN regards this proposal as having 'game changing' potential for nephrology in Africa, where registries are still in an early stage of development. This proposal will not only ensure a solid and expanding future for the South African Renal Registry but will go on to share that platform collaboratively elsewhere in Africa.

If this proposal is successful, ISN will give it ongoing support, working with the lead investigators to provide access to ISN's existing capacity building programmes. The partnership between the UK and the South African Renal Registries will provide an excellent training environment for ISN Fellows from Africa, and it will also be well placed to bid for support for additional projects through the ISN Clinical Research programme. It will also provide a valuable contribution to our recently formed ISN-ACT

(Advancing Clinical Trials) initiative, which is leveraging existing infrastructures to generate more high quality clinical trials in nephrology.

Yours sincerely

John Feehally DM, FRCP

ISN Programs Chair

ERA-EDTA Registry

Leading European Nephrology

Amsterdam, 12 January 2017

TO WHOM IT MAY CONCERN

This letter is to support the application by Dr. Fergus Caskey (UK Renal Registry/ University of Bristol) and Prof. Razeen Davids (South African Renal Registry/ University of Stellenbosch) to establish a Global Health Research Group linking the two registries and universities to explore efficient ways to use data to reduce inequity and harm from kidney disease in South Africa and ultimately wider sub-Saharan Africa.

Independently, both Dr. Caskey and Prof. Davids have demonstrated considerable interest in global health research in relation to chronic kidney disease and performed some work in the area as shown by their participation in and organization of related international workshops and research projects. Dr. Caskey has co-led the EVEREST study together with myself. EVEREST aimed to study the general population, health care system and renal service characteristics that are associated with the incidence and outcomes of renal replacement therapy. As a result of a collaboration with 51 renal registries across the globe this effort led to four scientific publications. Professor Davids has set up the South-African Renal Registry and has taken the initiative for a pan-African registry, the AFRAN/APNA Registry.

Where the UK Renal Registry serves as an example for other national renal registries across the world, especially by their use of the registry infrastructure for efficient studies and trials, the South African Renal Registry has great potential in this direction.

I therefore gladly support this project as well as its overall leadership by Dr. Caskey and Prof. Davids leading the work in South-Africa. In addition, I am very willing to accept the invitation to support the collaboration as a member of the Steering Committee.

Yours Sincerely,

Kitty J. Jager MD PhD
Professor of Medical Informatics & Kidney Epidemiology
ERA-EDTA Registry Director

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ARBOR RESEARCH COLLABORATIVE FOR HEALTH

20 YEARS

January 20, 2017

Dr. Fergus Caskey
Consultant Nephrologist, North Bristol NHS Trust
Honorary Senior Clinical Lecturer, School of Social and Community Medicine, University of Bristol
Medical Director, UK Renal Registry, Bristol

Dear Dr. Caskey,

This letter confirms my interest in supporting your efforts to form a Global Health Research Group that will bring together the excellent skills, knowledge, experiences, and perspectives of the proposing researchers from the UK Renal Registry and the University of Bristol with that of colleagues in the South African Renal Registry (SARR), the University of Cape Town, and the University of Stellenbosch in South Africa.

I find this proposed project very exciting and would be delighted to offer my expertise as a Steering Committee member for the Global Health Research Group. For the past 20 years, I have been involved as a Lead Investigator and Deputy Principal Investigator for the international Dialysis Outcomes and Practice Patterns Study (DOPPS). DOPPS is an ongoing prospective cohort study for identifying hemodialysis practices associated with the best clinical and patient-reported outcomes for hemodialysis patients. DOPPS is coordinated by Arbor Research Collaborative for Health which is a non-profit research organization in Ann Arbor, MI USA. The DOPPS is the largest, international cohort study of its kind, having collected very detailed patient- and facility-level data on >80,000 randomly selected HD patients across 21 countries since 1996 using the same data collection instruments across all countries via a facile in-house custom-made web-based data collection system. These countries include the UK plus 8 other European countries, Australia, New Zealand, Japan, China, the Gulf Cooperation Council countries, Canada, and the US. DOPPS includes close involvement from >80 nephrology leaders worldwide as part of this large international study, and a collaborative EURODOPPS partnership with the ERA-EDTA Registry. The DOPPS has resulted in >200 published papers which have helped inform guideline development and national health initiatives including some in the UK. We have extended the DOPPS study design to two other international studies during the past 5 years: a study of peritoneal dialysis (PDOPPS) and of chronic kidney disease (CKDopps).

