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EDITORIAL

Kidney health for all: bridging the gap in kidney health education and literacy[†]

The challenging issue of bridging the well identified gap in the health literacy (HL) of kidney disease, from both an individual and a global perspective, is the theme for World Kidney Day (WKD) 2022. HL, simply put, is the degree to which persons and organisations have – or equitably enable individuals to have – the ability to find, understand and use information and services to inform health-related decisions and actions for themselves and others.¹ Not only is there growing recognition of the role that HL has in determining outcomes for persons affected by kidney disease and the community in general, but there is also an emergent imperative for policy-makers worldwide to be informed and cognisant of opportunities and measurable outcomes that can be achieved through kidney-specific preventative strategies. Promoted in health policy for around a decade, current approaches that increase partnerships between health-centred policy, community health planning and health literacy² need to be shifted forward (Table 1).

The global community of people with kidney disease

Most in the community do not even know what their kidneys do or where their kidneys are, amplifying the challenge for those afflicted by chronic kidney disease (CKD). Effective healthcare provider communication is critical in supporting individuals in not only understanding their condition, but in what to do, in making decisions and taking action. Optimal HL includes not only the functional, but also the cognitive and social skills needed to gain access to, understand and use information to manage health conditions. HL is also contextual in that as health needs change, so too does the level of understanding required and the ability to problem solve change. This is particularly so with CKD when disease progresses, as health changes and treatments become increasingly complex, in turn making it more challenging for individuals to manage.³

While it has been recognised in some studies that low HL abilities in people with CKD have demonstrated an association with poor CKD knowledge, self-management behaviours and health-related quality of life, most CKD studies have measured only functional HL.² Because of

this, the evidence that low HL increases healthcare utilisation and mortality⁴ and reduces access to transplantation⁵ is weak. There is a need for studies that assess HL using appropriate multidimensional patient-reported measures such as the World Health Organization (WHO) recommended Health Literacy Questionnaire, rather than tools measuring only functional health literacy.⁶

HL is considered an important bridge between lower socioeconomic status and other social determinants of health.⁷ However, this is not a feature that can be measured by the gross domestic product (GDP) of a country, notably that the effects of low HL on the extent of CKD in the community is recognised as a global phenomenon regardless of GDP. The lack of awareness of risk factors of kidney disease, even in those with high HL, is testament to the difficulties in understanding this disease. The United States, for instance, recommends that a ‘universal precautions’ approach be undertaken towards improving HL.⁸ Imperatives around HL are now recognised as indicators for the quality of local and national healthcare systems and healthcare professionals within it.⁹

So, what does the perfect HL programme look like for people with CKD? In several high-income countries there are national HL action plans with the emphasis shifted to policy directives, organisational culture and healthcare providers,¹⁰ some with compulsory HL accreditation standards ensuring healthcare providers are cognisant of individual HL requirements. Despite the increasing array of web-based programmes that provide detailed information and self-care training opportunities, there is substantial evidence that improving healthcare provider communication skills are more likely to improve understanding of health problems and abilities to adhere to complex treatment regimens.¹¹

Access to information that is authentic and tailored specifically to the needs of the individual and the community is the aim, specifically the provision of culturally appropriate knowledge. In developing an approach to improving HL, incorporating local consumers in a co-design approach will ensure outcomes that are more appropriate to need in different regions of the world. This applies especially to communities that are smaller, with less access to electronic communication and healthcare services, where the level of HL is shared

Table 1 Summary characteristic of kidney health promotion, involving kidney health-centred policy, community kidney health planning and kidney health literacy, and proposed future direction

