

Living well with kidney disease

TOWARDS PATIENT-CENTERED CARE
FOR PEOPLE LIVING WITH KIDNEY DISEASE

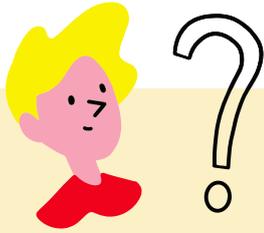


World Kidney Day
is a joint initiative of

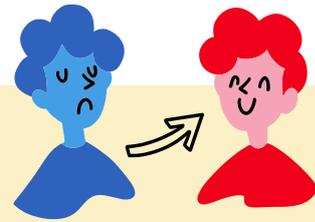




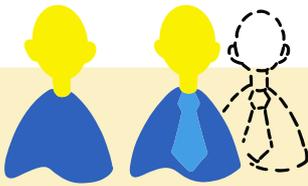
Chronic Kidney Disease (CKD), its associated symptoms, and its treatment - including medications, dietary and fluid restrictions, and kidney replacement therapy - can disrupt and constrain daily living and impair the quality of life of patients and their family members including treatment satisfaction and clinical outcomes. There is an increasing recognition of the need to identify and address patient priorities, values and goals in order to advance research, practice and policy which improve the quality of life of people with CKD. (World Kidney Day, 2020) Regardless of the type of kidney disease or treatment stage, patients want to be able to live well, maintain their role and social functioning, protect some semblance of normality, and have a sense of control over their health and wellbeing. (World Kidney Day, 2020) With health professionals consistently giving higher priority to mortality and hospitalization, and patients prioritizing those outcomes which impact their life, such as the ability to travel, advancing education, engagement and shared decision-making is vital. (Banerjee, et al., 2020)



35% of patients with pre-end stage kidney disease (ESKD) had no knowledge of any treatment modalities post kidney failure ¹



Insufficient education about treatment affects patient choice of therapy and levels of satisfaction, e.g. patients on a home therapy or with a kidney transplant were found to be **more satisfied** than those with in-center hemodialysis (ICHD) ²



Only 58% of the participants in a recent survey reported existing patient involvement in clinical trials in nephrology ³



Patients least involved with their care have **8% to 21%** higher health costs, than patients with the highest level of activation ⁴



Non-adherence rates to dialysis among CKD patients can range from **2% to 98%** and is linked among other to contributing factors (e.g. side effects) reducing the quality of life ⁵



About 2/3 of care-partners of hemodialysis patients reported that their mental health and vitality was affected by 1.7-1.8 points on the Caregiver Burden scale (ranging 1 to 4) ⁶

