Kidney Research UK response to the Health, Social Care and Sport Committee (Scotland) – Inquiry into Health Inequalities

1. **What progress, if any, has been made towards tackling health inequalities in Scotland since 2015? Where have we been successful and which areas require more focus?**

Health inequalities are defined as avoidable, unfair and systematic differences in health between different groups of people. In Scotland they represent thousands of avoidable premature deaths every year, including people dying from kidney disease.

Kidney disease affects over 3 million people in the UK and the numbers are rising. It severely impacts people's lives and is associated with high levels of morbidity and mortality. In 2020, over 2,000 people in Scotland were receiving dialysis and 3,300 had a functioning kidney transplant (Scottish Renal Registry). Kidney disease accounts for a significant proportion of the NHS' costs, with dialysis alone costing around £30,000 per patient per year.

Kidney Research UK is the leading kidney research charity in the UK and in 2019 we published a report on health inequalities. The report found that kidney disease disproportionally affects people from socially deprived and ethnic minority communities. People from South Asian and Black backgrounds are three to five times more likely to require dialysis and wait on average much longer for a kidney transplant than people from a Caucasian background. In addition, people from socially deprived communities are more likely to develop chronic kidney disease (CKD), progress faster towards kidney failure and die earlier.

Within the South Asian and ethnic minority communities of Scotland there is a lack of knowledge on many of the major health issues that affect these communities. These could be due to language barriers, health literacy, awareness, and fear and mistrust of the NHS. Following successful, similar projects in England, since 2014 Kidney Research UK has been working in partnership with the Scottish Government (with the latter's invitation and commissioned funding) to run the Scottish Peer Educator (PE) project amongst the South Asian (Sikh, Hindu and Muslim) communities of Glasgow, Edinburgh and surrounding areas. The PEs are volunteers from the

community who visit community and faith settings to raise awareness of kidney disease and deceased/living organ and tissue donation.

Faith is a very important issue in South Asian communities as this factor alone has a huge influence on health decision making especially about a sensitive subject such as organ donation after death. To that end, over several years, we have made valuable connections with a significant number and diverse range of faith leaders to help us promote kidney health and organ donation. Without their influential collaboration and lead in their respective communities, our success in addressing health inequalities would be far less effective.

People from ethnic minority communities wait between 168 and 262 days longer (NHS Blood and Transplant) for an organ transplant as the best match will usually come from a donor with the same tissue and blood type. Our project has therefore focused on raising awareness of the lack of donors within these communities. Over the last eight years we have spoken to over 9000 people and, as a result, over 1200 people have signed onto the NHS organ donor register. To put this into context, one donor can help to save or enhance the lives of up to 9 people. With the change of the organ and tissue donation law in March 2021, and a concerning proportion of people from ethnic minorities opting out, more awareness amongst these communities is essential to encourage people to make a decision on donation and share their wishes with their loved ones. We hope this project will lead to a reduction in transplant waiting times for people from South Asian communities in Scotland and therefore achieve better patient outcomes.

We believe much greater focus needs to be paid to prevention and early detection of CKD amongst socially deprived and ethnic minority communities in Scotland. The two most common causes of CKD are diabetes and high blood pressure. A significant proportion of kidney disease and kidney failure could be prevented if people at high risk of CKD have their kidney function regularly monitored and steps taken to reduce damage to the kidneys. The role of primary care is key here, in order to identify people who are at risk/in the early stages of CKD and where steps can be taken to prevent progression to kidney failure. The charity has an impressive track record in addressing this and so could support the bespoke needs of the Scottish people.

2. What are the most effective approaches to tackling health inequalities and how successful is Scotland in pursuing such approaches?

We believe our evidence-based peer educator model (Buffin et al 2015, Clinical Kidney Journal) we describe above for organ and tissue donation could be effectively deployed to tackle health inequalities in other areas. Training, supporting and accrediting volunteers with a coveted qualification to work within their own communities has the potential to deliver health messaging and change practice and behaviours more widely. A personal connection often resonates better with the individual and results in better engagement and is more likely to result in the desired outcome.