In contributing as a Steering Committee member I would also draw upon my experience as the Lead Investigator for the International Chapter of the United States Renal Data System (USRDS). This chapter provides international trends in the incidence, prevalence and treatment of end-stage kidney disease (ESKD) – with the chapter updated annually and grown to include representation of 60 countries. It has been a great pleasure as part of this effort during the past 3 years to have numerous interactions with Prof. Razeen Davids, Chairperson of the South African

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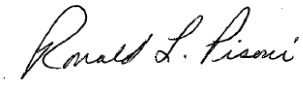
Renal Registry, in discussing their initial efforts to start SARR, and more recently the successes they have achieved through their great efforts. I have encouraged inclusion of data from SARR into the USRDS International Comparisons Chapter, which has occurred for the past 2 years, and allows very helpful and informative comparisons with data reported by numerous other countries including the UK. Our DOPPS data collection team also provided feedback to Prof. Davids to help inform the creation of SARR's initial data collection approach in South Africa. I have great respect and admiration for the efforts of the many folks in South Africa involved in creating this Registry and the potential for the information collected by SARR to improve care and outcomes for ESKD patients in South Africa in the future. As a Steering Committee member for the Global Health Research Group, I would be willing to explore possibilities by which the various data collection platforms we have created and utilize in the DOPPS program could be shared or coordinated with efforts by SARR.

Finally, I am also involved as an investigator as part of an international collaboration across numerous national registries, called INTEGRATED, for developing a standardized methodology for calculating and reporting renal replacement therapy (RRT) transition rates with a goal of providing comparative findings across many countries as a first step towards ultimately improving outcomes associated with RRT transitions. I along with other USRDS investigators currently have developed an analytic plan and the programming code for the above purpose with a goal of sharing this code with registries to help facilitate this effort. I would look forward to bringing the experiences from involvement in this international INTREGRATED collaboration to be as useful as possible to the proposed Global Health Research Group.

In summary, I feel the proposed project is very exciting with great potential to have a very substantial impact for improving the health care of persons with kidney disease in South Africa via the efforts of SARR as informed through the proposed Global Health Research Group. I offer my best wishes for the success of this proposal.

Sincerely,



Ronald L. Pisoni, PhD, MS
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The Renal Association

UK RENAL REGISTRY

Chief Executive: Mr R. Cullen
Medical Director: Dr F. J. Caskey

Learning & Research
Southmead Hospital
Bristol BS10 5NB

Tel: +44 117 414 8150
www.renalreg.org

Friday 20th January 2017

Dear NIHR Global Health Research Panel,

The PROTEA Global Health Research Group: Partnership for Renal registry Opportunities in Translational public health research and Efficient studies in Africa

The renal community has historically been a leader in information technology in the UK, with a national renal registry collecting data on all dialysis and transplant patients through automatic electronic extraction. More recently it has developed the Rare Diseases Register RaDaR which now has more than 10,000 patients signed up and PatientView which gives patients web-access to their electronic health record. The Registry also has experience building and managing the electronic case record forms and databases for a number of observational studies, including the NIHR PGfAR-funded Access to Transplant and Transplant Outcome Measures Study. Led by Dr Caskey, our Medical Director and Director of this Global Health Research Group, we are learning to use this infrastructure for pragmatic clinical trials, with two NIHR HTA-funded individual level "registry" RCTs (NIHR HTA 15/57/39 and NIHR HTA 15/80/52) and two Health Foundation-funded cluster RCTs underway or getting started. This research success has been greatly helped by the strong links built with the biostatisticians, epidemiologists, clinical trialists and health economists at the University of Bristol over the last couple of years.

The Registry has also had a direct impact on clinical practice and policy through national programmes on acute kidney injury and patient reported outcomes. This work has been led through our innovative "Think Kidneys" collaboration with NHS England (www.thinkkidneys.nhs.uk). We are also working with a partnership of all key stakeholders in the UK renal community through the Kidney Quality Improvement Partnership (www.thinkkidneys.nhs.uk/kquip), which uses the Registry's data collection infrastructure to underpin coordinated quality improvement projects based on identifying variation and promoting best practice in a structured, systematic manner.

