

INEQUITIES IN KIDNEY HEALTH AND KIDNEY CARE

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43 **Abstract (200words)**

44 Health inequity refers to unnecessary and unfair differences in the capacity to
45 achieve optimal health and appropriate accessibility of care. Kidney diseases
46 [including acute kidney injury (AKI) and chronic kidney disease (CKD)] have
47 strong associations with inequity. This is largely due to the intrinsic risks of
48 kidney diseases, the heavy burden of comorbidities and the high cost of
49 therapies, e.g. for dialysis on which survival for many may depend. However,
50 inequities occur across the entire clinical course of kidney diseases. This review
51 offers a comprehensive overview of the array of inequities in kidney health and
52 kidney care, including inequities between countries, regions and social classes,
53 inequities in healthcare, inequities specific to therapeutic modalities, and health-
54 economic and ethical implications. This review also proposes solutions, which
55 may inspire nephrology professionals to recognize and mitigate inequities. In
56 addition to the main text that summarizes the relevant elements, and interested
57 readers are referred to the comprehensive tables (including case stories) and
58 references, which review some facets more deeply. It is the responsibility of all
59 implicated to call attention to inherent risks of inequity in their immediate and
60 broader environments, and to pursue the best possible solutions together with
61 their communities.

62

63 **Introduction (7915 words)**

64 Health inequality refers to differences in health or health resources between
65 persons, populations or nations such as those caused by age or genetic
66 predisposition¹. Inequities in healthcare are unfair, avoidable and remediable
67 differences between groups, based on socioeconomic, demographic or
68 geographic factors². The distinction between inequities and inequalities is not
69 always clear. Importantly, underlying inequalities frequently contribute to
70 inequities, e.g. when genetic predisposition, age or sex intersect with
71 race/ethnicity, socio-economic status, possibilities to adhere to healthy lifestyle
72 or level of education

73 In this manuscript we review different aspects of inequity which impact kidney
74 health and kidney care across the globe. For all the discussed elements a
75 number of potential solutions are reviewed at the end. The aim here is to offer
76 practical guidance to all those involved on how to avoid inequities, as these are
77 among the most concerning social injustices in modern clinical nephrology.
78 Throughout this manuscript, inequalities will sporadically be referred to if they
79 impact inequities.

80

81

82

83 Health inequities affect the capacity to achieve optimal health, which also
84 includes appropriate accessibility of care⁴. This capacity is far from equally
85 distributed globally, especially across regions and social classes⁵⁻⁸. The
86 awareness of health inequities has not translated into sufficient corrective and
87 collective action, because health inequities are multifactorial and multisectoral.
88 They arise from differences not only in medical care but also from differences
89 in global policy, sociology, ecology, geography, ethics, economics, psychology,

90 culture, religion and tradition (Table 1) . A further barrier is the fatalistic view
91 that the problem is too large, too broad, or too complex⁹. Inequities evolve
92 over the life course, such that disadvantaged fetal or childhood development
93 may predispose to compromised health throughout life^{10,11}. An avoidable lack
94 of screening and preventive care may also lead to late presentation of disease
95 and seriously jeopardize health outcomes¹². Kidney diseases do not escape
96 these rules, but rather epitomize them¹³.

97 Appreciation of the importance of kidney diseases by the medical community,
98 policy makers, and the public has lagged behind that of other common
99 conditions for multiple reasons^{14,15}. First, the rapid growth of dialysis and
100 transplantation since 1960 has focused on the needs of patients requiring these
101 expensive therapies diverting attention from prevention that is more scalable
102 and applicable everywhere^{15,16}. Second, the lack of consistent definitions of
103 kidney diseases until the 2000s, and of reliable epidemiologic data in some
104 regions, has hidden the full extent of the problem, limiting the development of
105 appropriate interventions^{17,18}. Third, the lack of awareness among primary care
106 providers, together with deficiencies in health information systems, have also
107 hampered prevention, detection and early treatment¹⁹⁻²¹.

108
109 Based on the mounting evidence regarding population prevalence and poor
110 outcomes²²⁻²⁴, kidney diseases should be considered a public health priority,
111 but thus far have not been prioritized on the global non-communicable disease
112 (NCD) agenda²⁵. This has resulted in the most fundamental inequity that affects
113 all kidney patients without distinction: insufficient investment in screening,
114 prevention, research, and innovation compared to other common NCDs, which
115 themselves remain chronically underfunded ²⁶. Chronic kidney disease (CKD),

116 despite affecting 10-15% of society globally^{17,26}, is not a health research focus
117 for the European Union (EU)²⁷. Neither does CKD figure among the 56 health
118 topics considered relevant by World Health Organization (WHO) Europe²⁸. In
119 the 2022 EU Healthier Together Initiative, four disease-specific NCD strands are
120 targeted, excluding CKD^{25,29}. This lack of awareness among policy makers is
121 compounded by the ignorance of the kidney's functions and its pathologies.
122 Most individuals do not know what the kidneys do, let alone how to care for
123 them³⁰. At best, policy makers see kidney diseases as a co-morbidity of
124 cardiovascular disease (CVD) or diabetes, which postpones diagnosis for many,
125 and leaves others entirely behind³¹.

126 This manuscript is coordinated by European Kidney Health Alliance (EKHA), a
127 non-governmental organization advocating for kidney health at European
128 Union (EU) level and beyond³. This article collates in a global context
129 perspectives from diverse inequity experts, representing various continents,
130 age groups and backgrounds, including kidney patients. It seeks to reposition
131 the need for equity in kidney health and care as a global priority and offers a
132 basis for further exploration for all involved stakeholders.

133

134 **Inequities across countries/regions**

135 ***Epidemiologic distribution***

136 The Global Burden of Disease (GBD) study attributed more than 3 million
137 deaths in 2019 to kidney dysfunction³². Most CKD deaths occurred in India and
138 China¹⁷. In Latin-America, the Middle-East and North- Africa, CKD falls within
139 the top 5 most common causes of death³³. Globally millions of deaths probably
140 result each year from the lack of accessibility of kidney replacement therapy
141 (KRT),³⁴ and from acute kidney injury (AKI)³⁵, and those remain largely
142 uncounted in lower-resource countries.^{36,37}. Inequities across regions are also

143 further enhanced by environmental factors, such as increasing number of heat
144 waves and droughts, pollution, water contamination and increased distribution
145 of tropical diseases³⁸⁻⁴⁰, **which do not affect all countries and people equally.**

146 Applying the definition of CKD^{41,42}, a systematic analysis of worldwide
147 population-based data estimated the age-adjusted global prevalence of all-
148 stage CKD in 2010 at 10.4% in men and 11.8% in women more than 20-years-
149 old⁴³. Subsequent estimates yielded relatively consistent results, although with
150 regional variations from 6 to 20%^{44,45}. CKD prevalence increases with age and
151 appears higher in lower-resource settings⁴³.

152 The GBD study showed a 15-fold global variation between countries of CKD
153 burden [specified as age-standardized CKD-linked disability-adjusted life-years
154 (DALYs)] , highlighting potential inequities in both accessibility of diagnostic
155 possibilities and risk factor distribution³³. It is even more difficult to estimate
156 the contribution of AKI⁴⁶. A pooled incidence of hospital-acquired AKI was
157 reported as 34 and 22% among hospitalized children and adults⁴⁷ respectively
158 but with pronounced regional variations, raising questions of plausibility and
159 generalizability^{37,48}.

160 ***Risk distribution***

161 The risk of kidney diseases is associated with country income level⁵¹ with
162 people developing CKD and dying from CKD at a younger age in lower-resource
163 settings compared to high income countries (HICs)^{52,53}. The association
164 between age-adjusted CKD prevalence and KRT incidence is positive in HICs,
165 but explains only 40% of the variance⁵⁴. This association is negative in Central
166 and Eastern-Europe, and null elsewhere⁵⁴, which highlights differences in
167 incident KRT that cannot be explained by CKD prevalence, even in HICs where
168 accessibility of KRT is generally unlimited.

169 In Central and Eastern-European countries, gross domestic product (GDP) is
170 highly heterogeneous, a legacy of the Cold War and the Iron Curtain. Many CKD
171 risk factors are more prevalent than in Western-Europe, especially in countries
172 with lower GDPs, likely contributing to a higher regional incidence of CKD⁵⁵.
173 Other disparities in this region related to kidney care include variable
174 availability of specific KRT modalities and expensive medication, relative
175 number of nephrologists, and tracking of the prevalence of CKD⁵⁶⁻⁶¹.

176 Within HICs, in part due to the legacy of colonialism and slavery, stark
177 disparities across racial, geographic and socio-economic strata exist^{13,68,69}.
178 Moreover, patients with socio-economically deprived backgrounds develop
179 kidney impairment 5 years earlier in their life course and suffer from more
180 comorbidities¹³.

181 ***Global distribution of KRT***

182 Registries of KRT were introduced in the 1960s-1970s in Europe and the US and
183 have expanded to most HICs but are less available elsewhere. Across countries
184 reporting to the United States Renal Data System (USRDS), the incidence of KRT
185 ranged from 16 per million people (pmp) in South-Africa (2018) to 570 pmp in
186 Jalisco, Mexico (2019), and the prevalence of treated kidney failure varied over
187 30-fold across countries (2019), which reflects disparities in accessibility of KRT
188 rather than in true incidence^{34,70}. KRT incidence is rising in most lower-income
189 settings⁷⁰, however predominantly in the private sector (e.g. South-Africa and
190 India), leaving many without possibilities to be treated or exposed to significant
191 catastrophic health expenditures (CHE – out-of-pocket healthcare payments
192 which impoverish a household)⁷¹⁻⁷⁴.

193 To permit equitable accesibility of care, provision of sustainable KRT requires
194 robust health systems and financing. A higher country Gini coefficient (indicating

195 greater within-country inequity) directly correlates with greater prevalence of
196 stage 5 CKD remaining untreated by KRT^{75,76}. In areas with greater equity, there
197 is more accessibility of KRT^{75,76}. In lower-resource settings a small fraction of
198 those requiring KRT receive it long-term³⁴. For example, most African countries
199 have healthcare systems with poor/no health insurance coverage, leaving the
200 vast majority of people with kidney failure unable to obtain KRT^{77,78}. Elsewhere,
201 macro-economic factors and services for kidney care are also more strongly
202 related to KRT incidence than demographics or general health⁷⁹. In Eastern-
203 Europe, variability in incidence and prevalence of KRT results in multiple-fold
204 differences in dialysis and transplantation uptake between countries, as well as
205 less home dialysis and conservative care compared with Western-Europe^{60,61}.
206 In brief, country location and wealth distribution substantially impact kidney
207 health and accessibility of kidney care across the world. Inequities exist even
208 within a relatively homogeneous region like Europe.

209

210 **Factors associated with inequitable health care**

211 ***Diagnosis and treatment***

212 A complex interplay between structural risk factors for AKI and CKD and rapid
213 progression of disease due to limited accessibility of primary care limits
214 possibilities to mitigate these risks⁶⁴⁻⁶⁷. Diagnosis of CKD and AKI requires blood
215 and urine tests, which are not routinely available everywhere⁴⁹. In 2017, two-
216 thirds of low income countries (LICs) were unable to measure serum creatinine
217 in primary care, and none provided quantitative albumin or protein urinalysis⁴⁹.
218 Availability of medicines required for kidney care is often limited in lower-
219 resource settings, but even within HICs inequities may arise based on coverage
220 differences between patients and insurers^{62,63}. Similarly the nephrology
221 workforce is unequally distributed across the globe: the number of nephrologists

222 per million population (pmp) ranges from 31 in Western Europe to 1 or less in
223 Africa⁵⁰. Thus, diagnosis, availability of treatment and tracking of the burden of
224 kidney diseases is highly inequitable globally.

225

226 ***Inequities conflicting with living well***

227 Good healthcare is a key component to living well⁸⁰. To achieve this equitably,
228 health providers must meet people at their different levels of disadvantage
229 (Figure 1) and support them to face personal challenges and priorities. Patient
230 priorities may, but do not always align with those of healthcare providers^{81,82}.
231 Kidney diseases exacerbate vulnerabilities, including health, social, and
232 financial hardship^{83,84}. Of note, most often, vulnerability is not an intrinsic
233 condition but due to system failures. Health decision-making is influenced by
234 wider contexts, including one's own understanding, finances, social support,
235 geography, culture, beliefs, and freedoms. Healthcare providers must
236 appreciate these wider determinants, both to consider patients holistically, and
237 to avoid blaming individuals for risks and outcomes caused by external
238 factors.¹⁰

239 A complex relationship exists between the unique challenges posed by kidney
240 diseases, broader individual and environmental contexts, and healthcare and
241 societal factors which promote or undermine health. Accessibility of kidney
242 care is complex, with many intersecting and compounding challenges, as
243 discussed elsewhere^{5,10,13,30,65,80,84-120} and summarized in Table 1. Many of
244 these factors are global problems. The Sustainable Development Report
245 2022¹²¹ highlights major challenges and insufficient data regarding inequity
246 indicators especially across lower-resource settings¹²¹, which exacerbate the
247 inherent "invisibility" of kidney diseases. The implications for specific groups

248 are expanded on below, with accompanying scenarios and quotes in box 1,
249 partly based on published observations^{115,122-129}.

250 ***Socio- economics***

251 Social and economic position (SEP) is consistently associated with health risks
252 and accessibility of care, across countries, and across lifecourse¹⁰⁴. People of all
253 ages are at risk of kidney diseases, which constrains opportunities for well-
254 being, education, employment, and attaining life-goals. The relationship
255 between SEP and kidney health is bidirectional, with increased risk of falling
256 into poverty as kidney diseases progress¹³⁰.