Moreover, our experience in England helped us, right at the beginning in 2014, to start invaluable dialogue and partnership working with the highly influential and revered faith leaders. They have been pivotal in supporting our work in Scotland. For example, one of the first Peer Educators, was, in fact, the President of the Sikh temple and he continues to be a driving force for the project.

Intuitively, this model has strong and wide appeal, having garnered support and accolades from the business, health and communities for it is now a multi award winning initiative, now in Scotland as it has been in England too.
For example, the project has received awards from the South Asian Business Awards and CEMVO – Centre for Ethnic Minority Volunteering Organisations – both based in Scotland. Moreover, in recent years, two of our longest serving Peer Educators have been recognised in the Queen's Honours for their life saving contributions to our project in Scotland.

The effective use of data will also be crucial in identifying the most significant health challenges within each locality and tailoring the intervention according to local characteristics/need.

3. What actions would you prioritise to transform the structural inequalities that are the underlying cause of health inequalities?

We would recommend the establishment of community programmes with educational training and awareness amongst the affected population. More funding into community led projects, local schools and organisations. Education has to be initiated at a young age within the target area as we know a child's early life circumstances and experiences shape their physical, social, mental, cognitive and emotional development and negative experiences and learned behaviours can have a lifelong impact on health, learning and behaviour traits.

We would also prioritise access to GPs and primary care to ensure regular blood pressure checks and/or urine checks take place; access to secondary care to ensure dialysis is close to home or at home where possible; and access to specialist psycho-social support to support the patient's adherence to treatment regimes). We would also support a greater focus on access to appropriate housing, as this can have an impact on kidney patients' ability to dialyse at home.

Language, culture and religious health misconceptions, disadvantage and barriers can significantly contribute to structural inequalities. Hence, a culturally sensitive and culturally congruent community outreach educational programme, will help overcome major obstacles. The Peer Educator model can achieve this through meaningful and therefore effective dialogue and engagement, by engendering all important trust which is crucial to support healthy behaviours and lifestyle changes.

Our track record would once again, see us working collaboratively with grassroots organisations and groups to have a more effective, partnership approach to

addressing inequalities, while building capacity locally to enhance sustainability and long-lasting change, post project end.

We have trained over 160 Peer Educators around UK – from a cross section of ages, ethnicities, religion and socio-economic status. We have engaged with more than 40,000 people 'at risk' in many UK cities across a myriad of projects. Hence, as an organisation we could "hit the ground running" to establish work in Scotland to urgently address diverse health inequalities that inflict so many in its many forms.

4. What has been the impact of the pandemic both on health inequalities themselves and on action to address health inequalities in Scotland? Please note, the Committee is interested in hearing about both positive and negative impacts.

With the closure of all organisation and face to face events during the pandemic, this expounded the issue of health inequalities within the deprived and hardest to reach communities. Many were left isolated and affected mentally, physically and emotionally in this period. Within the South Asian communities of Scotland, the lack of our face-to-face interactive events made a huge impact on our Peer Educator project. We were required to switch to online platforms for the project.

The project used digital platforms to host a total of 13 webinars with the South Asian (Muslim, Hindu and Sikh) communities and the wider Interfaith Scotland. Webinars have been held with medical students and the British Medical Association and Café Scientifique. Participation in webinars for nursing staff, staff working in NHS Blood and Transplant (NHSBT) and doctors in training have also helped to inform healthcare workers about the faith and cultural needs of diverse communities. The webinars were attended by a total of 540 people and recorded links for each webinar were available to view online. A total of 300 people have viewed the webinars post-event. Engagement with local media such as community radio (Awaz FM and Radio Ramadan) and digital magazines such as Asian Voice have aided the dissemination of information. These initiatives have resulted in positive outcomes with improved quantity and tone of media coverage on organ donation, number of events and followers.

While it is difficult to quantify the tangible impact on organ donor registrations, continued engagement since 2015 in Scotland with commitment from NHSBT (hosting Scotland's first faith seminar in June 2019) has resulted in an increase in ethnic minority opt-ins from 5.8% (2015) to 7.8% in 2019-2020. In summary we have harnessed the reach, impact and value of digital and social media platforms to continue this vital piece of work during a pandemic.

