

Safe and Warm – Kidney Care UK and PSR Scotland

Vulnerability and Carbon Monoxide Allowance

1st March, 2023

UPDATE May 24
SGN



SGN

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1 Description

Funding GDN(s)	SGN
For Collaborative VCMA Projects:	N/A
New/Updated	Updated May 24
Date of PEA submission:	1 st March 2023
Project contact name:	Safe and Warm – Kidney Care UK and PSR Scotland
Project contact number/email:	Linda Spence
Total cost (£k)	£28,260 Update May 24 £28,349.50
Total VCMA funding required (£k)	£15,760 Update May 24 £15,849.50 – £89.50 additional costs for resource delivery due to remote locations

2 Problem statement

On a daily basis Utilities in Scotland interact with many customers, some of whom may be impacted by Chronic Kidney Disease (CKD) and are missing out on vital support which will help them through the cost-of-living crisis. When CKD becomes part of someone's life, patients spend extensive time, often in isolation, recovering from 4–8-hour bouts of dialysis, three-to-four times per week. They feel the cold more acutely, live with extreme fatigue, itching, anxiety, and experience severe cognitive impairment (often known as 'brain fog'), which means completing even the simplest everyday tasks becomes hugely challenging. It is therefore essential for them to stay warm and feel comfortable, supported and safe within their homes.

- There are currently 180,000 people living with CKD in Scotland. (Based on historic data from the Quality and Outcomes Framework ([QOF](#)).
- 50% of people with CKD (c 90,000 patients) live in the 2 most deprived percentiles and are therefore extremely vulnerable to rising bills.
- 19,494 people have had a transplant or are on home dialysis/in centre dialysis.
 - 5,488 of these have a functioning kidney transplant, as of December 2021, around 14,000 patients are on dialysis waiting for a kidney transplant.¹
- Of the 14,000 people living with kidney failure, less than 10% are currently on the PSR and even fewer on the Water PSR, both of which are absolutely critical for people on dialysis who face a medical emergency if there is a power/water disruption or outage.
- Black, Asian and minority ethnic communities are five times more likely to develop CKD than other groups.
- Only 26% of dialysis patients are in any form of employment, so many are on low income as their ability to work full-time is highly compromised.

Safeguarding households is vital and we know from the PSR data available that Utilities in Scotland are unable to reach the majority of their customers with CKD, especially those on life-sustaining dialysis treatment who are struggling, vulnerable and in considerable need of support. These customers are unlikely to be on the most appropriate energy tariffs, and even fewer are engaged with vulnerability programmes, energy efficiency/water efficiency schemes and carbon monoxide awareness campaigns.

¹ https://publichealthscotland.scot/media/15512/pdf_srr_report_111022_final.pdf - Public Health Scotland

Increased energy use combined with a low income and lack of employment options, means that dialysis patients are at high risk of falling further into fuel poverty. Fears of overspending on energy and restricted income is leading to difficult and dangerous decisions for people on dialysis. The choice between heating or eating and living in cold homes can force them back into renal units or to hospitals, thus undermining their right to access the medical care that is best for them, putting them at greater risk of infection to which they are already very vulnerable.

For an increasing number of people with CKD, energy costs are simply too much for them to bear.

- The average cost of energy bills for a CKD patient is £2,238 annually (based on 47p per kWh x 35 hours per week). An estimated cost for home dialysis has increased to between £814 and £1918 per year based on Oct 22 prices. The cost of living increasing at alarming rate, this is leading to financial and welfare crisis for the kidney community in Scotland.

We know those on low income will be less likely to afford to have their gas appliances serviced or afford a carbon monoxide alarm, putting them at risk. National Energy Action and Gas Safety Trust research found 35% of low income and vulnerable households surveyed exceeded the 10ppm threshold for carbon monoxide levels. Older people and people in poor health have also been found to be particularly vulnerable to CO poisoning, spending more time at home and with a need to stay warm, resulting in them using the heating more regularly². People living in deprived areas are also less likely to own an audible CO alarm than homes in non-deprived areas, further increasing the risk of CO poisoning³.

In 2022, the Kidney Care UK helpline received over 10,000 calls requiring support services, which is an increase of 31% on 2021. The increase in demand (47%) was for immediate hardship grants, to help people with CKD keep warm and cope with the cost-of-living crisis. In total, they gave £752,000 in grants to more than 1,500 patients and their families in 2022 and have already awarded 3x the number of fuel and hardship grants in the first 2 months of 2022 than we did in January and February 2021.