257 Particular challenges exist in lower-resource settings^{78,131}. In most of Africa for
258 example, many people with CKD are of working age. They often present late,
259 with kidney failure resulting in poor outcomes^{132,133}. This is driven in part by low
260 health literacy, and a preference for potentially nephrotoxic traditional
261 remedies and faith-based healers^{134,135}, but also by a lack of infrastructure and
262 adequate workforce to enable early detection, prevention, and community
263 surveillance^{50,101}. If lower-resource countries provide coverage for dialysis, it
264 typically is limited to only two sessions per week¹⁰⁰. Others exclude kidney
265 failure from coverage schemes⁹⁹, necessitating prohibitive out-of-pocket costs
266 if dialysis or transplantation are available^{77 85,136}. Thus, many people in lower-
267 resource settings are unable to sustain treatment for kidney failure, and
268 struggle with the economic burden on their family, creating difficult moral
269 trade-offs in the allocation of household resources^{137,138}.

270 Even in HICs with universal health coverage (UHC), deprived individuals
271 experience less preventative care, more rapid progression of kidney diseases, a
272 greater need to rely on emergency services, and stigmatisation¹³. Poor
273 neighborhoods are associated with poor education and employment
274 opportunities. Residents have less ability to obtain and navigate preventative

275 healthcare, limited availability of recreation services or exercise facilities, and
276 greater exposure to environmental toxins, overcrowding, and food
277 insecurity^{65,88,97}. These represent barriers to a healthy lifestyle, good nutrition,
278 and ability to cope with stressors^{5,95}.

279 Those who are uninsured, homeless or undocumented migrants also suffer
280 limited accessibility of preventive care. One in three undocumented migrants
281 with kidney failure in the U.S. receive only emergency dialysis, with grave
282 prognostic implications¹¹⁷. Irrespective of country, refugees experience similar
283 difficulties to the disadvantaged in navigating healthcare and maintaining a
284 healthy lifestyle¹¹⁸. During humanitarian crises, this includes reduced
285 accessibility of life-saving treatments such as dialysis and
286 immunosuppression¹³⁹.

287

288 ***Discrimination***

289 Systemic racism continues to drive persistent inequities in kidney health,
290 whereby race should be understood as a social construct rather than a
291 biological indicator and disparities in health and outcomes as the
292 consequences¹⁴⁰.

293 Globally, people of Black race and minoritized backgrounds are more likely to
294 have kidney diseases, and progress to kidney failure^{141,142}. In the U.S., Black
295 patients with kidney failure are less likely to be evaluated and referred for
296 transplantation¹⁴³⁻¹⁴⁵, are listed later^{144,146-148}, wait longer for
297 transplantation¹⁴⁹⁻¹⁵², and receive poorer overall care¹⁵³⁻¹⁵⁶ than White patients.

298 Discrimination against minority groups, including race and sexual and gender
299 minorities (SGM), occurs at the intersection with wider health determinants
300 and causes differences in how healthcare is used and experienced^{65,94}. Due to
301 systemic inequities and policies (e.g. redlining), patients from minoritized

302 backgrounds are overrepresented in poorer neighborhoods^{65,157-159}. Inequitable
303 structural investment in local community environments perpetuates these
304 disadvantages into future generations^{160,161}. In addition, the direct experience
305 of discrimination can cause long-term stress and negative coping, leading to
306 overeating, alcohol or other drug abuse, smoking, poorer mental health, and
307 less trust in sources of support^{65,162,163}. Importantly such discrimination not only
308 impacts individuals, but markedly increases total health care costs, which
309 further weakens health systems. In 2018, the economic burden of racial and
310 ethnic health inequities and education-related health inequities in the US,
311 (measured as excess medical care expenditures, lost productivity, and the
312 value of excess premature death combined), were estimated at over \$420 billion
313 and over \$940 billion respectively¹⁶⁴. Most of the excess costs was contributed
314 by the Black population and those without a high school education.

315 Patients from minoritized groups may distrust professionals if discrimination is
316 witnessed, with a detrimental impact on health-related decision-making⁹⁴. A
317 patient experiencing discrimination may leave and never return. Effort should
318 be made to provide education and support that is culturally and socially
319 sensitive, but clinician-patient relationships vary across minorities and cultural
320 groups¹⁴⁹, with clinicians investing unconsciously more in people with whom
321 they have greater affinity. Without awareness of these biases, nephrologists
322 may be prone to spend less time with those from minorities discussing
323 treatment options such as transplantation, or new therapeutic options such as
324 sodium-glucose transporter (SGLT)-2 inhibitors⁹³ (if reimbursed).

325 ***Algorithms and guidelines***

326 Algorithms are used to assess, monitor, predict, and support clinical decisions.
327 Such tools risk introducing biases, if based only on selected (privileged) groups
328 or only approximative parameters with a magnitude of error that depends on

329 person characteristics^{165,166} (label bias). These biases carry the risk of hidden
330 discrimination¹⁶⁷. For example, healthcare policies are often based on analytical
331 algorithms of health event administrative coding. Such codes usually represent
332 expenditure on care, rather than illness severity or need. This can lead to
333 structural discrimination, because people of Non-White race experience
334 reduced accessibility of care compared to their White counterparts with similar
335 illness severity^{166 168,169}. Such analyses invisibly perpetuate unfair
336 recommendations hidden behind algorithms that assume that Non-White
337 people need less care.

338 Kidney care is especially dependent on measurement. However, availability of
339 possibilities and capacity to monitor kidney health is uneven between and
340 within social groups, regions, and countries⁹⁸. This compromises
341 interpretability, and the visibility of underrepresented groups. The inadequacy
342 of explicit inclusion of a Black race coefficient within kidney function (eGFR)
343 estimating equations in previous formulae (i.e. MDRD and CKD-EPI equations)
344 was especially important because GFR estimates are cascaded as presumed
345 “results” into numerous kidney and non-kidney tools and guidelines beyond
346 the reach of the kidney specialist¹⁷⁰. This over-medicalization and biological
347 misinterpretation of race may inadvertently have led to unfair barriers to
348 referral, guideline-based care and provision of support^{93,140}. Although not
349 supported universally¹⁷¹, leading nephrology societies now recommend using
350 eGFR equations without the Black race coefficient¹⁷²⁻¹⁷⁴. Coefficients for age
351 and sex remain, and similarly may require cautious interpretation^{111-113,175}.

352 ***Health illiteracy***

353 Health literacy is “the degree to which individuals have the capacity to obtain,
354 process and understand basic health information” to inform their health
355 decisions¹⁷⁶. [Health illiteracy is to a considerable extent attributable to failures](#)

356 in the education system, as well as failures in information systems. This may be
357 exacerbated by insufficient health, social and cultural literacy of care providers,
358 as kidney diseases require not only medical understanding, but also
359 understanding how to support patients with living with an increasingly complex
360 chronic disease. Low health literacy is linked to increased mortality,
361 hospitalization, medication errors and poor management of chronic
362 diseases^{177,178}. Efforts to improve health literacy in patients with CKD have
363 focused on the individual, with little attention for the health system
364 environment or the appropriateness of information¹⁷⁹. For patients and
365 families, their ability to understand CKD and treatments is variable and
366 impacted by many factors including the skills and patience of the clinician
367 providing education, patient health, presence of a caregiver, time of day of
368 appointment, and current and anticipated future treatment modality. These
369 factors cannot be changed by those needing care¹⁸⁰, and may result in
370 decreased healthcare accessibility and utilization of services.

371 ***Geography and accessibility***

372 People from rural/remote communities often commence their journey with
373 CKD in a disadvantaged position, especially regarding socioeconomic status,
374 educational attainment, and opportunities to benefit from primary
375 prevention¹⁸¹. Regarding KRT, many barriers, including late referral to
376 nephrologists, necessary relocation to obtain treatment, transportation
377 barriers, and financial hardship¹²⁵ contribute to an increased risk of mortality,
378 morbidity and hospitalization among those residing in more remote
379 locations¹⁸¹. For in-center hemodialysis, longer travel time to treatment is
380 associated with higher mortality, and decreased quality of life¹⁸². Centralisation
381 of most transplantation units to major cities, adds an extra layer of difficulty for

382 patients from remote areas as possibilities to complete transplant work-up and
383 specialist care may not be available locally..

384 **Inequities among therapeutic options**

385 Inequities in kidney care pervade across individual conditions (cause of kidney
386 diseases, lifestyle, the timing of preventive and therapeutic interventions and
387 disparate accessibility of different KRT modalities), wider communities,
388 healthcare systems (e.g. private *versus* public healthcare sectors) and countries
389 (Figure 1). Combined, these have major impacts on patient outcomes.

390 ***Acute kidney injury***

391 Although AKI is potentially preventable and reversible, accessibility of
392 appropriate diagnosis and care is inequitable. In HICs, AKI is common among
393 multimorbid individuals who often need prolonged dialysis in intensive care
394 with little chance of recovery.³⁵ In many lower-resource countries,
395 awareness/confidence to manage AKI is low among healthcare workers¹⁸³.

396 Although AKI is common in children and young adults, often as a single
397 condition³⁵, even basic intravenous fluids for rehydration may be lacking¹⁸⁴, let
398 alone accessibility and affordability of dialysis^{37,184,185}

399 ***Chronic kidney disease***

400 In the early stages of CKD, only people with specific kidney conditions such as
401 polycystic kidney disease or glomerulonephritis typically receive care in
402 specialist nephrology clinics. For many people with early stage CKD due to
403 more common causes (e.g. related to hypertension or diabetes), care is
404 coordinated through primary care or non-nephrology specialty units and is
405 subject to inequities in surveillance, diagnosis and quality of care¹³.

406 Multiple barriers in CKD care, including lack of accessibility of essential
407 diagnostics and drugs to slow progression of kidney diseases, and of knowledge
408 among healthcare professionals, contribute to inequities (Table 1).

409 Accessibility of appropriate medication depends on availability, reimbursement
410 and/or ability to self-pay. A survey of resource-limited countries reported that
411 approximately 75% of patients had to pay themselves for diagnosis and
412 treatment of glomerulonephritis, while the lack of kidney biopsy and
413 subsequent interpretation often led to inappropriate immunosuppression¹⁸⁶.

414 Quality of care is therefore an additional concern even if some resources may
415 be available/accessible, highlighting the need for capacity building among the
416 nephrology workforce¹⁶.

417 ***Advanced kidney disease: dialysis and conservative care***

418 Accessibility and quality of dialysis, availability of home dialysis and focus on
419 patient well-being varies between and within countries and between individual
420 nephrologists as outlined above (Table 1). Most variations in dialysis
421 accessibility and availability relate to economic factors – cost, health coverage,
422 distribution of dialysis centers, number of nephrology professionals including
423 nurses, quality of patient education, support for vascular and peritoneal access
424 creation, and management of comorbidities⁵⁸.

425 Hemodialysis is available (although not necessarily accessible to all) in most
426 countries and tends to be the default form of KRT¹⁶. In-center hemodialysis is
427 time- and resource-intensive and is highly centralized. PD is more scalable and
428 flexible, less hospital dependent, can be done anywhere with rudimentary
429 infrastructure, is preferred by many patients¹⁸⁷, and is especially suitable for
430 children¹⁸⁸. Counterintuitively, however, PD costs more than hemodialysis in
431 many lower resource settings¹⁸⁹⁻¹⁹¹. Efforts to make PD supplies less expensive

432 and to increase awareness of the advantages and impact of PD are key to
433 increasing its global availability¹⁹². In terms of quality, cost is again a major
434 source of inequity where reduced hemodialysis sessions or PD exchanges are
435 often used as compromises to cut costs, but unavoidably reduce dialysis
436 quality¹³⁷.

437 Older or frail individuals, and those with learning difficulties are usually
438 committed to in-center hemodialysis unless assistance is provided at home.
439 Even in high-income Western European countries, healthcare-funded assistants
440 for dialysis were available in only 5 of 13 surveyed countries ¹⁹³.

441 Similar arguments hold for inequity of availability of conservative care, with less
442 than half of countries providing support from multi-professional teams, or
443 enabling shared decision making needed to embark on conservative care⁶¹.

444 Even in countries which purportedly support conservative care, such as France,
445 this option is often not discussed as an alternative to dialysis¹⁹⁴.

446 ***Advanced kidney disease: transplantation***

447 Many patients in need of KRT prefer kidney transplantation over dialysis, due
448 to better survival and quality of life^{195,196}. Globally, the WHO estimates that
449 only 10% of the demand for kidney transplantation is met¹⁹⁷. The donor organ
450 shortage is worsening as more people worldwide require KRT.

451 Transplantation is available in 74% of countries (publicly funded in 53%) with
452 waiting lists in only 62%¹⁹⁸. Pre-emptive transplantation is only recorded in 10%
453 of countries¹⁹⁸. Higher-resource settings have higher rates of deceased and
454 living donation than other countries^{199,200}, along with transplant registries
455 enabling greater transparency. The availability of kidney transplantation
456 through UHC in higher-resource settings enables people from lower socio-

457 economic classes to obtain transplantation. Nevertheless, even in higher-
458 resource settings inequities remain pervasive¹⁴³⁻¹⁴⁵ and there are huge
459 disparities among countries in transplantation uptake²⁰¹. In LICs accessibility is
460 largely restricted to those who can pay.

461 Racial disparities are well documented particularly in minority groups, migrants
462 and Indigenous and First Nations People, who despite a higher burden of
463 kidney failure, are less likely to receive a transplant²⁰². Females are more likely
464 to be living donors than men²⁰³, an observation likely impacted by multiple
465 factors, including the slower progression of kidney diseases among women²⁰⁴

466 In 2007, approximately 10% of transplantations worldwide resulted from organ
467 trafficking after graft purchase from poor and individuals rendered vulnerable
468 by their life circumstances^{205,206}. The Declaration of Istanbul provides guidance
469 for organ donation and transplantation worldwide, to promote equitable
470 sharing of the limited transplant resources by those in need, and prevent harm
471 through exploitation²⁰⁷. Nevertheless, equitable allocation of graft organs
472 remains complex and changing viewpoints might necessitate revision of rules
473 when appropriate²⁰⁶.