Having developed these skills and infrastructure in the UK, I am very keen that the Registry, as a charity, shares them with colleagues in other countries where they can be translated into much wider public health benefits. This would be our first attempt to do this and the South African Renal Registry seems in the perfect position to benefit, with a clear political will yet a human and IT infrastructure that is still quite vulnerable. To demonstrate my commitment to this proposal I am happy for my Registry to provide the following support in kind:

- Free use of our open source, common language, data collection platform RaDaR as a possible replacement database for the South African Renal Registry and African Renal Registry.
- Free support from our data team and clinical informatics team and information governance lead, who have not been costed in grant.
- Free access to UK Renal Registry data (through the usual application process) for any early career researchers or senior researchers visiting from South Africa or wider Africa.

- Free desk space and computer access at the UK Renal Registry for any visiting South African Renal Registry staff, early career researchers or senior researchers visiting from South Africa or wider Africa.

I am therefore delighted to give this Global Health Research Group application my full support.

Yours sincerely,

Mr Ron Cullen,
Chief Executive Officer
The Renal Association UK Renal Registry

The South African Renal Registry
An initiative of the South African Renal Society

18 January 2017

Letter of Support – UK NIHR Global Health Research Group

The South African Renal Registry (SARR) has been established under the auspices of the South African Renal Society since 2010. I, Dr Julian Jacobs, and Prof MR Davids (Co-Chair), have been mandated by the SA Renal Society to develop this data collection platform and to manage the functions of the SARR on behalf of the greater South African renal community.

The first SARR annual report (December 2012 data) was published in 2014 and provided the first official data on renal replacement therapy (RRT) in South Africa in almost 2 decades. The previous SA Dialysis and Transplant Registry had last reported 1994 data then stopped functioning because of insufficient resources.

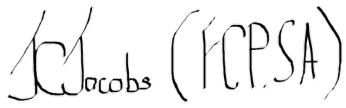
Securing sustainable funding remains an ongoing challenge, especially now that the Registry platform needs further development to serve the needs of the African Renal Registry.

We strongly support this proposed funding application and fully support the developing collaboration between the SARR, Stellenbosch University, the UKRR and the University of Bristol.

We look forward to a mutually beneficial partnership which will assist in addressing important knowledge gaps regarding kidney disease in South Africa, and the rest of Africa.

We believe that generating good data on the provision of renal care, highlighting disparities within and between African countries, and evaluating the outcomes of RRT and other interventions will positively influence the allocation of resources and the quality of renal care provided, and make a real contribution to nephrology on the African continent.

Thank you



Dr Julian Jacobs

On behalf of the South African Renal Registry

Registry Team

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MR Davids: mrd@sun.ac.za
N Marais: nicola.marais@gmail.com
Website: http://www.sa-renalsociety.org/Registry.asp

SOUTH AFRICAN RENAL SOCIETY

Prof. Graham Paget (President) *grahampag@mweb.co.za*

Dr Vakhtang Rekhviashvili (Secretary) vakhtang@telkomsa.net

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Contact: Deidré Roets - Deidren@turnergroup.co.za

20 January 2017

The UK National Institute for Health Research

Letter of support from the South African Renal Society: Funding application for an NIHR Global Health Research Group

Dear Colleagues

I wish to express the strong support of the South African Renal Society for this funding application. Prof Razeen Davids and Dr Julian Jacobs have been mandated to establish and manage a national renal registry on behalf of the Society. They have succeeded in establishing it as the new SA Renal Registry and have produced valuable annual reports for the past 3 years. This data was the first official data on the provision of renal replacement therapy in South Africa for almost 20 years. It had immediate impact via press coverage and also drew the attention of our national health minister, who subsequently convened a summit on an effective approach to chronic kidney disease for South Africa.

Securing funding to develop and maintain our registry platform, and to support data collection efforts, has been difficult. We have received some support from Stellenbosch University (where Prof Davids is based and where Dr Jacobs has had a part-time appointment), there have been ad-hoc donations from industry, and more recently, a contribution from the National Department of Health. However, overall funding is inadequate and we are therefore excited at the possibility of having sufficient resources via this NIHR Global Health Research Group funding to ensure that our platform is robust and scalable, and our human resources stronger, so that we can accommodate data collection on behalf of the African Renal Registry, and engage in vital research around these registry initiatives.