Kidney health promotion	Definition	Stakeholders	Current status	Limitations/challenges	Suggested solutions/future research
Kidney health-centred policy	<ul style="list-style-type: none"> Incorporate kidney health into policy decision-making Prioritise policies with primary prevention for CKD 	<ul style="list-style-type: none"> Governance Policy-makers Insurance agencies 	<ul style="list-style-type: none"> Policy emphasising treatment for CKD and kidney failure rather than kidney health prevention 	<ul style="list-style-type: none"> Economic-driven situation challenging CKD risk factor minimisation (e.g. food policy) 	<ul style="list-style-type: none"> Promote implementation of public health programme for primary CKD prevention Promote sustainable treatment for CKD and dialysis <ul style="list-style-type: none"> Increase kidney transplant awareness Enhance visibility and encourage brother-sister nephrology and transplant programme in LMIC Support research funding from government <ul style="list-style-type: none"> Healthcare cost-effectiveness for caring for CKD Kidney failure, including maintenance dialysis and transplant Promote surveillance programmes for kidney diseases and their risk factors Improve role model of community Enhance kidney support networks
Community kidney health planning	<ul style="list-style-type: none"> Building up preventive strategies to promote healthy communities and primary healthcare facilities 	<ul style="list-style-type: none"> Community leadership Kidney patient advocacy 	<ul style="list-style-type: none"> Belief in community leaders in LMIC 	<ul style="list-style-type: none"> Education and understanding kidney health promotion of community leadership and people 	
Kidney health literacy	<ul style="list-style-type: none"> Receive knowledge, skills and information to be healthy 	<ul style="list-style-type: none"> People with CKD Care partners Healthcare providers 	<ul style="list-style-type: none"> Lack of awareness of CKD and risk factors Care partner burden and burnout Inadequate healthcare workers High patients-to-healthcare workers ratio, especially in rural areas 	<ul style="list-style-type: none"> Inadequate policy direction Ineffective healthcare providers' communication skills 	<ul style="list-style-type: none"> Organisational paradigm shift towards health literacy Improving communication between healthcare providers with patients and care partners Using teach-back methods for consumer education Adapting technologies for appropriate health literacy and sociocultural environments Family engagement in the patient care Incentive for community healthcare providers in rural areas

CKD, chronic kidney disease; LMIC, low- to middle-income country.

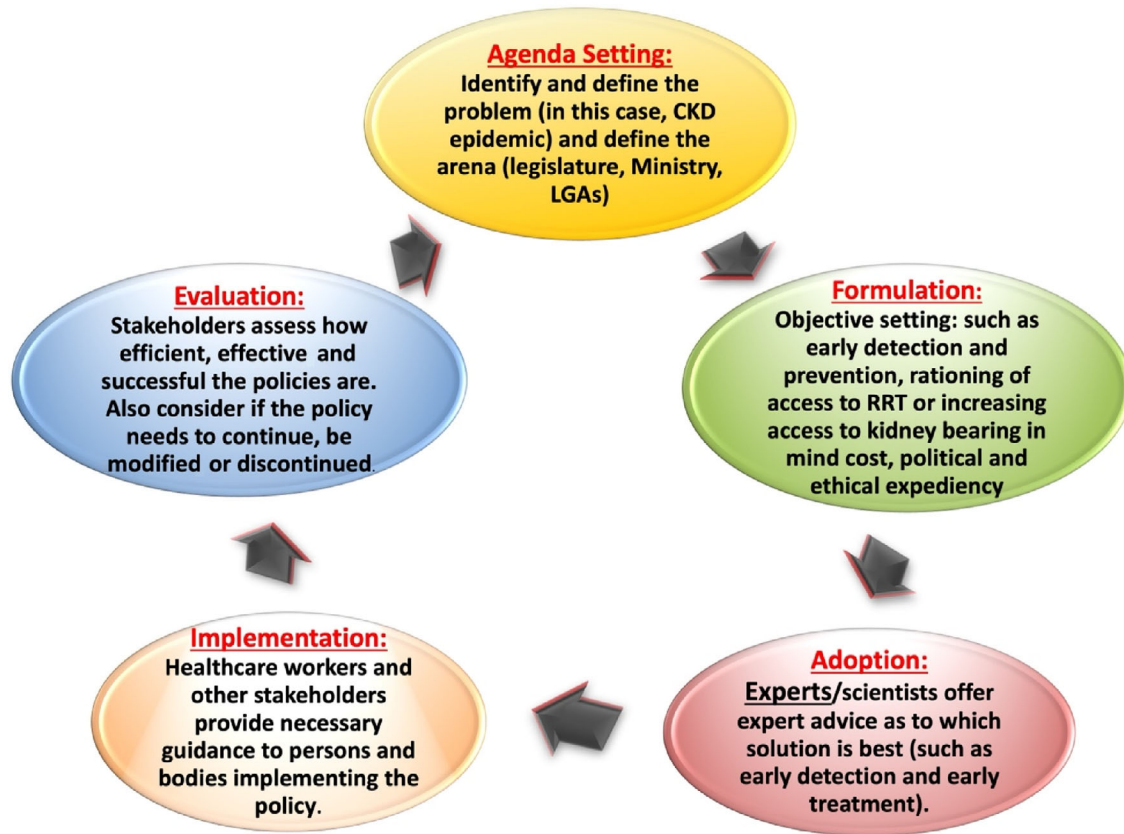


Figure 1 Policy cycle involving five stages of policy development. CKD, chronic kidney disease; RRT, kidney replacement therapy; LGA, local government area.