474 ***Pediatric care***

475 Accessibility of specialized pediatric nephrology is very limited in LICs, but
476 regional variations occur everywhere²⁰⁸. Data on the epidemiology and
477 outcomes of pediatric kidney diseases are limited to registries in HICs and small
478 studies from lower-resource settings, probably underestimating true disparities
479 in care.

480 The 0 by 25 initiative highlighted the disparities in early diagnosis and
481 accessibility of dialysis for children with AKI in lower-resource settings³⁷.

482 Community-acquired, preventable AKI due to infections like dengue,
483 dehydration or nephrotoxic drugs is more common in low-resource settings
484 and exacerbated by poverty and malnutrition^{35,37,185}. Mortality in children with
485 AKI is >50 times higher in lower-resource settings than in HICs, especially when
486 dialysis unaccessible²⁰⁹. Non-recovery of kidney function is 3 times more
487 frequent²⁰⁹.

488 Pediatric CKD is often diagnosed late, especially in countries with poor
489 antenatal and primary healthcare, and in rural/remote areas²¹⁰. Accessibility of
490 pediatric dialysis and subsequent outcomes correlate with national wealth,
491 even in Europe²¹¹. Mortality risk is also greater with late diagnosis requiring
492 ‘urgent start’ dialysis²¹¹ and is very high if dialysis cannot be provided or
493 continued⁷⁸.

494 The barriers to pediatric kidney transplantation in lower-resource settings
495 include unavailability of pediatric transplantation expertise, catastrophic out-
496 of-pocket expenditure and the absence of deceased donor organ sharing
497 networks^{212,213}.

498 **Inequities resulting from health economic factors**

499 ***Differences driven by country wealth***

500 Kidney care comes at a high societal and personal cost²⁶. Global reimbursement
501 for maintenance dialysis (excluding out-of-pocket payments) amounts to
502 around 57 billion US dollars, 80% of which is spent in HICs, 17% in MICs, and
503 only 3% in LICs¹⁹⁰. Dialysis, if universally provided, is funded by varying state
504 financing schemes²¹⁴. In HICs, >2% of national healthcare budgets is directed to
505 KRT, for only 0.15% of the population¹⁵. Global costs for AKI are unknown, but

506 in the US, in 2013, AKI reportedly caused \$9 billion excess annual hospital
507 costs³⁵.

508 In higher income settings, expenses for associated non-kidney care further
509 increase the financial burden^{15,215}. Productivity loss (unemployment, sick leave,
510 premature retirement, death) impacts patients, their next of kin and society
511 overall²¹⁶. Individuals in vulnerable positions (temporary, contractual, physical
512 workers, unemployed) are at higher risk of productivity loss and
513 impoverishment when struck by CKD⁸⁴.

514 In low-resource settings where the direct and indirect costs of kidney care and
515 KRT often must be paid out-of-pocket, the risk of impoverishment is even
516 higher. A systematic review comparing out-of-pocket payments for several
517 diseases revealed kidney diseases as the leading cause of catastrophic health
518 expenditure (CHE), across lower-resource settings, thus exacerbating inequities
519 between countries, individuals and groups.

520 Both higher and lower-income countries are therefore at risk of inequities but
521 the problems are not necessarily the same (table 2). Accessibility of kidney care
522 without experiencing financial hardship is highly inequitable across the globe,
523 with the most severe consequences (death and/or CHE) especially affecting the
524 poorest^{78,138,185,217-219}.

525 ***Kidney replacement therapies***

526 Dialysis is available in almost all countries¹⁶, but the clinical, financial and
527 ethical dilemmas associated with its (un)accessibility cannot be ignored. Cost-
528 effectiveness assessments are used to rank healthcare interventions aiming at
529 maximal population health gains, often expressed in Quality Adjusted Life Years
530 (QALYs), for a given cost²²⁰. A systematic review of cost-effectiveness analyses
531 concluded that the ability to identify the mix of dialysis modalities that provides

532 best outcomes for patients and health budgets is uncertain, particularly given
533 the frequent inconsistencies between published studies and non-consideration
534 of societal perspectives²²¹. In addition, cost-effectiveness as sole criterion for
535 decision making has been criticized, since it overlooks crucial factors such as
536 budgetary impact, financial risk protection for individuals, and equity in
537 distribution of interventions^{222,223}.

538 In many higher income countries, the budgetary impact of dialysis has been
539 accepted, as the choice to save lives has prevailed over costs²¹⁷. This has led to
540 exponential growth in patient numbers and a dialysis industry generating
541 considerable profit in a sector with few competitors. Rising patient numbers,
542 especially in emerging countries, will further inflate costs²²⁴. Health system and
543 societal costs for PD, home hemodialysis and transplantation are lower than for
544 in-center hemodialysis in many countries^{58,190,201,225-227}, but their uptake and/or
545 availability is inadequate and divergent^{190,228,229}. Additionally, health-economic
546 factors favoring one therapeutic alternative over another in HICs differ in
547 lower-resource settings, where labor is cheaper and imports more expensive²²⁵.

548
549 Especially in low-income settings, policy makers face the challenge of
550 simultaneously pursuing UHC, setting priorities across the whole health system
551 and progressively fulfilling the human right to health^{217,230}. It would be naive to
552 insist that KRT be funded immediately everywhere for all, as the opportunity
553 costs (money spent on KRT cannot be spent elsewhere) are high. For example,
554 if Kenya, Nigeria and Senegal would try to meet their estimated national
555 dialysis needs, this would require from 8 to close to 40% of government health
556 expenditure²³¹. Consequently, in lower-resource settings, KRT is currently
557 largely available only to those who can pay¹³⁷.

558 ***CKD not on kidney replacement therapies***

559 The costs of kidney care do not only impact those on KRT. The poor may not
560 even be able to afford simple care to prevent the evolution of early CKD to
561 kidney failure. This intensifies inequities because as disease progresses, higher
562 levels of care and personal expenditure are required¹³⁷.

563 The optimal solution to forestall CKD costs is to reduce disease risk and/or
564 progression, both intimately intertwined with inequities in many places^{15,232,233}.

565 However, in most countries investment in initiatives to promote prevention is
566 minimal, in spite of the high value for money compared to the financing of
567 treatment or cure^{12,15,190,234,235}. The value for money gained through prevention
568 of illness is not restricted to the health sector. A recent publication from the
569 WHO highlighted the important long-term return on investment of prevention
570 of NCDs. For example, investment of 1 dollar in lower-resource settings to
571 reduce population salt intake in 2018 would yield 13 dollars in return by 2030,
572 given the lower subsequent health expenditures and greater productivity
573 gained with healthier people²³⁶. Thus, there are also longer-term opportunity
574 costs, which apply especially to many lower-resource settings, where current
575 health budgets are disproportionately channeled to secondary and tertiary
576 care, necessitated by the poor investment into prevention^{190,225,237}.

577

578 ***Marketing of drugs***

579 A threat to reimbursement systems and costs is the marketing of therapies for
580 specific kidney diseases which are often only available at extremely high prices,
581 either because of patents, or the small market size if a condition mainly affects
582 children (e.g. cysteamine)^{238,239}. There is little transparency in the price setting
583 of such drugs (e.g. eculizumab)²⁴⁰, for which in addition evidence may be
584 low²⁴¹. They are also frequently used off-label for indications for which they are

585 not approved and not evidenced, or used in children and adolescents where
586 they have not been tested (e.g. tolvaptan)²⁴². Inflated costs and excessive
587 profits not corresponding to investment²⁴⁰ initiate and exacerbate inequities
588 among countries and regions²⁴³, and depend on whether countries have
589 orphan drug legislation and reimbursement schemes. Inequities in accessibility
590 of such medications have a negative impact on patient outcomes²⁴⁴, in low-
591 income but also in high-income settings, as incomplete or absent coverage may
592 necessitate out-of-pocket payments, that are not possible for all.

593 In summary, the current health-economic model supporting kidney care is
594 flawed. The focus on expensive and/or late stage therapies favors inequity,
595 both across countries and among individuals. Differences in cost of essential
596 therapies between countries, without clear transparency about the prices and
597 the reasons, further exacerbate global inequities²⁴⁵.

598

599 **The ethical context**

600 ***Inequitable accessibility: an ethical dilemma***

601 Clinicians are familiar with the 4 principles of biomedical ethics. The principles
602 of autonomy, beneficence (doing good) and non-maleficence (not doing harm)
603 are readily applicable at the bedside. The principle of justice, however, has
604 implications beyond the bedside and addresses issues of fairness and inequities
605 between individuals. In resource-constrained settings, physicians often realize
606 that autonomy, beneficence and non-maleficence conflict with justice, as an
607 individual patient's needs may be overridden by lack of available therapies,
608 poverty or the needs of others competing for the same treatment⁷⁸.

609 Inequities in nephrology constitute moral dilemmas because patient outcomes
610 are adversely affected by structural injustice and vulnerability, that increase
611 risk of kidney diseases and impact accessibility of care⁶⁸. Although inequity is

612 often thought to begin with a lack of accessibility of healthcare, patients with
613 kidney diseases encounter inequities that extend beyond the healthcare sector,
614 beginning with the conditions in which they are conceived, born, work and
615 live²³³. The social and structural determinants of health include factors like age,
616 gender, poverty and geographical location in the world and within a country.
617 These factors are inequitably distributed, resulting in vastly different outcomes
618 for patients with the same disease living under different circumstances - highly
619 resourced versus low resource settings, or people who are wealthy versus the
620 poor. These social determinants of health play a large role in pre-determining
621 who lives longer and who dies earlier²⁴⁶. Accessibility of kidney care is also
622 inequitably distributed at all levels – from screening, early diagnosis and
623 preventative care up to KRT or comprehensive conservative care for kidney
624 failure.

625 If inequity in healthcare is inherently 'unjust', an ethical dilemma arises for the
626 provider (the principle of justice is violated)⁷⁸. Inequities in kidney care occur in
627 all resource settings and at any stage of disease, but the impact is compounded
628 with worsening kidney function, as life-saving but expensive treatments
629 become necessary. Out-of-pocket costs exacerbate these inequities in low-
630 resource settings, where minorities, women, the poor, elderly and health
631 illiterate, as well as those living remotely, are disproportionately affected.

632 Examples of structural inequities in nephrology are presented as case studies in
633 **Table 3**, highlighting the ethical dilemmas encountered^{137,206,217,247-256}. Such
634 moral dilemmas are omnipresent: at the bedside, during shared decision-
635 making, in society, for national governments and at a global level (**Figure 2**).

636

637 ***Responsible stakeholders***

638 In his philosophical approach to health justice, Venkatapuram states that
639 health is not the absence of disease, but a positive ability to be and to do
640 things²⁵⁷. People have a moral entitlement to be as healthy as they can, and
641 patients need to be capable of leading productive and quality lives.
642 Expressing health as a human right is an important complement to advancing
643 health equity because it stresses that the responsibility for care delivery lies
644 with the state, which has an obligation to provide care to whatever extent
645 possible in an equitable manner²³⁰.
646 The global nephrology community also has an ethical imperative to address/call
647 attention to all the factors underlying inequity, including the social
648 determinants of health, as well as every level of accessibility of kidney care. It is
649 the ethical responsibility of all professionals to reduce inequities in kidney care
650 and improve patient outcomes and to advocate this objective²⁵⁸. Governments
651 must be held accountable to acknowledge this and to commit to the
652 progressive realization of the right to kidney care for all.

653

654 **Solutions**

655 As outlined above, inequities in opportunities to optimize kidney health and to
656 provide accessibility of all forms of kidney care are multiple across the globe.
657 The origin of health inequities can often be narrowed down to both social and
658 systemic injustices²⁵⁹, related to complex, multisectoral factors. Solutions
659 require leadership, responsibility, and political will. Improvement in
660 accessibility of health care may mitigate the immediate impact of social and
661 systemic injustices to an individual, but lasting progress can only be made
662 through seeking system solutions that prevent the underlying causes at a
663 population level. Accordingly, if medical communities are to make collective
664 progress towards dismantling inequities, the underlying causes must first be

665 acknowledged and understood before they can be solved. This in turn requires
666 collaboration on global, local and individual levels. Suggested actions to tackle
667 the global inequities in kidney health and kidney care per stakeholder group
668 are summarized in table 4 and outlined relative to policy/individual level in
669 what follows.

670

671 ***Global level***

672 *Recognize kidney diseases as an important public health problem*

673 Multiple factors have contributed to kidney diseases being relatively
674 overlooked as a public health concern, which include lack of data in many
675 places due to global inequities in accessibility of essential and reliable
676 diagnostics for kidney diseases and rudimentary health information systems
677 which do not track kidney diseases. The focus of global health agendas was
678 initially driven by funding and targets set for infectious diseases and maternal
679 and child health, and subsequently for cardiovascular, cancer, respiratory
680 diseases, diabetes and mental health, but not kidney diseases^{29,260}. If the
681 burden of kidney diseases is to be meaningfully impacted, advocacy and strong
682 leadership are required to acknowledge and reduce existing inequities in
683 disease risk and accessibility of care, to strengthen the provision of integrated
684 quality care for NCDs including kidney diseases, to generate robust health-
685 economic evidence on interventions and their impact to guide financing, to
686 improve data capture to identify areas that lag behind, and to track
687 achievement of all sustainable development goals (SDGs), as each SDG impacts
688 kidney health world-wide²³³.

689 Just as health inequities cut across countries, so also do potential solutions.

690 Over the short and medium term, harmonization among countries and classes
691 can be advanced by material, financial or in-kind external support, and by

692 promoting exchange of learning, innovations and best practices²⁶¹. Such
693 initiatives might be optimally managed by umbrella institutions, including
694 governments, supranational political structures (e.g. the European Union),
695 coordinating agencies (e.g. WHO), or non-governmental organizations (e.g.
696 Médecins sans Frontières, European Kidney Health Alliance), but may also
697 result from private initiatives (e.g. Gates Foundation) and professional societies
698 (e.g. International Society of Nephrology, European Renal Association). Over
699 the longer term, countries must be encouraged and supported to finance and
700 deliver sustainable and comprehensive local quality kidney care.