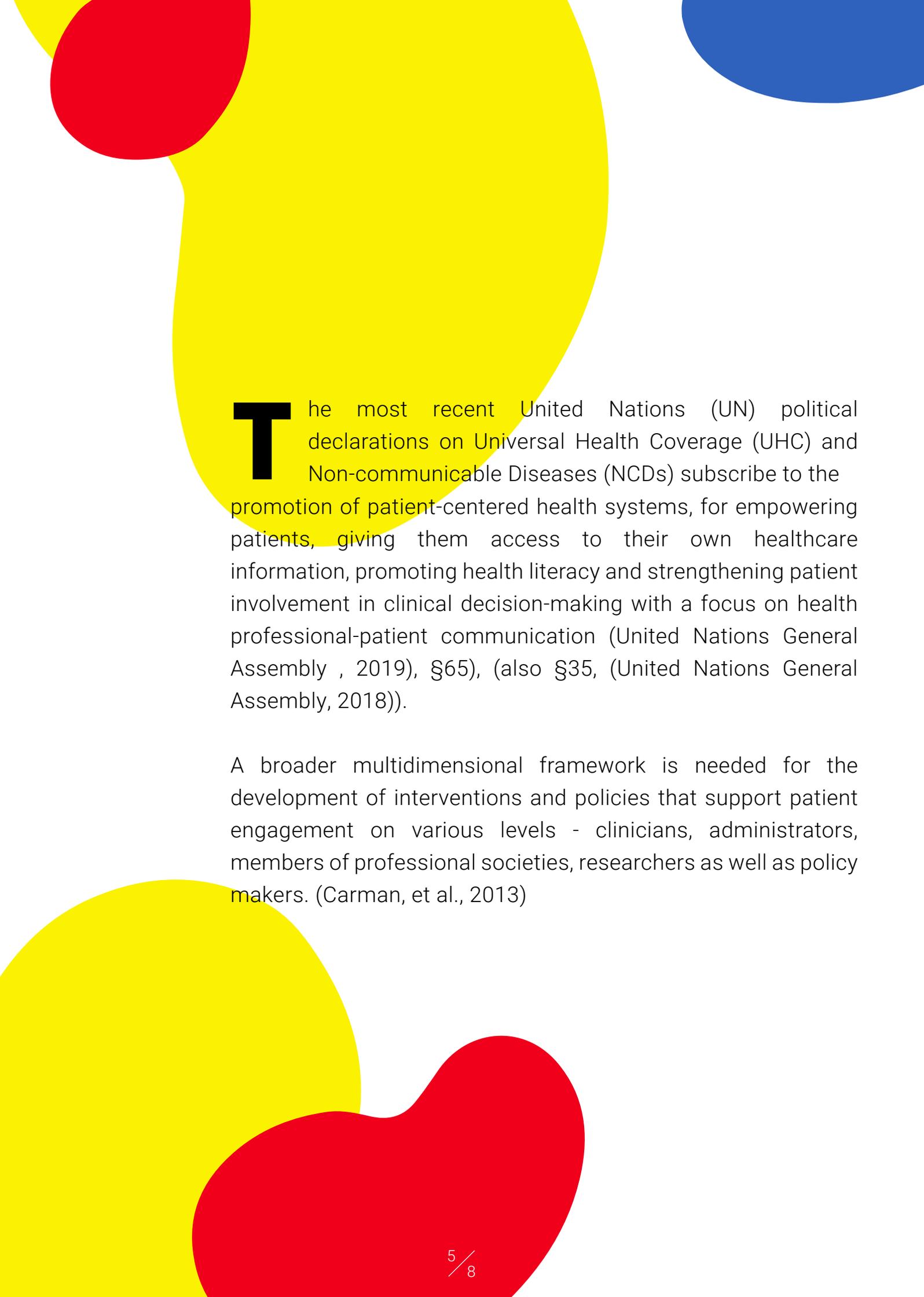
¹ (Finkelstein, et al., 2008) ² (Fadem, et al., 2011) ³ (Banerjee, et al., 2020) ⁴ (Hibbard, et al., 2013); 'Patient activation' describes the knowledge, skills and confidence a person has in managing their own health and care. (National Health Service (NHS) England, n.d.) ⁵ (Chironda & Bhengu, 2016) ⁶ (Belasco & Sesso, 2002)

Policy landscape and change

Patient-centeredness –the idea that care should be designed around patients’ needs, preferences, circumstances, and well-being– is a central tenet of health care delivery. (Cosgrove, et al., 2013) The World Health Organization (WHO) defines empowerment as “a process through which people gain greater control over decisions and actions affecting their health” and should be seen as both an individual and a community process. (World Health Organization , 1998) Four components have been reported as being fundamental to the process of patient empowerment: 1) understanding by the patient of his/her role; 2) acquisition by patients of sufficient knowledge to be able to engage with their healthcare provider; 3) patient skills; and 4) the presence of a facilitating environment. Based on these four components, empowerment can be defined as:

A process in which patients understand their role, are given the knowledge and skills by their health-care provider to perform a task in an environment that recognizes community and cultural differences and encourages patient participation.