We are pleased to note that the proposal includes opportunities for nephrologists, other interested scientists and postgraduate students from around the country to be involved with the Registry and its research projects. We would be happy to nominate a member of the SA Renal Society executive committee to serve on an advisory panel, if required.

Finally, in my capacity as head of the Division of Nephrology at the University of the Witwatersrand, I have agreed to the request by Professor Davids that I, or one my nephrology colleagues, participate in this initiative as a “regional champion” in the Johannesburg and Pretoria area.

Regards

Prof Graham Paget

President, the South African Renal Society

School of Public Health and Family Medicine
Head of Department and Director: Professor Mohamed F Jeebhay

Division of Public Health Medicine
Head: Professor Leslie London

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20 January 2017

Global Health Research
National Institute of Health Research
United Kingdom

To whom it may concern

Re: A University of Bristol - South African Renal Registry NIHR Global Health Research Group

I am very happy to write this letter supporting the proposal led by colleagues at the University of Bristol and the South African Renal Registry to build renal epidemiological and efficient trials capacity in South Africa. In particular, I would be keen to work with this group to explore ways that existing routine healthcare databases in Western Cape and beyond could be used to underpin such research. This connects with my own special interest and on-going work to the use of context-appropriate routine information and monitoring systems.

The School of Public Health and Family Medicine at the University of Cape Town hosts four University-Recognised Research groupings: Centre for Infectious Diseases Epidemiology and Research (CIDER); Centre for Environmental and Occupational Health Research (CEOHR); Health Economics Unit (HEU); and the Women's Health Research Unit (WHRU). A substantial body of research is also conducted in the eight disciplinary divisions of the School. The research questions derive from local and regional public health priorities – HIV/AIDS, tuberculosis, cervical cancer, occupational and environmental lung disease, other chronic diseases, health care access and financing, health and human rights, social and behavioural aspects of health and many more. This enables the School to sustain a range of research projects, from student initiated dissertation research to multicentre trials, many of these in collaboration with local and international partners. I have previously worked with several of the Bristol team in the area of HIV cohort studies based on routine observational data, and can see real opportunities extending this to non-communicable diseases, such as kidney disease.

Yours sincerely,

Andrew Boulle
Professor of Public Health Medicine, School of Public Health and Family Medicine, University of Cape Town
Public Health Specialist, Department of Health, Provincial Government of the Western Cape

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jou kennisvennoot • your knowledge partner

18 January 2017

The UK National Institute for Health Research
Evaluation, Trials and Studies Coordinating Centre
University of Southampton, Southhampton
SO167NS

Letter of support: Funding application for an NIHR Global Health Research Group

Dear Colleagues

As the Executive Head of our newly-formed Department of Global Health here at the Faculty of Medicine and Health Sciences of Stellenbosch University, I strongly support this NHIR Global Health funding application of Dr Fergus Caskey and Prof Razeen Davids to support the development of the South African and African renal registries and promote research and postgraduate training around these initiatives. The collaboration between the SA Renal Registry and the UK Renal Registry, and the universities supporting these registries, promises to have a huge impact on the treatment of renal disease in Africa. The registry platform and its databases will foster collaboration between scholars in nephrology, epidemiology, public health, biostatistics, bioinformatics and other disciplines, and provide training for African researchers and students as an important consequence of this initiative.

The Department of Global Health is willing to support the proposed project through teaching and training, collaborating in the research, and facilitating student and staff exchanges with the University of Bristol and UKRR. The Department houses the following divisions/units which are of relevance: the Centre for Evidence-based Healthcare (housing the MSc in Clinical Epidemiology), the Biostatistics Unit (which now offers an MSc in Biostatistics), and the Division of Community Health (which has the research focus areas of measurement sciences in public health, and health systems research). Charles Wiysonge, the current Director of the SA Cochrane Centre, holds a professorship in the Department of Global Health.

Fakulteit Geneeskunde en Gesondheidswetenskappe
•
Faculty of Medicine and Health Sciences

Department of Global Health

PO Box 241 Cape Town, 8000 • South Africa
Tel: +27 21 938 9095 • Fax: +27 21 938 9723

In my personal capacity, I am happy to serve on an advisory committee for the larger project, and also be more directly involved as a supervisor or mentor to students and other colleagues on the team.