701

702 *Support affordable innovation to improve kidney care for all*

703 Transparency in investment and in development and production of novel
704 technologies and drugs, especially for orphan kidney diseases, is urgently
705 needed²⁴⁰. Structured stakeholder networks, like the virtual European
706 Reference Network on rare diseases of the European Commission, may help to
707 support high quality, sustainable and equitable therapies²⁶². Tiered pricing
708 mechanisms adapting the cost of technologies and material to the welfare of a
709 country in mutual agreement between rich and poor countries may improve
710 affordability²⁶³.

711 Innovation should not only focus on sophisticated technologies, but must also
712 include the development of new approaches to improve uptake of prevention
713 strategies, and accessibility and delivery of primary care for those currently left
714 behind. Implementation and operational research are needed to identify and
715 scale up effective and affordable strategies, including dialysis²⁶⁴. Governments,
716 learned societies, clinicians, researchers and patient organizations should work
717 hand in hand to foster innovation at all levels as a means to reduce global
718 inequities.

719 ***Country level***

720 *Prevention and early detection*

721 The best approach to reduce the burden and cost of NCDs, especially kidney
722 diseases, is prevention¹⁵. This universal tenet applies to all countries.

723 Unfortunately, only small proportions of healthcare budgets world-wide target
724 prevention^{15,58,190}. Timely and appropriate screening for kidney diseases occurs
725 rarely and is often not systematized or harmonized²⁶⁵.

726 Prevention is most efficient when risk or disease are identified early. This
727 requires identification of barriers, creating awareness and building trust,
728 especially among vulnerable populations, where the deficiencies in early
729 identification and delivery of evidence-based care are most prominent.

730 Governments should invest in prevention and screening, especially among high
731 risk groups^{53,266} and vulnerable populations^{267,268}. Not doing so forces health
732 systems towards more expensive “rescue” solutions like dialysis, which
733 exacerbate inequities⁹¹.

734 Socio-economic status relates differently to healthy lifestyle across the globe,
735 with higher socio-economic status being related to lower risk of NCDs in high-
736 income settings, but higher NCD risk in lower-income settings as middle classes
737 emerge^{65,269}. Modification of these inherent sources of inequity requires a
738 multi-sectoral approach to health and well-being such as that embodied by the
739 SDGs, as well as population education about healthy lifestyle^{233,270}.

740

741 *Data required to support decision making*

742 The core social determinants that make up the building blocks of health
743 represent societal injustices in how governments and authorities prioritise the
744 vulnerable, spend resources on those in need, and ensure adequate provision
745 for those affected by ill health. To motivate those who have power to act,

746 knowledge and understanding must be guided by good quality data, moral
747 advice, and a society that holds policymakers to account. Social and healthcare
748 data from real-life practice, research efforts and actions by charities/NGOs
749 should be integrated to improve the availability of meaningful intersectional
750 health. Decision-making and priority setting processes are hampered when
751 incidence, prevalence and health-economic data is lacking²¹⁷. Countries must
752 invest in systematic data collection to permit understanding of disease burden,
753 distribution, costs of care, financial hardships incurred, and to identify and
754 address inequities. Rigorous health technology assessments, based on reliable
755 local evidence of disease burden and costs to the health system and to
756 individuals, are required to support priority setting.

757

758 *Facilitate fair reimbursement of treatment costs*

759 Universal Health Care (UHC) is a crucial target of the SDG3²⁷¹. True UHC is
760 needed to prevent exclusion of the disadvantaged and reduce inequities²⁷²
761 (Figure 3). Even if UHC is not currently affordable, governments should commit
762 to its expansion through transparent processes, to progressively realize the
763 right to health for all²³⁰, with stepwise inclusion of expensive therapies, when
764 this becomes possible. Clear societal thresholds should be set regarding the
765 willingness to pay for gain of Quality Adjusted Life Years (QALYs), accounting
766 for the medical need and affordability, also called Value Informed and
767 Affordable Pricing²⁷³. Such processes should not only include cost and disease
768 burden, but must also take financial hardship and equity into account²⁷⁴. For
769 example, two health sector interventions which score highly in terms of equity
770 in the poorest nations are acute dialysis and kidney transplantation for
771 children, but lack of cost-effectiveness data precludes their recommendation

772 for coverage²⁷⁵. Cost-effectiveness analyses can however only be based on
773 intervention studies including diasadvantaged groups.

774

775 *Improve affordable care*

776 Technologic options like hemodialysis should be made affordable and more
777 reliable, accounting for the harsher conditions frequently encountered in low
778 resource situations (e.g. more resistant to heat, humidity, energy-efficient)²⁷⁶.

779 Costs for dialysis supplies can be reduced by waiving importation taxes or by
780 local production of PD material^{190,228}. In higher-resource settings, home dialysis
781 uptake could be stimulated through financial incentives, policy measures (PD
782 first), fair price setting by industry, patient education, and benchmarking²⁷⁷.

783 Health systems should be strengthened to include safe and legal
784 transplantation programs.

785

786 ***Local level***

787 *Raise awareness of kidney diseases*

788 All those concerned with kidney health and care (including non-professionals)
789 have a responsibility to be aware of and to create awareness of the problems
790 related to kidney diseases²⁶. This includes addressing the causes and
791 consequences of the structural determinants of health which entrench
792 inequities. Healthcare professionals should be trained throughout their studies
793 and continued education to identify and address these problems through
794 advocay and/or concrete measures²⁷⁸. Patient associations and NGOs play an
795 important role in this process to improve equity and should engage in training
796 initiatives to optimize their own advocacy skills^{3,279}. Patients must raise their
797 voices in holding healthcare planners and leaders to account, activate
798 partnerships for harmonization among regions/countries and expose

799 organizational shortcomings, e.g. calling for availability of specific medication,
800 dialysis or transplantation.

801

802 *Improve accessibility of equitable quality care*

803 Holistic kidney care requires strong health systems and public health strategies
804 to reduce burden of kidney diseases, and to promote early detection and
805 treatment, integration of kidney care into existing programmes for NCDs and
806 some infectious diseases, and reduction of organ specialty-linked silos. The
807 common diagnostic tools for kidney diseases (serum creatinine and
808 albuminuria) are simple and affordable in many (but not all) countries, and
809 should be made available as much as possible, but also ensuring this is followed
810 by appropriate interpretation and therapeutic intervention. Primary care and
811 non-nephrology physicians and other healthcare workers could play an
812 essential role, but may be insufficiently familiar with kidney diseases and
813 should be educated appropriately^{19,280}. Since kidney patients have multiple
814 comorbidities and require multiple healthcare providers, integration of care is
815 quintessential. Capacity building and audit-based education may support
816 implementation of appropriate preventative measures²⁸¹. Accessibility of
817 essential medications should be assured to permit early intervention and
818 stop/delay progression of acute and chronic kidney diseases. Telemedicine and
819 eHealth should be harnessed for remote outreach²⁸². Quality assurance
820 activities, including tracking of inequities, should be integrated into clinical
821 routines.

822

823 *Avoid cherry-picking*

824 In poorly designed pay-for-performance systems, self-interest with utility as the
825 prevailing principle could lead clinicians, hospitals and dialysis units to target

826 high throughput by favoring inclusion of patients with greater resources and
827 more favourable (less complex) clinical characteristics²⁸³. If applied to the
828 extreme, this morally dubious practice creates an additional disadvantage for
829 the less privileged, as they will start with less favorable conditions and will be
830 driven towards less favorable therapeutic environments²⁸⁴. Conflicts of interest
831 may lead to fewer transplantation referrals from private dialysis units²⁸⁵.
832 Reporting and monitoring of patient mixes and outcomes is mandatory,
833 especially in dialysis units where this data is easily obtained.

834

835 ***Individual level***

836 *Tackle health illiteracy*

837 To improve health literacy, a coordinated health systems approach informed by
838 consumers and representatives of the concerned groups is needed, with
839 adapted and innovative educational methods to meet various needs. Specific
840 support may be needed for children and families affected by kidney diseases,
841 to optimize adherence and minimize disruptions associated with the high
842 demands of kidney care.

843 One system level change adopted in other chronic diseases such as diabetes is
844 the introduction of navigators^{120,125}, who assist patients and caregivers in
845 understanding diseases and treatments and optimize self-care. Such programs
846 have been successful in remote parts of Australia with Indigenous People. In
847 the US, animation has been applied successfully for diabetes education where
848 language barriers exist²⁸⁶. Medical professionals need to recognize their own
849 limitations in terms of social and cultural literacy. Since medical professionals
850 are usually not well-trained in education, advice should be sought from experts
851 in other fields (e.g. pedagogy, animation, telecommunication, health
852 illiteracy)²⁸⁷⁻²⁸⁹.

853

854 *Patient empowerment*

855 A move from paternalistic care (doctors making decisions without patient
856 input) to shared decision making (decisions guided by deliberation between
857 individual patients, their caregivers and practitioners)^{290,291} as an approach to
858 enhance equity in therapy choice contributes to more patient satisfaction,
859 adherence and health²⁹². All steps should be reported transparently, which
860 helps to avoid imposing therapies for financial or other reasons that may not
861 benefit the patient. Patient organizations may play a central role in facilitating
862 this shift of paradigm. When interacting with patients, decreases in cognitive
863 function should be taken into account, especially in advanced CKD²⁹³, as this
864 common complication affects alertness and hinders fast and accurate decision
865 making. Extra care must be taken in children with kidney diseases and their
866 families to enhance understanding of kidney care and cooperation.

867

868 **Conclusions**

869 Kidney diseases are associated with significant inequities that increase risk and
870 are imposed by the many social and structural factors, the relative invisibility of
871 the condition as a public health threat, and the time- and resource-intensive
872 therapies required for advanced disease, especially dialysis.

873 All professionals involved in kidney care should be alert for local inequities and
874 their impact on patient lives, as well as those occurring on a broader, regional,
875 national and international level. Recognition is the first step towards
876 developing actionable solutions.

877

878 Inequities include those specific to countries and regions, among social groups,
879 and those related to accessibility of preventive and therapeutic modalities. In

880 addition to adverse clinical outcomes, inequities also raise health economic and
881 ethical concerns, and are heavily compounded by non-medical social and
882 structural determinants such as poverty, social injustice, violence, racism, lack
883 of education, and cultural and religious barriers.

884 Solutions range from the individual to the global level. Awareness of potential
885 solutions is important to encourage advocacy and action by all stakeholders.

886 Although not all solutions may be universally applicable or implemented, there
887 is a collective need to develop and implement innovative strategies to tackle
888 barriers to equitable kidney health and kidney care. All nephrology
889 professionals should have the conviction to advocate within their communities,
890 armed with local and international data, and to engage with policy makers,
891 administrators and insurers, to raise awareness about inequities in kidney
892 health and to improve kidney care across the globe.

893

894 Keypoints:

- 895 - Insufficient investment across the spectrum of kidney health and kidney
896 care (from awareness raising, to prevention, diagnosis and treatment) is
897 a fundamental source of inequity. This affects all people at risk of, or
898 living with kidney diseases.
- 899 - Social and structural inequities are major risk factors for, and contribute
900 to poorer outcomes in kidney diseases both within and between
901 countries.
- 902 - There is insufficient accessibility of essential diagnostics and medications
903 to treat kidney diseases and to track their burden. This disadvantages
904 patients in low- and middle-income countries from the very beginning of
905 their disease course.
- 906 - Ability to access the entire spectrum of kidney care (from basic
907 medication to dialysis and transplantation) without experiencing
908 financial hardship is very inequitable across the globe. Transplantation is
909 the most equitable form of kidney replacement therapy, but is highly
910 inaccessible in lower income settings. This results in vastly different
911 outcomes and live courses for patients with the same diseases living
912 under different circumstances.
- 913 - Novel therapies for rare (orphan) diseases are often only available at
914 extremely high prices, which frequently affects or excludes children and
915 adolescents.
- 916 - All nephrology professionals should become skilled at advocating on
917 behalf of their patients to communities, policy makers, administrators
918 and insurers, to develop constructive strategies and collectively reach
919 optimal solutions to improve equity in accessibility of quality kidney care
920 locally and across the globe.

921

922 **CAPTIONS TO FIGURES**

923 **Figure 1:** Factors contributing to inequities by increasing risk and by affecting
924 accessibility of preventative measures, care and therapies. The description
925 considers global, national/regional, community-related, health system-related
926 and individual elements.

927 **Figure 2:** Ethical dilemmas in inequitable accessibility of kidney care: from
928 global to local.

929 **Figure 3:** The Universal Health Coverage cube: expanding universal healthcare
930 coverage for kidney diseases in low resource settings. The health needs of the
931 population are depicted by the larger transparent box, the funds available for
932 health financing are depicted in the blue box. In many high-income countries
933 the size of the blue and the transparent boxes are very similar (almost all
934 health needs are covered), whereas in low resource settings the blue box is
935 considerably smaller than the transparent box, meaning that many health
936 needs that do not fall within the blue box are not covered by the health system
937 and must be provided/paid for by individuals. As countries set health priorities
938 and expand their health coverage they must consider the impact across all 3
939 dimensions: who should be covered, which services should be provided and
940 how much of the costs can be covered by the health system. KRT falls outside
941 of the blue box in most low-resource settings. Suggestions here include how
942 accessibility of kidney care can be progressively expanded under universal
943 health coverage. Priority setting must consider prevalence of a condition, cost
944 of therapeutic options and available resources. AKI: acute kidney injury; CKD:
945 chronic kidney disease; KRT: kidney replacement therapy; CHE: catastrophic
946 health expenditure. *: data on disease burden missing in many places.