It's important for SGN and Utilities in Scotland to help and support people living with CKD, to make the most of every opportunity to adapt their services and actions to support those in need and do this by raising awareness of resources such as:

- The Priority Service Register and the support provided should they lose power/water at the home
- The range of energy safeguarding services that are available to them
- Providing advice and guidance on fuel efficiency and financial support options
- Providing education around CO Safety

In line with the Customer Vulnerability Strategy where a commitment has been made to 'identifying customer needs and joining up support services', we have joined up with the PSR Scotland partnership. Our intention is to deliberately engage and provide energy safeguarding to people suffering with CKD.

Working in partnership, together we can help safeguard customers by providing practical, immediate and transformational support to kidney patients who would greatly benefit from signing up to the Priority Service Register, accessing support services through Kidney Care UK (KCUK) and getting support with carbon monoxide awareness and energy/water efficiency.

3 Scope and objectives

Our project aims to target around 38,875 people in four areas in Scotland where there is high volume of CKD patients and low PSR registration and CO awareness. We will be providing specific services to 5,328 CKD people and their families in Scotland who are currently living with kidney failure in areas of severe deprivation. The areas we will support are Aberdeen, Dundee, Glasgow and Perth, raising vital awareness of energy

² SafeLink's, 2020, *Carbon monoxide poisoning: Who is most at risk?*

³ Kokkarinen et al, 2014, *Investigation of audible carbon monoxide alarm ownership.*

safeguarding, the PSR, and building a greater awareness of CKD and the support services available to ensure that they are safe and warm in their homes.

We will provide a face-to-face and referral service supported by Kidney Care UK Patient Support and Advocacy Officers. (PSAO's). These specialists will ensure that patients and their families at risk of financial hardship will receive counselling, advocacy, dietary advice and direct financial support through Kidney Care's own financial resources, through our ability to raise income from welfare benefits and other means, and vulnerability and priority service support through SGN, Scottish Water and SPEN.

The Patient Support and Advocacy Officers (PSAOs) will engage and communicate with Clinical Directors, Pre-Dialysis Clinics, GP surgeries, and Lead Nurses/Renal Unit Managers to raise awareness of the partnership and benefits that Priority Service Register and CO awareness can provide to patients under their care.

This project will be delivered over an initial period of 15 months, achieving sustainable, measurable outcomes for the patients they support and will:

- Reach 5,328 vulnerable and disadvantaged kidney failure households through various contact channels, community events and direct marketing, social media, newsletters, and other partnership communication channels
- Deliver free and impartial energy safeguarding and wellbeing support to kidney failure patients through community-based renal units and GP surgeries
- Identify and tackle under-heating, and those at risk of self-disconnection, thereby reducing the risks of cold homes and hospital admissions
- Support those most vulnerable to access financial support through income maximisation and benefit checks and help them manage their household costs going forward
- Ensure patients are on the priority services register for energy and water and they can access broader relevant support services
- Raise awareness of the CO risks and identify ways to make patients homes safer to live in
- Increase the level of knowledge of our services amongst other local support agencies

KCUK is the UK's leading kidney patient support charity. They ensure that the 3.5m people living with CKD across the UK do not face the condition alone. They do this by helping people live better with kidney disease.

Their patient support services include:

- free renal counselling
- advocacy support in the community through 18 Advocacy Officers across the UK
- hardship grants
- holiday grants
- hospital grants
- white goods grants
- funeral grants
- heating and utility grants
- education and training grants

The physical, on-the-ground engagement will be delivered by Kidney Care UK PSAOs in Scotland who have strong relationships across healthcare teams, local groups and networks. They will utilise local knowledge and understanding to breakdown any trust or cultural barriers.

This on-the-ground PSAO team will engage directly with patients and their families to understand their individual circumstances and challenges. Referrals will be made in real time using secure digital referral methods to streamline response times. A control loop will be in place to ensure referrals meet the agreed turnaround times, and to ensure safeguarding is managed appropriately.

People will receive:

- face to face support within each dialysis unit/hospital
- Carbon Monoxide information made available in different formats to kidney patients
- Kidney patients added to the PSR/extra care register to help safeguard them
- financial support through funded packages and access to onward support around energy usage

The objectives of the project include:

- 100% of people supported will receive a meaningful conversation about the PSR
- 70% of those people supported will have increased awareness of support available to them, including how to manage energy usage and costs, energy safeguarding services and CO safety

KCUK PSAO's will be equipped with the knowledge and resources to have conversations about the PSR, energy safeguarding and fuel poverty / energy efficiency with people suffering from CKD and other front-line organisations who provide support, so the indirect reach will be much greater. It is estimated that for every direct conversation that takes place, at least 25% of those people will pass on the awareness information to others outside of KCUK support service.