Kind Regards

Prof U.M.E. Chikte
Executive Head: Department of Global Health

Centre for Evidence Based Health Care

17 January 2017

To whom it may concern

Letter of support for funding application of an NIHR Global Health Research Group

The CEBHC www.sun.ac.za/cebhc is a recognized research centre at the Faculty of Medicine and Health Sciences (FMHS), Stellenbosch University, with a track record in research on evidence based health care (EBHC), promoting the use of best evidence in health policy and practice and training in EBHC. The centre conducts and promotes the use of robust research by various stakeholders and supports academic programmes with a focus in clinical epidemiology www.sun.ac.za/clinepi and evidence based practices.

We are supportive of this funding application for the South African and African Renal Registry initiatives and the data/research that will flow from it. Our Centre hosted and partially funded one of the previous registry managers (Gillian Singh). The proposal being submitted covers specific areas to strengthen and advance the existing South African Renal Registry, using research to inform heath service planning, promote training, career development and mentorship of clinician researchers and social scientists to use the registries and routine healthcare databases to support translational public health research, and support collaboration towards a pan-African Renal Registry.

The CEBHC will provide methodological support and mentorship in biostatistics, clinical epidemiology and translational research. Students doing MSc Biostatistics and Clinical Epidemiology will link with this programme and conduct relevant research projects. We look forward to collaborative engagement with faculty involved with the programme and in advancing our own expertise in this area. As a Centre with a vision to promote and advance EBHC in the African region we are excited to be part of this opportunity.

Sincerely,

Prof T Young, Director
MBChB, FCPHM, MMED, PhD

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Tel: +27 (0) 21 938 9886 Email: tyoung@sun.ac.za

23 January 2017

Letter of support for funding application of an NIHR Global Health Research Group

To whom it may concern:

I am the Director of the South African Cochrane Centre at the South African Medical Research Council. This is one of 14 Cochrane Centres around the world; and its mission is to prepare and maintain Cochrane Reviews of the effects of healthcare interventions, and to promote access to, and the use of best evidence in healthcare decision-making on the African continent. I am also an Extra-Ordinary Professor of Epidemiology and Biostatistics in the Department of Global Health at Stellenbosch University.

I strongly support this funding application for the South African and African Renal Registry initiatives and the data/research that will flow from it. The data from the registries will be very valuable for our work on estimating the burden of renal disease in Africa. I am a committee member of the Global Burden of Disease (GBD) Expert Group. The GBD is a global enterprise, involving individuals based in over 100 countries, which produces and disseminates comprehensive global burden of disease statistics. One of the greatest challenges for GBD is the paucity of data from Africa.

Yours sincerely,

Professor Charles Shey Wiysonge
MD, PhD
Director

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SCHOOL OF SOCIAL AND COMMUNITY MEDICINE
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Tuesday 24th January 2017

Dear Global Health Research Panel,

The PROTEA Global Health Research Group: Partnership for Renal registry Opportunities in Translational public health research and Efficient studies in Africa

The recently established South African Renal Registry now manages to collect a limited dataset on all people on dialysis with a kidney transplant across South Africa, but needs to:

1. Move towards prevention of harm from kidney disease in South Africa by linking to hospital and laboratory data capturing early stages.
2. Develop the health services research expertise and support to use their infrastructure to identify need, undertake efficient studies and monitor impact on population health.
3. Invest in this infrastructure so that it can respond to the request from the African Association of Nephrology to provide a platform for other African countries and an African Renal Registry.

This fantastic NIHR funding opportunity would allow that development to occur rapidly and in a global partnership led by the University of Bristol, tapping into expertise in Cape Town and other South African research organisations.

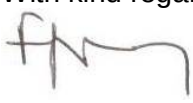
Aging populations, increasing urbanisation, the HIV epidemic and increasing rates of non-communicable diseases, like hypertension, diabetes and obesity pose a particular risk of kidney disease to populations living in Africa. Reflecting this, the International Society of Nephrology launched its “0by25” initiative in 2013 aiming to eliminate preventable deaths from acute kidney injury worldwide by 2025 (http://www.theisn.org/0by25) through:

- Evidence
- Education and awareness
- Action

Our proposed PROTEA Global Health Research Group will provide the data to plan and evaluate clinical and public health interventions, influence health policy and drive up standards of care in acute and chronic kidney disease and we are delighted to have the full support of the International Society of Nephrology in delivering this vision.