947 Reprinted from Publication

948 “Making fair choices on the path to universal health coverage: final report of
949 the WHO consultative group on equity and universal health coverage.
950 [https://apps.who.int/iris/bitstream/handle/10665/112671/9789241507158_en](https://apps.who.int/iris/bitstream/handle/10665/112671/9789241507158_eng.pdf?sequence=1&isAllowed=y)
951 [g.pdf?sequence=1&isAllowed=y](https://apps.who.int/iris/bitstream/handle/10665/112671/9789241507158_eng.pdf?sequence=1&isAllowed=y) Figure 1.1, page 5, Copyright (2014).”

952

Box 1: Motivating scenarios for inequitable care specific groups of people

Social and economic position

"When you enter through the emergency department, you arrive in bad shape...you need to have a high potassium or they send you home even though you feel you are dying. Sometimes, you crawl out when they decide to not do dialysis. You eat a banana because it is high in potassium even though you may die and you go back and wait and hope that they will do dialysis so that you don't feel like you are drowning and so that the anxiety goes away."
(An undocumented immigrant in the USA receiving only emergency dialysis services)¹²³

"We have a population of about 30 million people and have less than 20 trained nephrologists. Unfortunately, due to lack of knowledge about kidney disease and its management, over 70% of patients report late to the teaching hospital with kidney failure and since care is not reimbursed by the National Health Insurance scheme, about a third of patients with kidney disease die on admission for which we have to sign death certificates and this does not include those who are stable enough to be discharged home with no hope of sustaining themselves on dialysis. It's really sad. Without money you die when you have kidney failure."

(A health professional's perspective on kidney care in Ghana)¹²⁶

Discrimination

"In my doctors they used to have this thing that when you signed in it was on a screen and you had to select in front of everyone in the waiting room whether you were male or female. Even that half a second just breaks my brain every time and I'm like, I kind of don't want to go to this appointment now".

(An LGBTQ+ patient on attending their appointment)¹²⁷

"My doctor[s]... be shocked when I asked them, well why is there so many Black people on dialysis and they don't have no real answer for me. I really don't like that. And so then on top of that he only spends ninety seconds with me... I'm like wow, I feel like cattle."

(A patient receiving dialysis discussing mistrust in their nephrologists connected with race)¹²²

Inequity within algorithms and guidelines

A 54 year old woman of mixed race is opportunistically found to have a low eGFR when attending hospital with a minor injury. She is advised that this is probably due to muscle mass and goes home. Several months later she reattends hospital in need of emergency dialysis.

"The insights about sexist and racist biases... are important because information organizations, from libraries to schools and universities to governmental agencies, are increasingly reliant on being displaced by a variety of web-based "tools" as if there are no political, social, or economic consequences of doing so."

(Safiya Umoja Noble, on reinforcing structural discrimination by use of algorithms)²⁹⁴

Health literacy

"I'd say about the hardest part was when he was on the prednisolone when he's on a high dosage, it's very lunatic. And then we went to the doctor to what's going on. Oh, it's the prednisolone. It causes anger and stress. So, more information and education of the carers as to what possible side effects could be and talk to you about this is what's going to happen."

(A caregiver's perspectives on kidney transplant aftercare and education)¹¹⁵

"I would have really liked to have sat and talked with somebody who had gone the journey before me, and to give me a heads up on about what I'm going to experience from the importance of taking the medication, understanding what the kidney function is in my body, understanding about my fluids, my nutrition, all of those coming together of the importance, because as a primary school teacher, you're having to say it at least 20 times before it clicks."

(A care partner)¹²⁵

"All the patient navigators that I've met, have been on dialysis and going through transplant and their second transplant. They know exactly what it's like to sit in that chair, and have treatment for hours on end, the restrictions that you're on, the medications that your body must handle after transplant. And although someone can sit and tell you about this importance, I think it comes at another level with someone else who's experienced that and been successful, and that you can draw on and build a relationship with, and it's kind of upskilling."

(A patient's perspective of lay navigators)¹²⁸

Geography and accessibility of care

J lives in a town with no dialysis services, the closest is 175kms away. He is ineligible for a transplant or home dialysis. His only choice is to move or receive conservative care.

"Just the understanding, like if you're having a transplant, you've got to deal with the city hospital and they say, "Okay, I'll book you in 8:00 in the morning, tomorrow morning, can you make it?" Well, I live in XXX. All right, well can you travel? Well, it's six hours away and I've got a family to organize and I'm on dialysis so it's like they don't get it. And then they'll say, "Come back next week and see me." Like, you're kidding. Can't you have

the one stop thing?”
(A patient experience of lack of accessible care due to remoteness)¹²⁵

954

955 Abbreviations: LGBTQ+, lesbian, gay, bisexual, transgender, queer, and other

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INEQUITIES IN KIDNEY HEALTH AND KIDNEY CARE

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43 **Abstract (200words)**

44 Health inequity refers to unnecessary and unfair differences in the capacity to
45 achieve optimal health and appropriate accessibility of care. Kidney diseases
46 [including acute kidney injury (AKI) and chronic kidney disease (CKD)] have
47 strong associations with inequity. This is largely due to the intrinsic risks of
48 kidney diseases, the heavy burden of comorbidities and the high cost of
49 therapies, e.g. for dialysis on which survival for many may depend. However,
50 inequities occur across the entire clinical course of kidney diseases. This review
51 offers a comprehensive overview of the array of inequities in kidney health and
52 kidney care, including inequities between countries, regions and social classes,
53 inequities in healthcare, inequities specific to therapeutic modalities, and health-
54 economic and ethical implications. This review also proposes solutions, which
55 may inspire nephrology professionals to recognize and mitigate inequities. In
56 addition to the main text that summarizes the relevant elements, interested
57 readers are referred to the comprehensive tables (including case stories) and
58 references, which review some facets more deeply. It is the responsibility of all
59 implicated to call attention to inherent risks of inequity in their immediate and
60 broader environments, and to pursue the best possible solutions together with
61 their communities.

62

63 **Introduction (7915 words)**

64 Health inequality refers to differences in health or health resources between
65 persons, populations or nations such as those caused by age or genetic
66 predisposition¹. Inequities in healthcare are unfair, avoidable and remediable
67 differences between groups, based on socioeconomic, demographic or
68 geographic factors². The distinction between inequities and inequalities is not
69 always clear. Importantly, underlying inequalities frequently contribute to
70 inequities, e.g. when genetic predisposition, age or sex intersect with
71 race/ethnicity, socio-economic status, possibilities to adhere to healthy lifestyle
72 or level of education.

73 In this manuscript we review different aspects of inequity which impact kidney
74 health and kidney care across the globe. For all the discussed elements a
75 number of potential solutions are reviewed at the end. The aim here is to offer
76 practical guidance to all those involved on how to avoid inequities, as these are
77 among the most concerning social injustices in modern clinical nephrology.
78 Throughout this manuscript, inequalities will sporadically be referred to if they
79 impact inequities.

80

81 Health inequities affect the capacity to achieve optimal health, which also
82 includes appropriate accessibility of care³. This capacity is far from equally
83 distributed globally, especially across regions and social classes⁴⁻⁷. The
84 awareness of health inequities has not translated into sufficient corrective and
85 collective action, because health inequities are multifactorial and multisectoral.
86 They arise from differences not only in medical care but also from differences
87 in global policy, sociology, ecology, geography, ethics, economics, psychology,
88 culture, religion and tradition (Table 1). A further barrier is the fatalistic view
89 that the problem is too large, too broad, or too complex⁸. Inequities evolve

90 over the life course, such that disadvantaged fetal or childhood development
91 may predispose to compromised health throughout life^{9,10}. An avoidable lack of
92 screening and preventive care may also lead to late presentation of disease and
93 seriously jeopardize health outcomes¹¹. Kidney diseases do not escape these
94 rules, but rather epitomize them¹².

95 Appreciation of the importance of kidney diseases by the medical community,
96 policy makers, and the public has lagged behind that of other common
97 conditions for multiple reasons^{13,14}. First, the rapid growth of dialysis and
98 transplantation since 1960 has focused on the needs of patients requiring these
99 expensive therapies diverting attention from prevention that is more scalable
100 and applicable everywhere^{14,15}. Second, the lack of consistent definitions of
101 kidney diseases until the 2000s, and of reliable epidemiologic data in some
102 regions, has hidden the full extent of the problem, limiting the development of
103 appropriate interventions^{16,17}. Third, the lack of awareness among primary care
104 providers, together with deficiencies in health information systems, have also
105 hampered prevention, detection and early treatment¹⁸⁻²⁰.

106 Based on the mounting evidence regarding population prevalence and poor
107 outcomes²¹⁻²³, kidney diseases should be considered a public health priority,
108 but thus far have not been prioritized on the global non-communicable disease
109 (NCD) agenda²⁴. This has resulted in the most fundamental inequity that affects
110 all kidney patients without distinction: insufficient investment in screening,
111 prevention, research, and innovation compared to other common NCDs, which
112 themselves remain chronically underfunded²⁵. Chronic kidney disease (CKD),
113 despite affecting 10-15% of society globally^{16,25}, is not a health research focus
114 for the European Union (EU)²⁶. Neither does CKD figure among the 56 health
115 topics considered relevant by World Health Organization (WHO) Europe²⁷. In

116 the 2022 EU Healthier Together Initiative, four disease-specific NCD strands are
117 targeted, excluding CKD^{24,28}. This lack of awareness among policy makers is
118 compounded by the ignorance of the kidney's functions and its pathologies.
119 Most individuals do not know what the kidneys do, let alone how to care for
120 them²⁹. At best, policy makers see kidney diseases as a co-morbidity of
121 cardiovascular disease (CVD) or diabetes, which postpones diagnosis for many,
122 and leaves others entirely behind³⁰.

123 This manuscript is coordinated by European Kidney Health Alliance (EKHA), a
124 non-governmental organization advocating for kidney health at European
125 Union (EU) level and beyond³¹. This article collates in a global context
126 perspectives from diverse inequity experts, representing various continents,
127 age groups and backgrounds, including kidney patients. It seeks to reposition
128 the need for equity in kidney health and care as a global priority and offers a
129 basis for further exploration for all involved stakeholders.

130

131 **Inequities across countries/regions**

132 ***Epidemiologic distribution***

133 The Global Burden of Disease (GBD) study attributed more than 3 million
134 deaths in 2019 to kidney dysfunction³². Most CKD deaths occurred in India and
135 China¹⁶. In Latin-America, the Middle-East and North-Africa, CKD falls within
136 the top 5 most common causes of death³³. Globally millions of deaths probably
137 result each year from the lack of accessibility of kidney replacement therapy
138 (KRT),³⁴ and from acute kidney injury (AKI)³⁵, but those remain largely
139 uncounted in lower-resource countries.^{36,37} Inequities across regions are
140 further enhanced by environmental factors, such as increasing number of heat
141 waves and droughts, pollution, water contamination and increased distribution
142 of tropical diseases³⁸⁻⁴⁰, which do not affect all countries and people equally.

143 Applying the definition of CKD^{41,42}, a systematic analysis of worldwide
144 population-based data estimated the age-adjusted global prevalence of all-
145 stage CKD in 2010 at 10.4% in men and 11.8% in women more than 20-years-
146 old⁴³. Subsequent estimates yielded relatively consistent results, although with
147 regional variations from 6 to 20%^{44,45}. CKD prevalence increases with age and
148 appears higher in lower-resource settings⁴³.

149 The GBD study showed a 15-fold global variation between countries of CKD
150 burden [specified as age-standardized CKD-linked disability-adjusted life-years
151 (DALYs)] , highlighting potential inequities in both accessibility of diagnostic
152 possibilities and risk factor distribution³³. It is even more difficult to estimate
153 the contribution of AKI⁴⁶. A pooled incidence of hospital-acquired AKI was
154 reported as 34 and 22% among hospitalized children and adults⁴⁷ respectively
155 but with pronounced regional variations, raising questions of plausibility and
156 generalizability^{37,48}.

157 ***Risk distribution***

158 The risk of kidney diseases is associated with country income level ⁴⁹ with
159 people developing CKD and dying from CKD at a younger age in lower-resource
160 settings compared to high income countries (HICs)^{50,51}. The association
161 between age-adjusted CKD prevalence and KRT incidence is positive in HICs,
162 but explains only 40% of the variance⁵². This association is negative in Central
163 and Eastern-Europe, and null elsewhere⁵², which highlights differences in
164 incident KRT that cannot be explained by CKD prevalence, even in HICs where
165 accessibility of KRT is generally unlimited.

166 In Central and Eastern-European countries, gross domestic product (GDP) is
167 highly heterogeneous, a legacy of the Cold War and the Iron Curtain. Many CKD
168 risk factors are more prevalent than in Western-Europe, especially in countries

169 with lower GDPs, likely contributing to a higher regional incidence of CKD⁵³.

170 Other disparities in this region related to kidney care include variable
171 availability of specific KRT modalities and expensive medication, relative
172 number of nephrologists, and tracking of the prevalence of CKD⁵⁴⁻⁵⁹.

173 Within HICs, in part due to the legacy of colonialism and slavery, stark
174 disparities across racial, geographic and socio-economic strata exist^{12,60,61}.
175 Moreover, patients with socio-economically deprived backgrounds develop
176 kidney impairment 5 years earlier in their life course and suffer from more
177 comorbidities¹².

178 ***Global distribution of KRT***

179 Registries of KRT were introduced in the 1960s-1970s in Europe and the US and
180 have expanded to most HICs but are less available elsewhere. Across countries
181 reporting to the United States Renal Data System (USRDS), the incidence of KRT
182 ranged from 16 per million people (pmp) in South-Africa (2018) to 570 pmp in
183 Jalisco, Mexico (2019), and the prevalence of treated kidney failure varied over
184 30-fold across countries (2019), which reflects disparities in accessibility of KRT
185 rather than in true incidence^{34,62}. KRT incidence is rising in most lower-income
186 settings⁶², however predominantly in the private sector (e.g. South-Africa and
187 India), leaving many without possibilities to be treated or exposed to significant
188 catastrophic health expenditures (CHE – out-of-pocket healthcare payments
189 which impoverish a household)⁶³⁻⁶⁶.