4 Why the project is being funded through the VCMA

This project meets the VCMA eligibility criteria as it will address the specific needs of people with a chronic illness, deliver energy safeguarding services and a tailored package of support including where extreme vulnerability exists, whilst delivering a positive Social Return on Investment.

5 Evidence of stakeholder/customer support

5.1 Kidney Care UK – Support 2022

In 2022, Kidney Care UK provided £752,000 hardship grants to more than 1,500 patients and those affected by kidney disease. Through their Welfare and Benefits programme, they secured £1,235,030 in benefit entitlements for kidney patients across the UK during the year.

They received nearly 10,000 calls for support to their helpline, which was an increase of 31% on 2021. They have also invested nearly £10m into the NHS through their Hospital Grants Programme. During winter of 2022, demand for the patient support services has grown at an unprecedented rate and they are already on track to award nearly £1m in hardship grants in 2023. The goal in Scotland is as it is across the UK: is to support as many CKD patients and their families as possible, to improve their quality of life, while also building greater awareness of CKD, and to ultimately ensure that no one faces kidney disease alone.

5.2 Kidney Care UK – Money Advice Service Study

For every £1 invested, Kidney Care UK typically generate a minimum £10 return through its long-term partnership with Auriga Services. This is based on a previous study by the Money Advice Service ⁴(now Money Advice and Pensions Service) under their 'What Works Scheme', where our range of direct support services together demonstrated £14.52 Social Return on Investment for each £1 spent in the University Hospitals Birmingham (UHB) Trust. Indeed, we have supported more than 1,500 kidney patients at the Queen Elizabeth Hospital in Birmingham alone in the last couple of years, identifying £3.1 million of benefit entitlements, and helping patients to claim £3.02 million to date. We have supported patients in making 1,859 social impact applications, such as KCUK holiday grants, blue badges, wheelchairs and dialysis away from base submissions.

Because of our local and trusted relationships on the ground across Scotland in the 9 main renal units and 29 satellite units across the country, we are able to understand the complex and extensive needs of renal

⁴ https://masassets.blob.core.windows.net/fincap-cms/files/000/000/446/original/Auriga_Services_-_WWF.pdf

patients, working alongside them and their healthcare professionals to deliver genuinely transformational SROI, improving quality of life and maximising the support to which they are entitled to. This local knowledge and being a familiar presence in hospitals, community centres and dialysis units is key to patient engagement.

5.3 SGN Customer Engagement Group and Vulnerable Steering Group

During the shaping of our business plan, we committed to, over the 5-year price control, support over 250,000 vulnerable customers to use gas safely, affordably and efficiently. To ensure that we adapt to market conditions, we continue to engage our SGN Vulnerable Steering Group, who help us shape our vulnerability and CO strategies and our priorities for GD2 based on current need.

Our expert stakeholders representing a range of vulnerable customer segments guided us to work with existing organisations that already support those in crisis and where we are able to broaden the reach or increase the capacity of those established charities that support people most in need. It is with guidance and support from our dedicated Vulnerable Steering Group that SGN prioritise support for those most likely to need help from their utility company due to low incomes, those in extreme financial vulnerability and in fuel crisis.

Scottish Water

As part of Scottish Water's vulnerability strategy, informed by customers, special interest groups and stakeholders, they are committed to ensuring customers who may require additional support in the event of an interruption to their water or waste water supply are signed up to the Priority Services Register. This is especially relevant for customers who have a critical dependency on water, such as those on dialysis. Analysis of current PSR volumes has shown a gap in customers on the register who sit within this category.

6 Outcomes, associated actions and success criteria

6.1 Outcomes

KCUK will aim to reach around 38,875 people with CKD and directly communicate with 5,328 CKD patients living with kidney failure, using various communication channels, partners, GP and renal units to raise awareness of PSR and CO awareness.