across the community and where what affects the individual also affects all of the community.

HL research is still at an early stage.¹² The best evidence supports the provision of targeted programmes aimed at improving communication capabilities of healthcare professionals. Indeed, programmes that address the lack of culturally safe, person-centred and holistic care, along with improving the communication skills of health professionals, are crucial for those with CKD.¹³

The global kidney community of policy and advocacy

HL is not only an identified gap between individuals and their healthcare providers, but also central in advocacy with health policy-makers.⁷ Policy and advocacy are well recognised tools that can bring about change and paradigm shift at jurisdictional level, in turn improving community health. At the centre of advocating for policy change to better address health outcomes is an exercise in improving HL of the policy-makers. Good policy development requires good understanding of the

problem at hand. For the key stakeholder, for example the kidney community, who believes that a problem exists should be tackled through governmental action, there is an increasing recognition of the importance of formulating succinct, meaningful and authentic information, to present to government for action, akin to approaches for improving HL for those with CKD.

Having said that, the development and communication of this message, designed to bridge the gap in knowledge of relevant jurisdictions, is only part of the process of policy development. An awareness of the policy process is important to clinicians who are aiming to advocate for effective change in prevention or improvement of outcomes in the CKD community. Authentic information that is meaningful to the government is critical. The policy development process can be stratified into five stages¹⁴ (Fig. 1). The policy cycle constitutes an expedient framework for evaluating the key components of the process. Importantly, of the five principles of advocacy that underline policy-making,¹⁵ the most important for clinicians engaged in this space is that of commitment, persistence and patience.

Table 2 Social media that are more frequently used for kidney education and advocacy

Social media	Strength	Limitations	Additional comments
Facebook	<ul style="list-style-type: none"> Frequently used social media platform by many kidney patients and patient groups 	<ul style="list-style-type: none"> Widely used for entertaining purposes, which can dilute its professional utility 	<ul style="list-style-type: none"> User-friendly platform for kidney advocacy, enabling wide ranges of outreach goals
Instagram	<ul style="list-style-type: none"> Photo-predominating platform 	<ul style="list-style-type: none"> Not frequently used by healthcare professionals 	<ul style="list-style-type: none"> Picture friendly, potentially effective for illustrative educational purposes
Twitter	<ul style="list-style-type: none"> Often used by physician specialists and scientists, including nephrologists 	<ul style="list-style-type: none"> Less frequently used by patients and care partners 	<ul style="list-style-type: none"> Increasing popularity among physician and specialty circles
LinkedIn	<ul style="list-style-type: none"> More often used by professionals, including in industry 	<ul style="list-style-type: none"> Originally designed for employment and job-seeking networking 	<ul style="list-style-type: none"> Mostly effective to reach out to industry and managerial professionals
YouTube	<ul style="list-style-type: none"> Video-predominating platform 	<ul style="list-style-type: none"> Less effective with non-video-based formats 	<ul style="list-style-type: none"> Wide ranges of outreach and educational targets
WeChat	<ul style="list-style-type: none"> Widely used in mainland China 	<ul style="list-style-type: none"> Access is often limited to those living in China or its diaspora 	<ul style="list-style-type: none"> Effective platform to reach out to patients and healthcare professionals in China
Pinterest	<ul style="list-style-type: none"> Picture-based, often used by dietitians 	<ul style="list-style-type: none"> Currently limited use by some healthcare workers 	<ul style="list-style-type: none"> Useful for dietary and lifestyle education

Other popular social media at the time of this publication include, but not limited to, Tik Tok, Snapchat, Reddit, Tumblr, Telegram, Quora and many others that are currently only occasionally used in kidney advocacy activities. Mobile and social media messaging apps include, but not limited to, WhatsApp, Zoom, Facebook Messengers, Skype Teams and Slack. Note that platforms that are more often used as internet-based messaging are not included.