Covid -19 has further exposed and deepened health inequalities, especially among minority ethnic and socially deprived communities. The Peer Educator model is very adaptable and flexible and has been used (in England) in socially deprived communities (of any ethnicity), in younger and older age groups who experience inequalities. Such an approach could easily and quickly be adapted for Scottish

communities where there is an unmet need to tackle worsening inequalities, head on.

5. **Can you tell us about any local, regional or national initiatives throughout the pandemic, or prior to it, that have helped to alleviate health inequalities or address the needs of hard-to-reach groups? How can we sustain and embed such examples of good practice for the future?**

The Peer Educator project has helped to alleviate the health inequalities around kidney and related diseases, and organ transplant around Glasgow, Edinburgh and surrounding areas. During the pandemic we were able to utilise online events where we could reach out to larger communities throughout Scotland.

Projects like these need sustained funding from the Scottish Government, as the need to raise awareness of organ and tissue donation is ongoing. We believe the project could be extended to other geographical areas within Scotland and the role of the volunteers could be expanded to incorporate health checks such as blood pressure checks.

Moreover, the pandemic has re-emphasised the need for preventative health messaging and the adage “prevention is better than cure” could not be truer. Kidney disease and the related main causes (diabetes and hypertension) can be prevented with the correct and timely health promotion messages by the right messengers, such as Peer Educators. The team in Scotland provide some kidney health messages already and so this could easily be expanded to provide a greater focus on prevention of kidney and other life limiting cardio- vascular diseases.

Our teams have delivered such effective and successful initiatives in England over more than 15 years. In addition, these teams have worked with patients directly to reduce inequalities in their care and treatment in a number of settings such as in dialysis units and in patients’ homes. This vast experience could easily be deployed in the Scottish context, building on and enhancing the valuable work funded thus far, by Scottish Government.

6. **How can action to tackle health inequalities be prioritised during COVID-19 recovery?**

Several steps could be taken to tackle health inequalities in kidney disease as part of the Government’s work to recover from Covid.

Priority investment in health services (primary and secondary) in areas of high deprivation or areas with a higher proportion of residents from ethnic minority communities should be considered to tackle health inequalities post-Covid. Kidney Research UK has a long standing track record in England of addressing health inequalities in primary and secondary care. This experience and lessons learned could be invaluable in tackling ever pressing health inequalities in a timely manner.

Investment in further Peer Educator projects targeting people at risk of kidney disease should be considered, as well as incorporating kidney disease into initiatives on diabetes and hypertension, the two most significant risk factors for CKD.

Earlier diagnosis and/or prevention of kidney disease should be a priority for the Scottish Government.

7. What should the Scottish Government and/or other decision-makers be focusing on in terms of tackling health inequalities? What actions should be treated as the most urgent priorities?

Please see our comments above relating to targeting people at risk of kidney disease or in the early stages of CKD.

The Scottish Government approached Kidney Research UK in 2013 following our success with our community engagement approach in England. They have been hugely supportive of the Peer Educator model and from an initial 2 year funding, have clearly recognised its impact, as funding now continues beyond year 8. As highlighted above, there are many other opportunities and communities where this evidence based, multi award winning model could be effectively used. Such a proven method is urgently required to address the ever growing and deepening health inequalities, made even worse by the pandemic.

New drugs designed to delay and prevent disease progression and hence prevent people requiring dialysis or a transplant have recently been licensed. Ensuring these drugs reach those communities most at risk of renal failure should be a priority.

8. What the role should the statutory sector, third sector and private sector have in tackling health inequalities in the future?

The statutory, third and private sectors all have a role to play in tackling health inequalities. The partnership between the Scottish Government, Kidney Research UK and wide-ranging community groups (engaged by the charity) to raise awareness of kidney disease, organ donation and reduce waiting times for transplants is a model which could be replicated elsewhere with partner organisations from different sectors.

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