- Support 5,328 vulnerable and disadvantaged kidney failure households through various contact channels, community events and direct marketing, social media, newsletters and other partnership communication channels.
- Deliver free and impartial energy safeguarding and wellbeing support to kidney failure patients through community-based renal units and GP surgeries.
- Identify and tackle under-heating, and those at risk of self-disconnection, thereby reducing the risks of cold homes and hospital admissions.
- Support those most vulnerable to access financial support through income maximisation and benefit checks and help those manage their household costs going forward.
- Ensure patients are on the priority services register for energy and water and they can access broader relevant support services.
- Raise awareness of the CO risks and identify ways to make patients homes safer to live in.
- Increase the level of knowledge of our services amongst other local support agencies.
- Reduction in those suffering with low mood and depression
- Reduction in those suffering from anxiety
- Reduction in readmissions for in home dialysis day care
- Increase in financial and hardship support awarded to patients in Scotland
- Increase in patients feeling able to seek employment, feeling empowered to engage with additional support services in the community

- Improved diet and nutritional intake which helps to maintain a healthy kidney function via our ground-breaking Kidney Kitchen programme (<https://www.kidneycareuk.org/about-kidney-health/living-kidney-disease/kidney-kitchen/>)

Kidney Care UK will also continue to liaise with the overall kidney community in Scotland in renal units and in the community, to provide access to their wellbeing and support services as part of their charitable support, including counselling, financial hardship grants and holiday grants.

In addition, the following outcomes are expected as a result of KCUK PSAO's conversations with people suffering from CKD:

- Reduction in those suffering with low mood and depression
- Reduction in those suffering from anxiety
- Reduction in readmissions for in home dialysis day care
- Increase in financial and hardship support awarded to patients in Scotland
- Increase in patients feeling able to seek employment, feeling empowered to engage with additional support services in the community
- Improved diet and nutritional intake which helps to maintain a healthy kidney function via our ground breaking Kidney Kitchen programme (<https://www.kidneycareuk.org/about-kidney-health/living-kidney-disease/kidney-kitchen/>)

KCUK will invest in its physical presence at hospitals and renal units and support this with ongoing marketing and communications activity, such as geotargeted pay per click (PPC) activity. The approach to engaging with all professionals is based on listening to and understanding their needs, and those of the patients, and how to work alongside one another to secure the best possible outcomes. This allows the PSAOs to provide and promote the most appropriate range of services based on individual needs and challenges. This gives them the unique opportunity to support the most vulnerable people and educate them on a range of available support (e.g. the PSR, vulnerability programmes and energy/water efficiency schemes available in their community).

People will receive:

- face to face support within each dialysis unit/hospital
- Carbon Monoxide information made available in different formats to kidney patients
- Kidney patients added to the PSR/extra care register to help safeguard them
- financial support through funded packages and access to onward support around energy usage

6.2 Actions

Within the clinical environment, KCUK is a recognised and trusted partner often included as a member of local Multi-Disciplinary Team (MDTs). With KCUK being the funder of the Renal Social Worker Alliance, the organisation has strong connections and is widely known within the health and social care sector.

The broad range of engagement with health and social care professionals is critical to KCUK's ability to effectively engage with patients as it is known some patients receive support in clinical settings and some receive this support at home. KCUK also takes a holistic approach to professional engagement by understanding shift work, staff rotas, and redeployment. Furthermore, staff change and working cycles may mean the awareness raised may be time-limited and therefore KCUK's outreach must be consistent and ongoing.

KCUK's approach to engagement is driven by the following key activities which will lead to the successes of the project

- Being known, easy to reach and contact
- Engaging digitally and in person with teams in hospitals and units

- Building relationships with all teams supporting the end-to-end pathway of patient support – both health and social
- Using a varied approach with health and social care teams to ensure relationships developed and maintained
- Providing a physical presence or being part of an MDT as a critical engagement approach in a Trust
- Disseminating hardcopy publicity materials with social workers and unit managers
- Being present at local/regional events and conferences to introduce the work of the teams to those who may be new to the health & social care profession. These include town centre days and community centre hub days
- Being available at the right time when support is most needed and responding in a timely way to reduce the pressures on the healthcare professionals and any unnecessary stress or strain on the patient
- Understanding that no one team will engage in the same way and being flexible to local health and social care professional needs and those of the patients is also key to achieving long-term meaningful relationships

6.3 Success Criteria

Working together, KCUK, SGN, and PSR Scotland will be providing access to energy safeguarding and onward support for people with CKD in Scotland. We aim to deliver the following customer outcomes, which have formed the basis of our social return on investment modelling:

- Reach 38,875 people through various communication methods over 12 months
- Support 5,328 people living with kidney failure in 4 deprived areas in Scotland through a range of patient support services and access to energy safeguarding information
- 1,864 people going on to receive hardship grants, income maximisation and benefits support
- 2,664 patients to be able to access welfare and wellbeing support through Kidney Care UK's free renal counselling, helpline, and Patient Support and Advocacy services
- 3,729 people supported/referred to join PSR Scotland energy and water
- 3,729 customers provided with CO awareness sessions
- 300 customers provided with a CO alarm (where applicable)

To monitor the impact of our programme, we will monitor outcomes of those using the services provided by capturing data on who is using the services, including demographics, vulnerabilities and needs. We will work closely with our partners to ensure that we all understand the issues faced to continue to develop our services by need. KCUK will survey users of their service and provide case studies of the impact of the programme on frontline support and impact of individuals supported by the initiative (partner and individual). As partners, we will share referral numbers and regularly share web traffic to our partnership page to track engagement with PSR Scotland and CO awareness schemes.