The advocacy planning framework developed by Young and Quinn in 2002¹⁴ consists of three overlapping concepts that are key to planning any campaign:

1 'Way into the process': discusses the best approaches to translate ideas into the target policy debate and identify the appropriate audience to target.

2 Messenger: talks about the image maker or face of the campaign and other support paraphernalia that are needed.

3 Message and activities: what can be said to the target audiences that is engaging and convincing, and how best it can be communicated through appropriate tools.

As with improving HL, it is the communication of ideas to policy makers for adoption and implementation as policy that is key. There is much to be done with bridging this gap in understanding of the magnitude of community burden that results from CKD. Without good communication, many good ideas and solutions do not

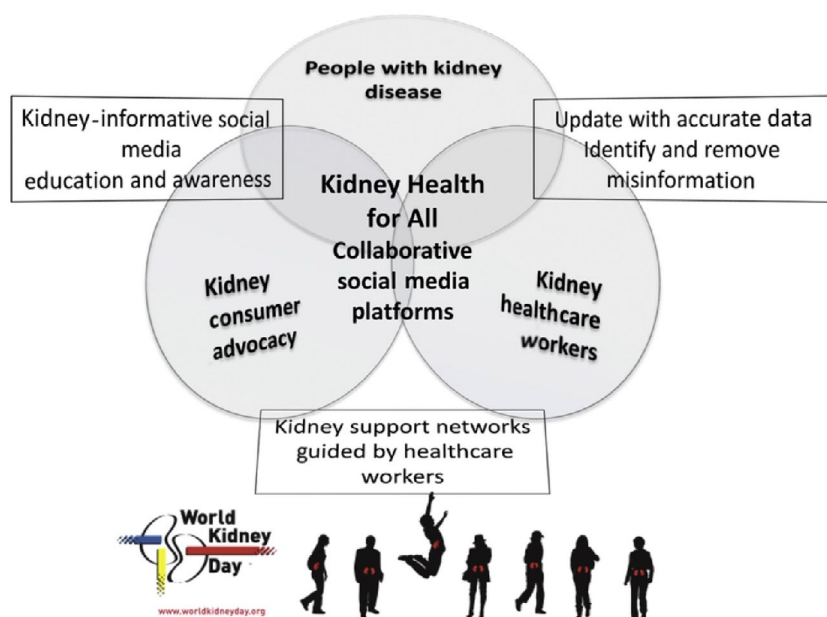


Figure 2 Schematic representation of consumer and healthcare professionals' collaborative advocacy using social media platforms with the goal of 'kidney health for all'.

reach communities and countries. Again, aligned with the principles of developing resources for HL for those who suffer CKD, the approach to jurisdictions also needs to be nuanced according to the local need, aimed at the needs of the local community.

Advocacy requires galvanising momentum and support for the proposed policy or recommendation. The process is understandably slow as it involves discussions and negotiations for paradigms, attitudes and positions to shift, and multiple factors must be considered.

Approaches to choose from include:^{15,16}












- Advising: providing new evidence-based proposals to assist in decision-making.
- Activism: involves petitions, public demonstrations, posters, fliers and leaflet dissemination often used by organisations to promote a certain value set.
- Media campaign: having public pressure on decision-makers helps in achieving results.
- Lobbying: entails face-to-face meetings with decision-makers; often used by business organisations to achieve their purpose.

Here lies the importance of effective and successful advocacy policy-makers, healthcare professionals, communities and key change makers in society. WKD has gained trust by delivering relevant and authentic messaging, supporting leaders in local engagement, and celebrated by kidney care professionals, and those with CKD and their caregivers all over the world. To achieve this goal, an implementation framework of sustainable success requires creativity, collaboration and communication. Utilising different social media platforms (Table 2) is an option to connect patients, family and healthcare professionals and provide kidney education (Fig. 2).

The ongoing challenge for the International Society of Nephrology and International Federation of Kidney Foundations – World Kidney Alliance, through the Joint Steering Committee of WKD, is to operationalise the policy-making process at the local, national and international levels, to inform or guide decision-making. This may be via increasing engagement of global organisations like WHO, the United Nations or through regional governments in low-resource settings. There is a clear need

for ongoing renewal of strategies, to increase efforts at closing the gap in kidney HL, ultimately empowering those affected with kidney disease and their families, giving them a voice to be heard.