190 To permit equitable accesibility of care, provision of sustainable KRT requires
191 robust health systems and financing. A higher country Gini coefficient (indicating
192 greater within-country inequity) directly correlates with greater prevalence of
193 stage 5 CKD remaining untreated by KRT^{67,68}. In areas with greater equity, there
194 is more accessibility of KRT^{67,68}. In lower-resource settings a small fraction of

195 those requiring KRT receive it long-term³⁴. For example, most African countries
196 have healthcare systems with poor/no health insurance coverage, leaving the
197 vast majority of people with kidney failure unable to obtain KRT^{69,70}. Elsewhere,
198 macro-economic factors and services for kidney care are also more strongly
199 related to KRT incidence than demographics or general health⁷¹. In Eastern-
200 Europe, variability in incidence and prevalence of KRT results in multiple-fold
201 differences in dialysis and transplantation uptake between countries, as well as
202 less home dialysis and conservative care compared with Western-Europe^{58,59}.
203 In brief, country location and wealth distribution substantially impact kidney
204 health and accessibility of kidney care across the world. Inequities exist even
205 within a relatively homogeneous region like Europe.

206

207 **Factors associated with inequitable health care**

208 ***Diagnosis and treatment***

209 A complex interplay between structural risk factors for AKI and CKD and rapid
210 progression of disease due to limited accessibility of primary care limits
211 possibilities to mitigate these risks⁷²⁻⁷⁵. Diagnosis of CKD and AKI requires blood
212 and urine tests, which are not routinely available everywhere⁷⁶. In 2017, two-
213 thirds of low income countries (LICs) were unable to measure serum creatinine
214 in primary care, and none provided quantitative albumin or protein urinalysis⁷⁶.
215 Availability of medicines required for kidney care is often limited in lower-
216 resource settings, but even within HICs inequities may arise based on coverage
217 differences between patients and insurers^{77,78}. Similarly the nephrology
218 workforce is unequally distributed across the globe: the number of nephrologists
219 per million population (pmp) ranges from 31 in Western Europe to 1 or less in
220 Africa⁷⁹. Thus, diagnosis, availability of treatment and tracking of the burden of
221 kidney diseases is highly inequitable globally.

222

223 ***Inequities conflicting with living well***

224 Good healthcare is a key component to living well⁸⁰. To achieve this equitably,
225 healthcare providers must meet people at their different levels of disadvantage
226 (Figure 1) and support them to face personal challenges and priorities. Patient
227 priorities may, but do not always align with those of healthcare providers^{81,82}.
228 Kidney diseases exacerbate vulnerabilities, including health, social, and
229 financial hardship^{83,84}. Of note, most often, vulnerability is not an intrinsic
230 condition but due to system failures. Health decision-making is influenced by
231 wider contexts, including one's own understanding, finances, social support,
232 geography, culture, beliefs, and freedoms. Healthcare providers must
233 appreciate these wider determinants, both to consider patients holistically, and
234 to avoid blaming individuals for risks and outcomes caused by external factors.⁹
235 A complex relationship exists between the unique challenges posed by kidney
236 diseases, broader individual and environmental contexts, and healthcare and
237 societal factors which promote or undermine health. Accessibility of kidney
238 care is complex, with many intersecting and compounding challenges, as
239 discussed elsewhere^{4,9,12,29,73,80,84-120} and summarized in Table 1. Many of these
240 factors are global problems. The Sustainable Development Report 2022¹²¹
241 highlights major challenges and insufficient data regarding inequity indicators
242 especially across lower-resource settings¹²¹, which exacerbate the inherent
243 "invisibility" of kidney diseases. The implications for specific groups are
244 expanded on below, with accompanying scenarios and quotes in box 1, partly
245 based on published observations^{115,122-129}.

246 ***Socio- economics***

247 Social and economic position (SEP) is consistently associated with health risks
248 and accessibility of care, across countries, and across lifecourse¹⁰⁴. People of all

249 ages are at risk of kidney diseases, which constrains opportunities for well-
250 being, education, employment, and attaining life-goals. The relationship
251 between SEP and kidney health is bidirectional, with increased risk of falling
252 into poverty as kidney diseases progress¹³⁰.

253 Particular challenges exist in lower-resource settings^{70,131}. In most of Africa for
254 example, many people with CKD are of working age. They often present late,
255 with kidney failure resulting in poor outcomes^{132,133}. This is driven in part by low
256 health literacy, and a preference for potentially nephrotoxic traditional
257 remedies and faith-based healers^{134,135}, but also by a lack of infrastructure and
258 adequate workforce to enable early detection, prevention, and community
259 surveillance^{79,101}. If lower-resource countries provide coverage for dialysis, it
260 typically is limited to only two sessions per week¹⁰⁰. Others exclude kidney
261 failure from coverage schemes⁹⁹, necessitating prohibitive out-of-pocket costs
262 if dialysis or transplantation are available^{69 85,136}. Thus, many people in lower-
263 resource settings are unable to sustain treatment for kidney failure, and
264 struggle with the economic burden on their family, creating difficult moral
265 trade-offs in the allocation of household resources^{137,138}.

266 Even in HICs with universal health coverage (UHC), deprived individuals
267 experience less preventative care, more rapid progression of kidney diseases, a
268 greater need to rely on emergency services, and stigmatisation¹². Poor
269 neighborhoods are associated with poor education and employment
270 opportunities. Residents have less ability to obtain and navigate preventative
271 healthcare, limited availability of recreation services or exercise facilities, and
272 greater exposure to environmental toxins, overcrowding, and food
273 insecurity^{73,88,97}. These represent barriers to a healthy lifestyle, good nutrition,
274 and ability to cope with stressors^{4,95}.

275 Those who are uninsured , homeless or undocumented migrants also suffer
276 limited accessibility of preventive care. One in three undocumented migrants
277 with kidney failure in the U.S. receive only emergency dialysis, with grave
278 prognostic implications¹¹⁷. Irrespective of country, refugees experience similar
279 difficulties to the disadvantaged in navigating healthcare and maintaining a
280 healthy lifestyle¹¹⁸. During humanitarian crises, this includes reduced
281 accessibility of life-saving treatments such as dialysis and
282 immunosuppression¹³⁹.

283

284 ***Discrimination***

285 Systemic racism continues to drive persistent inequities in kidney health,
286 whereby race should be understood as a social construct rather than a
287 biological indicator and disparities in health and outcomes as the
288 consequences¹⁴⁰.

289 Globally, people of Black race and minoritized backgrounds are more likely to
290 have kidney diseases, and progress to kidney failure^{141,142}. In the U.S., Black
291 patients with kidney failure are less likely to be evaluated and referred for
292 transplantation¹⁴³⁻¹⁴⁵, are listed later^{144,146-148}, wait longer for
293 transplantation¹⁴⁹⁻¹⁵², and receive poorer overall care¹⁵³⁻¹⁵⁶ than White patients.

294 Discrimination against minority groups, including race and sexual and gender
295 minorities (SGM), occurs at the intersection with wider health determinants
296 and causes differences in how healthcare is used and experienced^{73,94}. Due to
297 systemic inequities and policies (e.g. redlining), patients from minoritized
298 backgrounds are overrepresented in poorer neighborhoods^{73,157-159}. Inequitable
299 structural investment in local community environments perpetuates these
300 disadvantages into future generations^{160,161}. In addition, the direct experience
301 of discrimination can cause long-term stress and negative coping, leading to

302 overeating, alcohol or other drug abuse, smoking, poorer mental health, and
303 less trust in sources of support^{73,162,163}. Importantly such discrimination not only
304 impacts individuals, but markedly increases total health care costs, which
305 further weakens health systems. In 2018, the economic burden of racial and
306 ethnic health inequities and education-related health inequities in the US,
307 (measured as excess medical care expenditures, lost productivity, and the
308 value of excess premature death combined), were estimated at over \$420
309 billion and over \$940 billion respectively¹⁶⁴. Most of the excess costs was
310 contributed by the Black population and those without a high school education.
311 Patients from minoritized groups may distrust professionals if discrimination is
312 witnessed, with a detrimental impact on health-related decision-making⁹⁴. A
313 patient experiencing discrimination may leave and never return. Effort should
314 be made to provide education and support that is culturally and socially
315 sensitive, but clinician-patient relationships vary across minorities and cultural
316 groups¹⁴⁹, with clinicians investing unconsciously more in people with whom
317 they have greater affinity. Without awareness of these biases, nephrologists
318 may be prone to spend less time with those from minorities discussing
319 treatment options such as transplantation, or new therapeutic options such as
320 sodium-glucose transporter (SGLT)-2 inhibitors⁹³ (if reimbursed).

321 ***Algorithms and guidelines***

322 Algorithms are used to assess, monitor, predict, and support clinical decisions.
323 Such tools risk introducing biases, if based only on selected (privileged) groups
324 or only approximative parameters with a magnitude of error that depends on
325 person characteristics^{165,166} (label bias). These biases carry the risk of hidden
326 discrimination¹⁶⁷. For example, healthcare policies are often based on analytical
327 algorithms of health event administrative coding. Such codes usually represent
328 expenditure on care, rather than illness severity or need. This can lead to

329 structural discrimination, because people of Non-White race experience
330 reduced accessibility of care compared to their White counterparts with similar
331 illness severity^{166 168,169}. Such analyses invisibly perpetuate unfair
332 recommendations hidden behind algorithms that assume that Non-White
333 people need less care.

334 Kidney care is especially dependent on measurement. However, availability of
335 possibilities and capacity to monitor kidney health is uneven between and
336 within social groups, regions, and countries⁹⁸. This compromises
337 interpretability, and the visibility of underrepresented groups. The inadequacy
338 of explicit inclusion of a Black race coefficient within kidney function (eGFR)
339 estimating equations in previous formulae (i.e. MDRD and CKD-EPI equations)
340 was especially important because GFR estimates are cascaded as presumed
341 “results” into numerous kidney and non-kidney tools and guidelines beyond
342 the reach of the kidney specialist¹⁷⁰. This over-medicalization and biological
343 misinterpretation of race may inadvertently have led to unfair barriers to
344 referral, guideline-based care and provision of support^{93,140}. Although not
345 supported universally¹⁷¹, leading nephrology societies now recommend using
346 eGFR equations without the Black race coefficient¹⁷²⁻¹⁷⁴. Coefficients for age
347 and sex remain, and similarly may require cautious interpretation^{111-113,175}.

348 ***Health illiteracy***

349 Health literacy is “the degree to which individuals have the capacity to obtain,
350 process and understand basic health information” to inform their health
351 decisions¹⁷⁶. Health illiteracy is to a considerable extent attributable to failures
352 in the education system, and in information systems. This may be exacerbated
353 by insufficient health, social and cultural literacy of care providers, as kidney
354 diseases require not only medical understanding, but also understanding how
355 to support patients living with an increasingly complex chronic disease.

356 Low health literacy is linked to increased mortality, hospitalization, medication
357 errors and poor management of chronic diseases^{177,178}. Efforts to improve
358 health literacy in patients with CKD have focused on the individual, with little
359 attention for the health system environment or the appropriateness of
360 information¹⁷⁹. For patients and families, their ability to understand CKD and
361 treatments is variable and impacted by many factors including the skills and
362 patience of the clinician providing education, patient health, presence of a
363 caregiver, time of day of appointment, and current and anticipated future
364 treatment modality. These factors cannot be changed by those needing care¹⁸⁰,
365 and may result in decreased healthcare accessibility and utilization of services.

366 ***Geography and accessibility***

367 People from rural/remote communities often commence their journey with
368 CKD in a disadvantaged position, especially regarding socioeconomic status,
369 educational attainment, and opportunities to benefit from primary
370 prevention¹⁸¹. Regarding KRT, many barriers, including late referral to
371 nephrologists, necessary relocation to obtain treatment, transportation
372 barriers, and financial hardship¹²⁵ contribute to an increased risk of mortality,
373 morbidity and hospitalization among those residing in more remote
374 locations¹⁸¹. For in-center hemodialysis, longer travel time to treatment is
375 associated with higher mortality, and decreased quality of life¹⁸². Centralisation
376 of most transplantation units to major cities, adds an extra layer of difficulty for
377 patients from remote areas as possibilities to complete transplant work-up and
378 specialist care may not be available locally.

379 ***Inequities among therapeutic options***

380 Inequities in kidney care pervade across individual conditions (cause of kidney
381 diseases, lifestyle, the timing of preventive and therapeutic interventions and
382 disparate accessibility of different KRT modalities), wider communities,

383 healthcare systems (e.g. private *versus* public healthcare sectors) and countries
384 (Figure 1). Combined, these have major impacts on patient outcomes.

385 ***Acute kidney injury***

386 Although AKI is potentially preventable and reversible, accessibility of
387 appropriate diagnosis and care is inequitable. In HICs, AKI is common among
388 multimorbid individuals who often need prolonged dialysis in intensive care
389 with little chance of recovery.³⁵ In many lower-resource countries,
390 awareness/confidence to manage AKI is low among healthcare workers¹⁸³.
391 Although AKI is common in children and young adults, often as a single
392 condition³⁵, even basic intravenous fluids for rehydration may be lacking¹⁸⁴, let
393 alone accessibility and affordability of dialysis^{37,184,185}

394 ***Chronic kidney disease***

395 In the early stages of CKD, only people with specific kidney conditions such as
396 polycystic kidney disease or glomerulonephritis typically receive care in
397 specialist nephrology clinics. For many people with early stage CKD due to
398 more common causes (e.g. related to hypertension or diabetes), care is
399 coordinated through primary care or non-nephrology specialty units and is
400 subject to inequities in surveillance, diagnosis and quality of care¹².

401 Multiple barriers in CKD care, including lack of accessibility of essential
402 diagnostics and drugs to slow progression of kidney diseases, and of knowledge
403 among healthcare professionals, contribute to inequities (Table 1).