7 Project partners and third parties involved

- Kidney Care UK
- Renal Social Worker Alliance
- Scottish Water
- Scottish Power Energy Networks
- Scottish and Southern Energy Networks
- Scottish GP Surgeries and Renal Units
- NHS Scotland

8 Potential for new learning

Monitoring and evaluation

The following activities will be in place to monitor and evaluate project progress and impacts:

- Quantitative and qualitative customer outcomes including insights into the needs of those who are using the service (demographics / location / interventions)
- Customer before-and-after-support, case studies to understand the impact of the services and support provided
- PSR and CO referral numbers, shared between SGN and Scottish Water, to track the effectiveness of the promotional activity to raise awareness and engagement with the PSR and CO awareness schemes

Learning

We are keen to learn from this project and for the successes to be incorporated into future delivery initiatives and promoted to others. Below are opportunities we see for replication, learning and sharing:

- We can use the data and feedback required to create best practices for supporting kidney patients struggling to keep themselves warm and understand how to safeguard them in the home
- We will assess the variety of feedback tools used to evaluate the effectiveness and impact of the project advice and activities, documenting project learning and sharing best practice among organisations seeking similar outcomes for communities and groups who are hard to reach with existing services
- Partnership working will generate new joined up working practices and lessons learned to be replicated in future projects and to understand if there is a gap in providing support to kidney patients
- Evaluating delivery will support learnings and successes which will be shared with Utilities in Scotland to help them reach this hard-to-reach group more effectively

9 Scale of VCMA Project and SROI Calculations

In terms of ultimate scale, the figures above suggest just how impactful this programme of work will be if it is advanced to support all of the 180,000 patients across Scotland as well as demonstrating just how significant the SROI will be if extended to meet the full prevalence of CKD across the country.

Social Value Measurement

For this project, using SGN and Scottish Water's £25,000 initial investment, our initiative will directly aim to reach 5,328 of the most deprived kidney failure patients in Scotland with a particular focus on Aberdeen, Dundee, Perth and Glasgow through our various support services. Our initiative will help these acutely vulnerable kidney patients access energy safeguarding services and comprehensive, holistic support from Kidney Care UK, including hardship grants, counselling, community advocacy support.

However, the majority of these 5,328 patients would gain significant benefit from our community PSAOs and Counselling Service, as well as our Holidays Away from Base grants and white goods grants. Our typical conversion rate of those who go on to have a full benefits and welfare check is 35%, so in this case that would be 1,864 patients/homes through our direct income maximisation service and hardship grants.

Working closely with SSEN and using the DNO social value methodology developed by leading social impact research consultancy SIA Partners we have carried out an assessment of the financial and wellbeing outcomes applicable to our services for vulnerable kidney patients incorporated in this partnership. Carrying out an in-depth assessment of the predicted outcomes we forecast a positive net social return of £26.05.

5-year reporting figures		
Economic	Total cost	£28,260.00*
	Total gross present value	£764,335.83

	NPV	£736,075.83
	SROI	£26.05

*SROI not adjusted to add in additional £89.50 due to being such a small amount.

10 VCMA Project start and end date

The project will run from April 23 to March 24 with scope to expand project.

Update May 24

Project end date extended to 30 June 2024 due to mobilisation taking longer than expected.

11 Geographic area

Scotland (nationwide) with a focus Aberdeen, Dundee, Perth and Glasgow.

12 Internal governance and project management evidence

Update May 24

SGN has worked alongside Kidney care UK and PSR Scotland to co-design this partnership and ensure that its ambition contributes to the delivery of our Vulnerability Strategy, the guidance from our Vulnerable Customer Steering Group and adheres to the updated VCMA governance criteria.

The SROI was assessed in partnership with SSEN using the DNO methodology and additional GDN proxies, the partnership scope was forecast at adding an additional £26.05 for each £1 invested, this will be monitored closely to ensure we adhere to the VCMA governance criteria.

SGN and Kidney Care UK will meet monthly and quarterly to review outcomes, learn, share best practices, and address any delivery issues.

The PEA has been reviewed and approved by the business lead Linda Spence and the Director of Customer Services Maureen McIntosh.