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References

- 1 Healthy People 2030. *What Is Health Literacy*. Atlanta, GA: Centers for Disease Control and Prevention; 2020 [cited 2022 Mar 18]. Available from URL: <https://www.cdc.gov/healthliteracy/learn/index.html>
- 2 Dinh HTT, Nguyen NT, Bonner A. Healthcare systems and professionals are key to improving health literacy in chronic kidney disease. *J Ren Care* 2022; **48**: 4–13.
- 3 Mathias-Shah J, Ramsbotham J, Seib C, Muir R, Bonner A. A scoping review of the role of health literacy in chronic kidney disease self-management. *J Ren Care* 2021; **47**: 221–33.
- 4 Taylor DM, Fraser S, Dudley C, Oniscu GC, Tomson C, Ravanan R *et al*. Health literacy and patient outcomes in chronic kidney disease: a systematic review. *Nephrol Dial Transplant* 2018; **33**: 1545–58.

- 5 Taylor DM, Bradley JA, Bradley C, Draper H, Dudley C, Fogarty D *et al.* Limited health literacy is associated with reduced access to kidney transplantation. *Kidney Int* 2019; **95**: 1244–52.
- 6 Dobson S, Good S, Osborne R. *Health Literacy Toolkit for Low and Middle-Income Countries: A Series of Information Sheets to Empower Communities and Strengthen Health Systems*. New Delhi: World Health Organization; 2015.
- 7 Sorensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z *et al.* Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health* 2012; **12**: 80.
- 8 Brega AG. *AHRQ Health Literacy Universal Precautions Toolkit*, 2nd edn. Colorado Springs, CO: Agency for Healthcare Research and Quality; 2015.
- 9 Nutbeam D, Lloyd JE. Understanding and responding to health literacy as a social determinant of health. *Annu Rev Public Health* 2021; **42**: 159–73.
- 10 Australian Commission on Safety and Quality in Health Care. *Health Literacy: Taking Action to Improve Safety and Quality*. Sydney: ACSQHC; 2014 [cited 2022 Jan 17]. Available from URL: <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/health-literacy-taking-action-improve-safety-and-quality>
- 11 Visscher BB, Steunenberg B, Heijmans M, Hofstede JM, Deville W, van der Heide I *et al.* Evidence on the effectiveness of health literacy interventions in the EU: a systematic review. *BMC Public Health* 2018; **18**: 1414.
- 12 Boonstra MD, Reijneveld SA, Foitzik EM, Westerhuis R, Navis G, de Winter AF. How to tackle health literacy problems in chronic kidney disease patients? A systematic review to identify promising intervention targets and strategies. *Nephrol Dial Transplant* 2021; **36**: 1207–21.
- 13 Synnot A, Bragge P, Lowe D, Nunn JS, O’Sullivan M, Horvat L *et al.* Research priorities in health communication and participation: international survey of consumers and other stakeholders. *BMJ Open* 2018; **8**: e019481.
- 14 Young E, Quinn L, eds. *Writing Effective Public Policy Papers: A Guide to Policy Advisers in Central and Eastern Europe*. Budapest: Open Society Institute; 2002 [cited 2021 Dec 13]. Available from URL: https://www.icpolicyadvocacy.org/sites/icpa/files/downloads/writing_effective_public_policy_papers_young_quinn.pdf
- 15 Young E, Quinn L, eds. *Making Research Evidence Matter: A Guide to Policy Advocacy in Transition Countries*. Budapest: Open Society Foundations; 2012 [cited 2021 Dec 13]. Available from URL: https://advocacyguide.icpolicyadvocacy.org/sites/icpa-book.local/files/Policy_Advocacy_Guidebook_2012.pdf
- 16 Start D, Hovland I. Tools for policy impact. In: *A Handbook for Researchers, Research and Policy in Development Programme*. London: Overseas Development Institute; 2004; 1–64 [cited 2021 Dec 13]. Available from URL: <https://www.ndi.org/sites/default/files/Tools-for-Policy-Impact-ENG.pdf>