Innovations in dialysis: the user's perspective

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The need for innovation in dialysis is long overdue. As past and present users of dialysis we are fully aware of the limitations of current dialysis modalities. The time for complacency is over — developers must engage with dialysors to ensure that our needs are met so that we can live the best life possible. Let us share our dream for devices that will enable us to enjoy life.

> "Necessary developments to facilitate improvement in health care … have bypassed the world of kidney patients"

There is no doubt that the mainstay therapy for kidney failure — dialysis — has a negative impact on quality of life (QoL). Dialysis affects the ability of an individual to participate in activities such as family life, sports, travel or work. Although mortality has improved somewhat over the past 25 years, only ~24% of individuals aged 18–54 years remain employed — an important indicator of social participation — at initiation of dialysis, compared with 85% employment among healthy, age-matched individuals[1]. Given the negative impact of dialysis, how do we enable dialysors, in all their diversity, to find their new normal and achieve the best QoL possible while living with a chronic illness? We believe that technological advances may help to achieve this goal.

Notice that we avoid the term 'patient', which we perceive as a term used to describe a passive receiver of health-care services. Rather, we use 'dialysor' to describe an individual who lives an active lifestyle, including work, involvement in family life and travel, where the only limitation is that they must regularly connect to a machine to stay alive (Supplementary Box 1).

The current state of innovation for the treatment of kidney failure is appalling; devices have remained largely unchanged over the past few decades. This lack of innovation does not stem from a lack of demand. The global burden of chronic kidney disease (CKD) is enormous with tremendous societal and economic costs. Indeed, CKD has even been described as "the most neglected chronic disease"[2]. It is time to move past the status quo[3]. Dialysis technology has not followed the path of Moore's Law of rapid technological development[4] and we conclude that necessary developments to facilitate improvement in health care, such as miniaturization and optimal performance, have bypassed the world of kidney patients. What developers have seemingly failed to grasp is that most dialysors want, above all, a treatment that allows them to feel good and continue with their daily activities. Instead, most dialysis machines, either currently under development or recently arrived in the marketplace, may provide somewhat improved performance, but they are not user friendly nor do they markedly improve QoL over older models. Current devices often require extensive training in order to use them, complex water systems, consumables that overwhelm the average household and they cannot be easily transported (if they can be transported at all). Although performance and safety are important, few dialysors want to be tied to a machine controlled by others, or on a rigid schedule. Nor do they want a machine that is unwieldy, complicated and restrictive. In short, although research may have improved the specifications (that is, the clearance of solutes) of dialysers, these improvements have not been made with the needs and desires of dialysors in mind. Medical goals do not necessarily coincide with consumer preferences.

We consider the impact of such oversight by describing the experience of hypothetical personas. Personas are used as a tool to help developers imagine the user's challenges in daily life, their interests, characteristics, social environment, traits, age, job, preferences, likes and dislikes.

Our first persona is Mrs N. She loves to travel and refuses to be a passive dialysor. She lives alone and values her independence above everything else in her life. She has maintained excellent residual kidney function for the past 7 years, and because of this, she needs the ability to adjust her treatment daily to compensate for sporadic kidney function. An improvement over current options would be a smaller dialysis device that can analyse the amount and quality of dialysis, based on her residual kidney function. For example, because her kidneys are working, albeit not at 100%, a treatment may remove too much phosphorus or potassium, leaving her depleted. She needs a treatment that can fine-tune her blood purification and ultrafiltration. Additionally, she is energetic and travels extensively so she wants a device that maintains her QoL, can be adjusted at each treatment to compensate for existing function, and can be used without direct clinician supervision, all on her own schedule.

Now imagine Mr H. He has required specialized health care from the day he was born. Dialysis for him

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is only one of many obstacles to overcome and is not even the most influential on his QoL. Despite his diverse health needs, he has no trouble using a dialysis machine alone and has found independence from dialysis clinic schedules. He also needs a home dialysis device. His primary concern is the effectiveness of his dialysis, with the ability to do longer hours on dialysis to maintain his health. However, he also prefers a portable device since he works and travels extensively. His motorized wheelchair is perfect for storing dialysis equipment.

Mr W. is also a dialysor who was diagnosed with kidney failure at the age of 48. As a result of continuous fatigue, both mental and physical, he lost his job and his career, but not his spirit. He rigorously safeguards his independence and ability to care for his family. His goal is not to be a patient, but also not to bring his treatment home. He initially attended a nearby dialysis clinic for 12 hours a week, and ultimately — after 10 months on dialysis — received a transplant from a family member. He can't help but wonder what device he will use if or when his transplanted kidney fails. The most annoying part of centre dialysis was the strict schedule. He dialysed during 'home rush hours' and therefore missed socializing with his family while they enjoyed dinner and talked about their experiences of the day. Next time he would prefer a flexible schedule that allows him 'on demand' or 'drive through' dialysis, although preferably not at home. He prefers a social context like a community or shopping centre, with remote monitoring, click-on blood access, a comfortable chair, high blood purification and variation in the length and frequency of dialysis as he pleases independent of hospital restrictions and high-care specialist attention. To meet his demands a technology and health service provider is needed that enables this flexibility in time and place and that supports his quest to prolong independence on dialysis.

For each of these personas to live their best lives they must have the opportunity to identify the best treatment option for them and use a device that meets their individual needs and goals. For personas such as those we have described, the wait for innovation is long overdue. From manufacturers to dialysis providers, the field has been guided by complacency when it comes to improving QoL for dialysors, who are 'locked in' and can only escape by getting a transplant or dying. Fortunately, we are now beginning to see a movement towards innovation in kidney replacement therapy (KRT) that aims to improve lives. While we applaud that KRT innovation is finally emerging, when comparing the predicted time for these innovations to reach the market with the expected life span of a dialysor, our elation might be reserved for future generations.

We have a clear dream. We envision a dialysor in need of KRT walking into a full-service clinic, examining an array of options, devices and treatments, and, with the guidance of a knowledgeable and caring clinician, opting for the treatment and device that fits their personal lifestyle and goals. We appeal to KRT developers to obtain a thorough understanding of the values of dialysors by engaging with us from day one, in order to devise individualized solutions, and not one-size-fits-all modalities. We look forward to working with KRT innovators and stand ready to discuss what dialysors want, need and demand. The status quo is no longer acceptable. Help us to live a meaningful life; a life in which we dialyse to live and do not live to dialyse.

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Competing interests
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