Thank you for considering our application.

With kind regards



Dr Fergus Caskey
Medical Director, UK Renal Registry
Consultant Nephrologist, North Bristol NHS Trust
Honorary Senior Clinical Lecturer, University of Bristol

CURRICULUM VITAE

Associate Professor Mogamat Razeen Davids

Degrees and qualifications

- **1986:** MBChB, University of Cape Town
- **1993:** FCP(SA), registered as Specialist Physician
- **1994:** MMed (Internal Medicine), Stellenbosch University (cum laude)
- **1999:** Registered as Nephrologist with the SA Medical and Dental Council
- **2001:** Fellow of the International Society of Nephrology, University of Toronto, Canada
- **2015:** PhD, Stellenbosch University

Current positions held

- Associate Professor in the Department of Medicine (since 2005) and Head: Division of Nephrology (since 2006), Stellenbosch University and Tygerberg Hospital, Cape Town, South Africa
- Co-chair: South African Renal Registry
- Chairperson: African Renal Registry

ResearcherID: D-2303-2013 **ORCID:** 0000-0003-4900-0231
Google Scholar page: http://scholar.google.co.za/citations?user=qIMvng0AAAAJ&hl=en

Prof Razeen Davids is Head of the Division of Nephrology at Stellenbosch University and Tygerberg Hospital, Cape Town, South Africa. In 2000-2001 he spent a year at the University of Toronto as an International Society of Nephrology (ISN) Fellow with Professor Mitch Halperin studying electrolyte and acid-base disorders. Since returning to Cape Town he in turn has been a host mentor to ISN Fellows from Ghana, Kenya, Nigeria, Zambia and Nepal. Apart from electrolyte and acid-base disorders his interests include the epidemiology of chronic kidney disease (CKD) and end-stage renal disease (ESRD), and medical education, especially e-learning.

He was involved, with Professor Mitch Halperin, in conceptualising and writing a series of "Masterclasses in Medicine" teaching articles in the QJM (Quarterly Journal of Medicine). These "clinical detective stories" use narrative to engage the reader in solving challenging electrolyte and acid-base cases. He completed a PhD on the development and usability evaluation of a multimedia e-learning platform to help students and clinicians learn about electrolyte and acid-base disorders. The research clearly indicated that optimising the usability of e-learning resources is critical to improve the educational impact. These studies were the result of Prof Davids' keen interest in teaching and his interest and expertise in information and communications technology. He obtained formal Macromedia® certification as a ColdFusion® developer and instructor in 2001, and has been involved in the development and maintenance of several websites.

With respect to the epidemiology of CKD/ESRD, Prof Davids has been involved in establishing a Web-based national renal registry for South Africa. Once again, this involvement was a result of his interest in database design and programming, combined with an interest in epidemiology. The reports emanating from this initiative provided the first official data on renal replacement therapy in South Africa in nearly 20 years.

Following the early success of the South African Renal Registry, Prof Davids was mandated by the African Association of Nephrology (AFRAN) to lead an initiative to establish "a renal registry for Africa". The African Renal Registry has now been launched, with Ghana, Burundi and Zambia as the first countries to join during this pilot phase.

Prof Davids was recently appointed as Associate Editor of the African Journal of Nephrology. He has overseen the migration of the Journal from a traditional paper journal to an online, open access publication with a new editorial board. The re-launched Journal aims to establish itself as an effective vehicle for publishing nephrology research from Africa.