404 Accessibility of appropriate medication depends on availability, reimbursement
405 and/or ability to self-pay. A survey of resource-limited countries reported that
406 approximately 75% of patients had to pay themselves for diagnosis and
407 treatment of glomerulonephritis, while the lack of kidney biopsy and

408 subsequent interpretation often led to inappropriate immunosuppression¹⁸⁶.
409 Quality of care is therefore an additional concern even if some resources may
410 be available/accessible, highlighting the need for capacity building among the
411 nephrology workforce¹⁵.

412 ***Advanced kidney disease: dialysis and conservative care***

413 Accessibility and quality of dialysis, availability of home dialysis and focus on
414 patient well-being varies between and within countries and between individual
415 nephrologists as outlined above (Table 1). Most variations in dialysis
416 accessibility and availability relate to economic factors – cost, health coverage,
417 distribution of dialysis centers, number of nephrology professionals including
418 nurses, quality of patient education, support for vascular and peritoneal access
419 creation, and management of comorbidities⁵⁶.

420 Hemodialysis is available (although not necessarily accessible to all) in most
421 countries and tends to be the default form of KRT¹⁵. In-center hemodialysis is
422 time- and resource-intensive and is highly centralized. PD is more scalable and
423 flexible, less hospital dependent, can be done anywhere with rudimentary
424 infrastructure, is preferred by many patients¹⁸⁷, and is especially suitable for
425 children¹⁸⁸. Counterintuitively, however, PD costs more than hemodialysis in
426 many lower resource settings¹⁸⁹⁻¹⁹¹. Efforts to make PD supplies less expensive
427 and to increase awareness of the advantages and impact of PD are key to
428 increasing its global availability¹⁹². In terms of quality, cost is again a major
429 source of inequity where reduced hemodialysis sessions or PD exchanges are
430 often used as compromises to cut costs, but unavoidably reduce dialysis
431 quality¹³⁷.

432 Older or frail individuals, and those with learning difficulties are usually
433 committed to in-center hemodialysis unless assistance is provided at home.

434 Even in high-income Western European countries, healthcare-funded assistants
435 for dialysis were available in only 5 of 13 surveyed countries¹⁹³.

436 Similar arguments hold for inequity of availability of conservative care, with less
437 than half of countries providing support from multi-professional teams, or
438 enabling shared decision making, if patients need to embark on conservative
439 care⁵⁹. Even in countries which purportedly support conservative care, such as
440 France, this option is often not discussed as an alternative to dialysis¹⁹⁴.

441 ***Advanced kidney disease: transplantation***

442 Many patients in need of KRT prefer kidney transplantation over dialysis, due
443 to better survival and quality of life^{195,196}. Globally, the WHO estimates that
444 only 10% of the demand for kidney transplantation is met¹⁹⁷. The donor organ
445 shortage is worsening as more people worldwide require KRT.

446 Transplantation is available in 74% of countries (publicly funded in 53%) with
447 waiting lists in only 62%¹⁹⁸. Pre-emptive transplantation is only recorded in 10%
448 of countries¹⁹⁸. Higher-resource settings have higher rates of deceased and
449 living donation than other countries^{199,200}, along with transplant registries
450 enabling greater transparency. The availability of kidney transplantation
451 through UHC in higher-resource settings enables people from lower socio-
452 economic classes to obtain transplantation. Nevertheless, even in higher-
453 resource settings inequities remain pervasive¹⁴³⁻¹⁴⁵ and there are huge
454 disparities among countries in transplantation uptake²⁰¹. In LICs accessibility is
455 largely restricted to those who can pay.

456 Racial disparities are well documented particularly in minority groups, migrants
457 and Indigenous and First Nations People, who despite a higher burden of
458 kidney failure, are less likely to receive a transplant²⁰². Females are more likely

459 to be living donors than men²⁰³, an observation likely impacted by multiple
460 factors, including the slower progression of kidney diseases among women²⁰⁴

461 In 2007, approximately 10% of transplantations worldwide resulted from organ
462 trafficking after graft purchase from poor and individuals rendered vulnerable
463 by their life circumstances^{205,206}. The Declaration of Istanbul provides guidance
464 for organ donation and transplantation worldwide, to promote equitable
465 sharing of the limited transplant resources by those in need, and prevent harm
466 through exploitation²⁰⁷. Nevertheless, equitable allocation of graft organs
467 remains complex and changing viewpoints might necessitate revision of rules
468 when appropriate²⁰⁶.

469 ***Pediatric care***

470 Accessibility of specialized pediatric nephrology is very limited in LICs, but
471 regional variations occur everywhere²⁰⁸. Data on the epidemiology and
472 outcomes of pediatric kidney diseases are limited to registries in HICs and small
473 studies from lower-resource settings, probably underestimating true disparities
474 in care.

475 The 0 by 25 initiative highlighted the disparities in early diagnosis and
476 accessibility of dialysis for children with AKI in lower-resource settings³⁷.

477 Community-acquired, preventable AKI due to infections like dengue,
478 dehydration or nephrotoxic drugs is more common in low-resource settings
479 and exacerbated by poverty and malnutrition^{35,37,185}. Mortality in children with
480 AKI is >50 times higher in lower-resource settings than in HICs, especially when
481 dialysis is unaccessible²⁰⁹. Non-recovery of kidney function is 3 times more
482 frequent²⁰⁹.

483 Pediatric CKD is often diagnosed late, especially in countries with poor
484 antenatal and primary healthcare, and in rural/remote areas²¹⁰. Accessibility of
485 pediatric dialysis and subsequent outcomes correlate with national wealth,
486 even in Europe²¹¹. Mortality risk is also greater with late diagnosis requiring
487 ‘urgent start’ dialysis²¹¹ and is very high if dialysis cannot be provided or
488 continued⁷⁰.

489 The barriers to pediatric kidney transplantation in lower-resource settings
490 include unavailability of pediatric transplantation expertise, catastrophic out-
491 of-pocket expenditure and the absence of deceased donor organ sharing
492 networks^{212,213}.

493 **Inequities resulting from health economic factors**

494 *Differences driven by country wealth*

495 Kidney care comes at a high societal and personal cost²⁵. Global reimbursement
496 for maintenance dialysis (excluding out-of-pocket payments) amounts to
497 around 57 billion US dollars, 80% of which is spent in HICs, 17% in MICs, and
498 only 3% in LICs¹⁹⁰. Dialysis, if universally provided, is funded by varying state
499 financing schemes²¹⁴. In HICs, >2% of national healthcare budgets is directed to
500 KRT, for only 0.15% of the population¹⁴. Global costs for AKI are unknown, but
501 in the US, in 2013, AKI reportedly caused \$9 billion excess annual hospital
502 costs³⁵.

503 In higher income settings, expenses for associated non-kidney care further
504 increase the financial burden^{14,215}. Productivity loss (unemployment, sick leave,
505 premature retirement, death) impacts patients, their next of kin and society
506 overall²¹⁶. Individuals in vulnerable positions (temporary, contractual, physical

507 workers, unemployed) are at higher risk of productivity loss and
508 impoverishment when struck by CKD⁸⁴.

509 In low-resource settings where the direct and indirect costs of kidney care and
510 KRT often must be paid out-of-pocket, the risk of impoverishment is even
511 higher. A systematic review comparing out-of-pocket payments for several
512 diseases revealed kidney diseases as the leading cause of catastrophic health
513 expenditure (CHE), across lower-resource settings, thus exacerbating inequities
514 between countries, individuals and groups.

515 Both higher and lower-income countries are therefore at risk of inequities but
516 the problems are not necessarily the same (table 2). Accessibility of kidney care
517 without experiencing financial hardship is highly inequitable across the globe,
518 with the most severe consequences (death and/or CHE) especially affecting the
519 poorest^{70,138,185,217-219}.

520 ***Kidney replacement therapies***

521 Dialysis is available in almost all countries¹⁵, but the clinical, financial and
522 ethical dilemmas associated with its (un)accessibility cannot be ignored. Cost-
523 effectiveness assessments are used to rank healthcare interventions aiming at
524 maximal population health gains, often expressed in Quality Adjusted Life Years
525 (QALYs), for a given cost²²⁰. A systematic review of cost-effectiveness analyses
526 concluded that the ability to identify the mix of dialysis modalities that provides
527 best outcomes for patients and health budgets is uncertain, particularly given
528 the frequent inconsistencies between published studies and non-consideration
529 of societal perspectives²²¹. In addition, cost-effectiveness as sole criterion for
530 decision making has been criticized, since it overlooks crucial factors such as
531 budgetary impact, financial risk protection for individuals, and equity in
532 distribution of interventions^{222,223}.

533 In many higher income countries, the budgetary impact of dialysis has been
534 accepted, as the choice to save lives has prevailed over costs²¹⁷. This has led to
535 exponential growth in patient numbers and a dialysis industry generating
536 considerable profit in a sector with few competitors. Rising patient numbers,
537 especially in emerging countries, will further inflate costs²²⁴. Health system and
538 societal costs for PD, home hemodialysis and transplantation are lower than for
539 in-center hemodialysis in many countries^{56,190,201,225-227}, but their uptake and/or
540 availability is inadequate and divergent^{190,228,229}. Additionally, health-economic
541 factors favoring one therapeutic alternative over another in HICs differ in
542 lower-resource settings, where labor is cheaper and imports more expensive²²⁵.

543
544 Especially in low-income settings, policy makers face the challenge of
545 simultaneously pursuing UHC, setting priorities across the whole health system
546 and progressively fulfilling the human right to health^{217,230}. It would be naive to
547 insist that KRT be funded immediately everywhere for all, as the opportunity
548 costs (money spent on KRT cannot be spent elsewhere) are high. For example,
549 if Kenya, Nigeria and Senegal would try to meet their estimated national
550 dialysis needs, this would require from 8 to close to 40% of government health
551 expenditure²³¹. Consequently, in lower-resource settings, KRT is currently
552 largely available only to those who can pay¹³⁷.

553
554 ***CKD not on kidney replacement therapies***

555 The costs of kidney care do not only impact those on KRT. The poor may not
556 even be able to afford simple care to prevent the evolution of early CKD to
557 kidney failure. This intensifies inequities because as disease progresses, higher
558 levels of care and personal expenditure are required¹³⁷.

559 The optimal solution to forestall CKD costs is to reduce disease risk and/or
560 progression, both intimately intertwined with inequities in many places^{14,232,233}.
561 However, in most countries investment in initiatives to promote prevention is
562 minimal, in spite of the high value for money compared to the financing of
563 treatment or cure^{11,14,190,234,235}. The value for money gained through prevention
564 of illness is not restricted to the health sector. A recent publication from the
565 WHO highlighted the important long-term return on investment of prevention
566 of NCDs. For example, investment of 1 dollar in lower-resource settings to
567 reduce population salt intake in 2018 would yield 13 dollars in return by 2030,
568 given the lower subsequent health expenditures and greater productivity
569 gained with healthier people²³⁶. Thus, there are also longer-term opportunity
570 costs, which apply especially to many lower-resource settings, where current
571 health budgets are disproportionately channeled to secondary and tertiary
572 care, necessitated by the poor investment into prevention^{190,225,237}.

573

574 ***Marketing of drugs***

575 A threat to reimbursement systems and costs is the marketing of therapies for
576 specific kidney diseases which are often only available at extremely high prices,
577 either because of patents, or the small market size if a condition mainly affects
578 children (e.g. cysteamine)^{238,239}. There is little transparency in the price setting
579 of such drugs (e.g. eculizumab)²⁴⁰, for which in addition evidence may be
580 low²⁴¹. They are also frequently used off-label for indications for which they are
581 not approved nor evidenced, or used in children and adolescents where they
582 have not been tested (e.g. tolvaptan)²⁴². Inflated costs and excessive profits not
583 corresponding to investment²⁴⁰ initiate and exacerbate inequities among
584 countries and regions²⁴³, and depend on whether countries have orphan drug

585 legislation and reimbursement schemes. Inequities in accessibility of such
586 medications have a negative impact on patient outcomes²⁴⁴ in low-income but
587 also in high-income settings, as incomplete or absent coverage may necessitate
588 out-of-pocket payments, that are not possible for all.

589 In summary, the current health-economic model supporting kidney care is
590 flawed. The focus on expensive and/or late stage therapies favors inequity,
591 both across countries and among individuals. Differences in cost of essential
592 therapies between countries, without clear transparency about the prices and
593 the reasons, further exacerbate global inequities²⁴⁵.

594

595 **Ethical context**

596 ***Inequitable accessibility: an ethical dilemma***

597 Clinicians are familiar with the 4 principles of biomedical ethics. The principles
598 of autonomy, beneficence (doing good) and non-maleficence (not doing harm)
599 are readily applicable at the bedside. The principle of justice, however, has
600 implications beyond the bedside and addresses issues of fairness and inequities
601 between individuals. In resource-constrained settings, physicians often realize
602 that autonomy, beneficence and non-maleficence conflict with justice, as an
603 individual patient's needs may be overridden by lack of available therapies,
604 poverty or the needs of others competing for the same treatment⁷⁰.

605 Inequities in nephrology constitute moral dilemmas because patient outcomes
606 are adversely affected by structural injustice and vulnerability, that increase
607 risk of kidney diseases and impact accessibility of care⁶⁰. Although inequity is
608 often thought to begin with a lack of accessibility of healthcare, patients with
609 kidney diseases encounter inequities that extend beyond the healthcare sector,
610 beginning with the conditions in which they are conceived, born, work and
611 live²³³. The social and structural determinants of health include factors like age,

612 gender, poverty and geographical location in the world and within a country.
613 These factors are inequitably distributed, resulting in vastly different outcomes
614 for patients with the same disease living under different circumstances - highly
615 resourced versus low resource settings, or people who are wealthy versus the
616 poor. These social determinants of health play a large role in pre-determining
617 who lives longer and who dies earlier²⁴⁶. Accessibility of kidney care is also
618 inequitably distributed at all levels – from screening, early diagnosis and
619 preventative care up to KRT or comprehensive conservative care for kidney
620 failure.