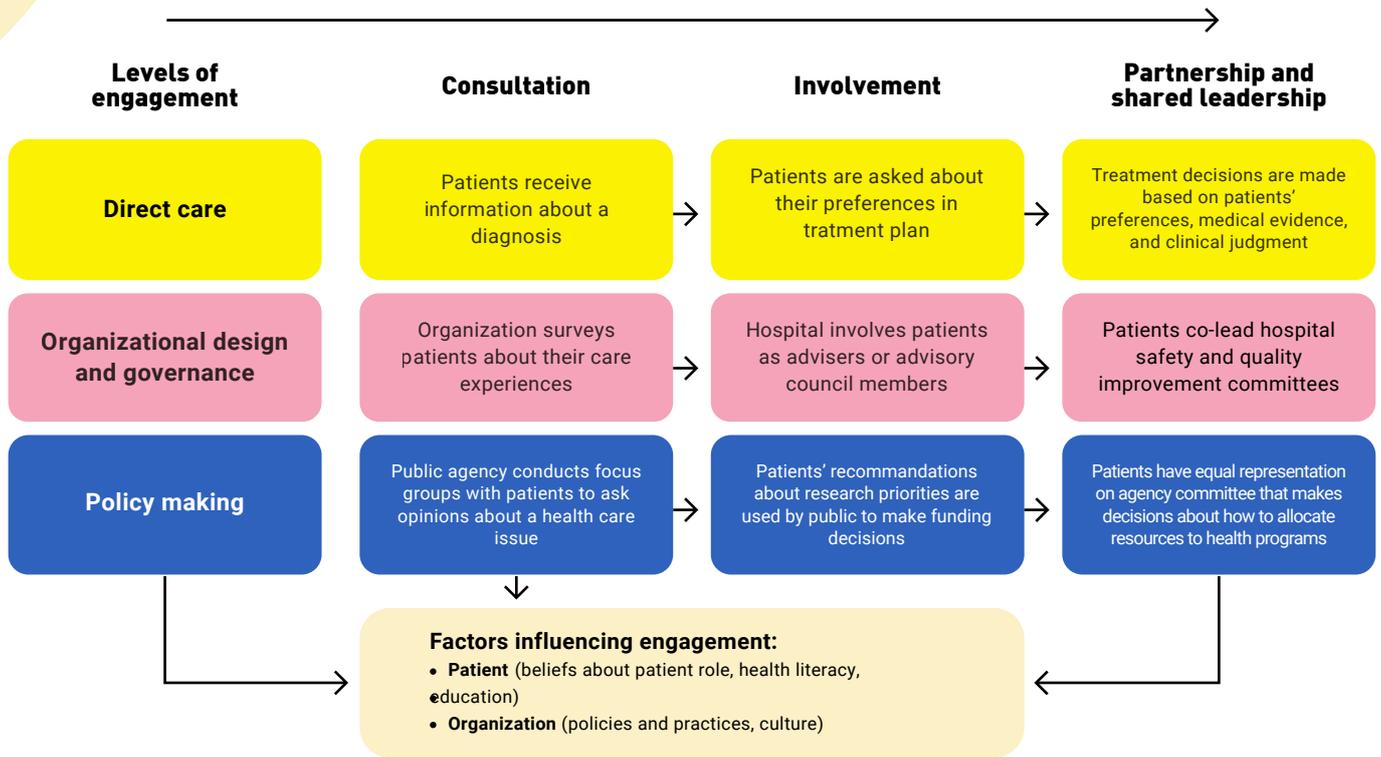
- World Health Organization · 2009 -



The most recent United Nations (UN) political declarations on Universal Health Coverage (UHC) and Non-communicable Diseases (NCDs) subscribe to the promotion of patient-centered health systems, for empowering patients, giving them access to their own healthcare information, promoting health literacy and strengthening patient involvement in clinical decision-making with a focus on health professional-patient communication (United Nations General Assembly , 2019), §65), (also §35, (United Nations General Assembly, 2018)).