Research grants held

1. **Renal Care Holdings Nephrology Fellowship**
   Project: Secured private funding for a training fellowship in nephrology for Dr Adriaan Slabbert.
   Year: 2016-17. Award R650,000 per annum for 2 years.
2. **National Research Foundation: Knowledge, Interchange and Collaboration (KIC) grant**
   Project: International workshop on developing renal registries in Africa – held March 2015.
   Year: 2014. Award R25,000.
3. **Fresenius Medical Care Nephrology Fellowship**
   Project: Secured private funding for a training fellowship in nephrology for Dr Nabeel Bapoo.
   Year: 2013-14. Award R650,000 per annum for 2 years.
4. **Stellenbosch University Faculty of Health Sciences: Clinical Research Doctoral Fellowship**
   PhD project: Development and usability evaluation of a multimedia e-learning resource for electrolyte and acid-base disorders.
   Year: 2010. Award R150,000.
5. **Nycomed Madaus Nephrology Fellowship**
   Project: Secured private funding for a training fellowship in nephrology for Dr Yazied Chothia.
   Year: 2009-10. Award R400,000 per annum for 2 years.
6. **International Society of Nephrology: Global Outreach Research & Prevention Program**
   Project: Prevalence of chronic kidney disease in South African teachers.
   Year: 2010. Award $15,000.
7. **Stellenbosch University: Fund for Innovation in Research on Learning and Teaching**
   Project: Development of an interactive e-learning resource for electrolyte and acid-base disorders.
   Year: 2007. Award R40,000
   Year: 2009. Awarded an additional R30,000
8. **South African Universities Health Sciences IT Consortium**
   Project: Further development of an interactive website for teaching electrolyte and acid-base disorders.
   Year: 2004. Award R100,000

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	Responsible lead/ frequency	Year 1				Year 2				Year 3			
		Apr Jul		Oct Jan		Apr Jul		Oct Jan		Apr Jul		Oct Jan	
		Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Funding obtained													
Phase 1													
Establishing needs and arrangements for joint working	All												
Progression assessment	NIHR												
Phase 2													
Investment in infrastructure													
The South African Renal Registry - dialysis and transplant	GS, RD												
The AFRAN/APNA Registry - dialysis and transplant	GS, RD												
Research activity													
Routine data & linkage - AKI and CKD	FC, AB												
Descriptive epidemiology - RRT, ESKD, AKI & CKD	YBS, TY												
Research priority setting	Commission from James Lind Alliance												
Economic evaluation - topic to be decided	WH												
Ethnographic research - topic to be decided	LR												
Phase 3													
Sentinel surveillance for quality assurance and research	FC												
Feasibility of using registries for efficient trials in Africa	SMcN												
Feasibility of using registries for cohort studies with biosamples	RC												
Training													
Workshops in South Africa	Annual												
Working visits to South Africa	3 per year												
ECR visits to Bristol	10 in total (up to 6 weeks)												
Senior research visits to Bristol	10 in total (up to 4 weeks)												
Oversight committees													
Management Group	Monthly												
Patient Council	Six monthly (F2F and TC, alternating)												
Steering Committee	Six monthly (F2F and TC, alternating)												

Progression assessment

Global Health Research

NHS National Institute for Health Research

Application number: 16/137/18
Director: Dr Fergus Caskey
Host organisation: University of Bristol
Application type: Group

Please provide details of your co-applicants and partner organisations.

Director and co-applicants		
Name	**Department**	**Organisation**
Dr Fergus Caskey (Director)	School of Social and Community Medicine	1. University of Bristol 2. UK Renal Registry
Prof Margaret May	School of Social and Community Medicine	University of Bristol
Prof Yoav Ben-Shlomo	School of Social and Community Medicine	University of Bristol
Prof Will Hollingworth	School of Social and Community Medicine	University of Bristol
Dr Stephanie MacNeill	School of Social and Community Medicine	University of Bristol
Dr Leila Rooshenas	School of Social and Community Medicine	University of Bristol
Prof Richard Coward	School of Social and Community Medicine	University of Bristol
Dr Philippa Bailey	School of Social and Community Medicine	University of Bristol

Partnerships and collaborations		
Name	**Department**	**Organisation**
Prof Razeen Davids (Joint Lead)	Division of Nephrology	1. Stellenbosch University 2. SA Renal Registry
Dr Julian Jacobs	Division of Nephrology	1. City Hospital, Cape Town 2. SA Renal Registry
Prof Taryn Young	Centre for Evidenced Based Healthcare	Stellenbosch University
Dr Tonya Esterhuizen	Centre for Evidenced Based Healthcare	Stellenbosch University
Prof Andrew Boulle	School of Public Health and Family Medicine	University of Cape Town
Prof Graham Paget	Division of Nephrology	1. University of Witwatersrand 2. SA Renal Society
Dr Sudesh Hariparshad	Division of Nephrology	University of KwaZulu-Natal
Mr Ron Cullen		UK Renal Registry
Dr Retha Steenkamp		UK Renal Registry
Mr George Swinnerton		UK Renal Registry
Mr Timothy Whitlock		UK Renal Registry
Dr Shona Methven		UK Renal Registry