A broader multidimensional framework is needed for the development of interventions and policies that support patient engagement on various levels - clinicians, administrators, members of professional societies, researchers as well as policy makers. (Carman, et al., 2013)

Continuum of engagement



Source: Carman, et al., 2013

Yet engagement is not a quick fix. Many patients and clinicians are still operating in an older paradigm of a paternalistic clinician and system. Efforts need to be made not only to raise patients' awareness about the benefits of engagement but also to encourage and support their increasing responsibility and leadership. (Carman, et al., 2013)

Concrete actions to further patient-centered care for people living with kidney disease

- 01 Empower patients to understand their role and have the knowledge, and confidence, to be able to engage with clinicians in shared decision-making, and support selfmanagement
- 02 Strengthen partnerships with patients and their care-partners in the development, implementation and evaluation of interventions, in both practice and policy settings, that enable patients to live well with kidney diseases
- 03 Develop and implement validated patient-reported outcome measures – monitored/ supported by regulatory agencies - as a metric for quality care to assess and address areas of life participation in routine care
- 04 Funding agencies should establish targeted calls for research that address the priorities of patients
- 05 Prevent or treat, as early as possible, the symptoms, side effects and psychological, social and spiritual problems related to kidney disease and/or its treatment
- 06 Promote self-management programs, cognitive behavioral therapy and group therapies for managing depression, anxiety and insomnia
- 07 Increase resources for, and access to, comprehensive healthcare provision to address patient wellness including drugs, nutrition and rehabilitation services
- 08 Promote home dialysis therapies in combination with appropriate 'assisted' dialysis programs, in order to reduce both patient and care partner fatigue and burnout.
- 09 Push for bespoke care guidelines for vulnerable and disadvantaged populations
- 10 Involve primary care and general physicians, especially in low and low and middle income countries (LICs and LMICs), to improve the affordability and access to services through the public sector by helping patients with CKD to manage symptoms and improve wellness
- 11 Provide additional structural support - such as community outreach, education, telemedicine, and collaboration with faith-based community leaders – in LMICs to lend psychological support and help build trust within the health care system and providers

Global practices

The International Society of Nephrology charged the research community with enrolling 30% of CKD patients by 2030. (ASN, et al., 2019). A call to action further cemented by the ISNACT project recently issuing a statement on including people with kidney disease in COVID-19 trials (International Society of Nephrology (ISN), 2020).

www.theisn.org

Can-SOLVE CKD is a pan-Canadian patient-oriented kidney research network. In partnership with patients, researchers, health care providers, and policy-makers, it is working to transform treatment and care for Canadians living with or at risk for chronic kidney disease.

www.cansolveckd.ca

Holidays away can be out of reach if you're on dialysis. Kidney Health Australia offers free haemodialysis services to holiday-makers impacted by kidney disease, thanks to the Big Red Kidney Bus.

www.kidney.org.au/ways-we-help/big-red-kidney-bus

The Standardised Outcomes in Nephrology (SONG) initiative aims to establish a set of core outcomes and outcome measures, for trials and other forms of research, across the spectrum of kidney disease. These outcomes will be based on the shared priorities of patients, caregivers, clinicians, researchers, policy makers, and relevant stakeholders. This will help to ensure that research is reporting outcomes that are meaningful and relevant to patients with kidney disease, their family, and their clinicians; to support decisions about treatment.

www.songinitiative.org

The Kidney Health Initiative (KHI) promotes inter alia the study of patient preferences for innovative renal replacement therapy (RRT) devices in its Technology Roadmap for Innovative Approaches to Renal Replacement Therapy (Kidney Health Initiative, 2019).

www.khi.asn-online.org

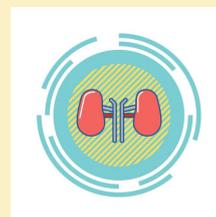
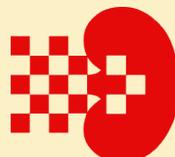
World Kidney Day (WKD) is the global campaign that aims at increasing awareness of the importance of our kidneys to our health and reduces the impact of kidney disease and its associated problems worldwide. WKD is a joint initiative of the International Society of Nephrology and the International Federation of Kidney Foundations that was started in 2006 and has not stopped growing ever since.

www.worldkidneyday.org

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This publication is co-signed by:



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