621 If inequity in healthcare is inherently ‘unjust’, an ethical dilemma arises for the
622 provider (the principle of justice is violated)⁷⁰. Inequities in kidney care occur in
623 all resource settings and at any stage of disease, but the impact is compounded
624 with worsening kidney function, as life-saving but expensive treatments
625 become necessary. Out-of-pocket costs exacerbate these inequities in low-
626 resource settings, where minorities, women, the poor, elderly and health
627 illiterate, as well as those living remotely, are disproportionately affected.
628 Examples of structural inequities in nephrology are presented as case studies in
629 **Table 3**, highlighting the ethical dilemmas encountered^{137,206,217,247-256}. Such
630 moral dilemmas are omnipresent: at the bedside, during shared decision-
631 making, in society, for national governments and at a global level (**Figure 2**).

632

633 ***Responsible stakeholders***

634 In his philosophical approach to health justice, Venkatapuram states that
635 health is not the absence of disease, but a positive ability to be and to do
636 things²⁵⁷. People have a moral entitlement to be as healthy as they can, and
637 patients need to be capable of leading productive and quality lives.

638 Expressing health as a human right is an important complement to advancing
639 health equity because it stresses that the responsibility for care delivery lies
640 with the state, which has an obligation to provide care to whatever extent
641 possible in an equitable manner²³⁰.

642 The global nephrology community also has an ethical imperative to address/call
643 attention to all the factors underlying inequity, including the social
644 determinants of health, as well as every level of accessibility of kidney care. It is
645 the ethical responsibility of all professionals to reduce inequities in kidney care
646 and improve patient outcomes and to advocate this objective²⁵⁸. Governments
647 must be held accountable to acknowledge this and to commit to the
648 progressive realization of the right to kidney care for all.

649

650 **Solutions**

651 As outlined above, inequities in opportunities to optimize kidney health and to
652 provide accessibility of all forms of kidney care are multiple across the globe.

653 The origin of health inequities can often be narrowed down to both social and
654 systemic injustices²⁵⁹, related to complex, multisectoral factors. Solutions
655 require leadership, responsibility, and political will. Improvement in
656 accessibility of health care may mitigate the immediate impact of social and
657 systemic injustices to an individual, but lasting progress can only be made
658 through seeking system solutions that prevent the underlying causes at a
659 population level. Accordingly, if medical communities are to make collective
660 progress towards dismantling inequities, the underlying causes must first be
661 acknowledged and understood before they can be solved. This in turn requires
662 collaboration on global, local and individual levels. Suggested actions to tackle
663 the global inequities in kidney health and kidney care per stakeholder group

664 are summarized in table 4 and outlined relative to policy/individual level in
665 what follows.

666

667 ***Global level***

668 *Recognize kidney diseases as an important public health problem*

669 Multiple factors have contributed to kidney diseases being relatively
670 overlooked as a public health concern, which include lack of data in many
671 places due to global inequities in accessibility of essential and reliable
672 diagnostics for kidney diseases and rudimentary health information systems
673 which do not track kidney diseases. The focus of global health agendas was
674 initially driven by funding and targets set for infectious diseases and maternal
675 and child health, and subsequently for cardiovascular, cancer, respiratory
676 diseases, diabetes and mental health, but not kidney diseases^{28,260}. If the
677 burden of kidney diseases is to be meaningfully impacted, advocacy and strong
678 leadership are required to acknowledge and reduce existing inequities in
679 disease risk and accessibility of care, to strengthen the provision of integrated
680 quality care for NCDs including kidney diseases, to generate robust health-
681 economic evidence on interventions and their impact to guide financing, to
682 improve data capture to identify areas that lag behind, and to track
683 achievement of all sustainable development goals (SDGs), as each SDG impacts
684 kidney health world-wide²³³.

685 Just as health inequities cut across countries, so also do potential solutions.

686 Over the short and medium term, harmonization among countries and classes
687 can be advanced by material, financial or in-kind external support, and by
688 promoting exchange of learning, innovations and best practices²⁶¹. Such
689 initiatives might be optimally managed by umbrella institutions, including
690 governments, supranational political structures (e.g. the European Union),

691 coordinating agencies (e.g. WHO), or non-governmental organizations (e.g.
692 Médecins sans Frontières, European Kidney Health Alliance), but may also
693 result from private initiatives (e.g. Gates Foundation) and professional societies
694 (e.g. International Society of Nephrology, European Renal Association). Over
695 the longer term, countries must be encouraged and supported to finance and
696 deliver sustainable and comprehensive local quality kidney care.

697

698 *Support affordable innovation to improve kidney care for all*

699 Transparency in investment and in development and production of novel
700 technologies and drugs, especially for orphan kidney diseases, is urgently
701 needed²⁴⁰. Structured stakeholder networks, like the virtual European
702 Reference Network on rare diseases of the European Commission, may help to
703 support high quality, sustainable and equitable therapies²⁶². Tiered pricing
704 mechanisms adapting the cost of technologies and material to the welfare of a
705 country in mutual agreement between rich and poor countries may improve
706 affordability²⁶³.

707 Innovation should not only focus on sophisticated technologies, but must also
708 include the development of new approaches to improve uptake of prevention
709 strategies, and accessibility and delivery of primary care for those currently left
710 behind. Implementation and operational research are needed to identify and
711 scale up effective and affordable strategies, including dialysis²⁶⁴. Governments,
712 learned societies, clinicians, researchers and patient organizations should work
713 hand in hand to foster innovation at all levels as a means to reduce global
714 inequities.

715 **Country level**

716 *Prevention and early detection*

717 The best approach to reduce the burden and cost of NCDs, especially kidney
718 diseases, is prevention¹⁴. This universal tenet applies to all countries.
719 Unfortunately, only small proportions of healthcare budgets world-wide target
720 prevention^{14,56,190}. Timely and appropriate screening for kidney diseases occurs
721 rarely and is often not systematized or harmonized²⁶⁵.
722 Prevention is most efficient when risk or disease are identified early. This
723 requires identification of barriers, creating awareness and building trust,
724 especially among vulnerable populations, where the deficiencies in early
725 identification and delivery of evidence-based care are most prominent.
726 Governments should invest in prevention and screening, especially among high
727 risk groups^{51,266} and vulnerable populations^{267,268}. Not doing so forces health
728 systems towards more expensive “rescue” solutions like dialysis, which
729 exacerbate inequities⁹¹.
730 Socio-economic status relates differently to healthy lifestyle across the globe,
731 with higher socio-economic status being related to lower risk of NCDs in high-
732 income settings, but higher NCD risk in lower-income settings as middle classes
733 emerge^{73,269}. Modification of these inherent sources of inequity requires a
734 multi-sectoral approach to health and well-being such as that embodied by the
735 SDGs, as well as population education about healthy lifestyle^{233,270}.

736

737 *Data required to support decision making*

738 The core social determinants that make up the building blocks of health
739 represent societal injustices in how governments and authorities prioritise the
740 vulnerable, spend resources on those in need, and ensure adequate provision
741 for those affected by ill health. To motivate those who have power to act,
742 knowledge and understanding must be guided by good quality data, moral
743 advice, and a society that holds policymakers to account. Social and healthcare

744 data from real-life practice, research efforts and actions by charities/NGOs
745 should be integrated to improve the availability of meaningful intersectional
746 health. Decision-making and priority setting processes are hampered when
747 incidence, prevalence and health-economic data is lacking²¹⁷. Countries must
748 invest in systematic data collection to permit understanding of disease burden,
749 distribution, costs of care, financial hardships incurred, and to identify and
750 address inequities. Rigorous health technology assessments, based on reliable
751 local evidence of disease burden and costs to the health system and to
752 individuals, are required to support priority setting.

753

754 *Facilitate fair reimbursement of treatment costs*

755 Universal Health Care (UHC) is a crucial target of the SDG3²⁷¹. True UHC is
756 needed to prevent exclusion of the disadvantaged and reduce inequities²⁷²
757 (Figure 3). Even if UHC is not currently affordable, governments should commit
758 to its expansion through transparent processes, to progressively realize the
759 right to health for all²³⁰, with stepwise inclusion of expensive therapies, when
760 this becomes possible. Clear societal thresholds should be set regarding the
761 willingness to pay for gain of Quality Adjusted Life Years (QALYs), accounting
762 for the medical need and affordability, also called Value Informed and
763 Affordable Pricing²⁷³. Such processes should not only include cost and disease
764 burden, but must also take financial hardship and equity into account²⁷⁴. For
765 example, two health sector interventions which score highly in terms of equity
766 in the poorest nations are acute dialysis and kidney transplantation for
767 children, but lack of cost-effectiveness data precludes their recommendation
768 for coverage²⁷⁵. Cost-effectiveness analyses can however only be based on
769 intervention studies including diasadvantaged groups.

770

771 *Improve affordable care*

772 Technologic options like hemodialysis should be made affordable and more
773 reliable, accounting for the harsher conditions frequently encountered in low
774 resource situations (e.g. more resistant to heat, humidity, energy-efficient)²⁷⁶.
775 Costs for dialysis supplies can be reduced by waiving importation taxes or by
776 local production of PD material^{190,228}. In higher-resource settings, home dialysis
777 uptake could be stimulated through financial incentives, policy measures (PD
778 first), fair price setting by industry, patient education, and benchmarking²⁷⁷.
779 Health systems should be strengthened to include safe and legal
780 transplantation programs.

781

782 ***Local level***

783 *Raise awareness of kidney diseases*

784 All those concerned with kidney health and care (including non-professionals)
785 have a responsibility to be aware of and to create awareness of the problems
786 related to kidney diseases²⁵. This includes addressing the causes and
787 consequences of the structural determinants of health which entrench
788 inequities. Healthcare professionals should be trained throughout their studies
789 and continued education to identify and address these problems through
790 advocacy and/or concrete measures²⁷⁸. Patient associations and NGOs play an
791 important role in this process to improve equity and should engage in training
792 initiatives to optimize their own advocacy skills^{31,279}. Patients must raise their
793 voices in holding healthcare planners and leaders to account, activate
794 partnerships for harmonization among regions/countries and expose
795 organizational shortcomings, e.g. calling for availability of specific medication,
796 dialysis or transplantation.

797

798 *Improve accessibility of equitable quality care*

799 Holistic kidney care requires strong health systems and public health strategies
800 to reduce burden of kidney diseases, and to promote early detection and
801 treatment, integration of kidney care into existing programmes for NCDs and
802 some infectious diseases, and reduction of organ specialty-linked silos. The
803 common diagnostic tools for kidney diseases (serum creatinine and
804 albuminuria) are simple and affordable in many (but not all) countries, and
805 should be made available as much as possible, but also ensuring this is followed
806 by appropriate interpretation and therapeutic intervention. Primary care and
807 non-nephrology physicians and other healthcare workers could play an
808 essential role, but may be insufficiently familiar with kidney diseases and
809 should be educated appropriately^{18,280}. Since kidney patients have multiple
810 comorbidities and require multiple healthcare providers, integration of care is
811 quintessential. Capacity building and audit-based education may support
812 implementation of appropriate preventative measures²⁸¹. Accessibility of
813 essential medications should be assured to permit early intervention and
814 stop/delay progression of acute and chronic kidney diseases. Telemedicine and
815 eHealth should be harnessed for remote outreach²⁸². Quality assurance
816 activities, including tracking of inequities, should be integrated into clinical
817 routines.

818

819 *Avoid cherry-picking*

820 In poorly designed pay-for-performance systems, self-interest with utility as the
821 prevailing principle could lead clinicians, hospitals and dialysis units to target
822 high throughput by favoring inclusion of patients with greater resources and
823 more favourable (less complex) clinical characteristics²⁸³. If applied to the
824 extreme, this morally dubious practice creates an additional disadvantage for

825 the less privileged, as they will start with less favorable conditions and will be
826 driven towards less favorable therapeutic environments²⁸⁴. Conflicts of interest
827 may lead to fewer transplantation referrals from private dialysis units²⁸⁵.
828 Reporting and monitoring of patient mixes and outcomes is mandatory,
829 especially in dialysis units where this data is easily obtained.

830

831 ***Individual level***

832 *Tackle health illiteracy*

833 To improve health literacy, a coordinated health systems approach informed by
834 consumers and representatives of the concerned groups is needed, with
835 adapted and innovative educational methods to meet various needs. Specific
836 support may be needed for children and families affected by kidney diseases,
837 to optimize adherence and minimize disruptions associated with the high
838 demands of kidney care.

839 One system level change adopted in other chronic diseases such as diabetes is
840 the introduction of navigators^{120,125}, who assist patients and caregivers in
841 understanding diseases and treatments and optimize self-care. Such programs
842 have been successful in remote parts of Australia with Indigenous People. In
843 the US, animation has been applied successfully for diabetes education where
844 language barriers exist²⁸⁶. Medical professionals need to recognize their own
845 limitations in terms of social and cultural literacy. Since medical professionals
846 are usually not well-trained in education, advice should be sought from experts
847 in other fields (e.g. pedagogy, animation, telecommunication, health
848 illiteracy)²⁸⁷⁻²⁸⁹.

849

850 *Patient empowerment*

851 A move from paternalistic care (doctors making decisions without patient
852 input) to shared decision making (decisions guided by deliberation between
853 individual patients, their caregivers and practitioners)^{290,291} as an approach to
854 enhance equity in therapy choice contributes to more patient satisfaction,
855 adherence and health²⁹². All steps should be reported transparently, which
856 helps to avoid imposing therapies for financial or other reasons that may not
857 benefit the patient. Patient organizations may play a central role in facilitating
858 this shift of paradigm. When interacting with patients, decreases in cognitive
859 function should be taken into account, especially in advanced CKD²⁹³, as this
860 common complication affects alertness and hinders fast and accurate decision
861 making. Extra care must be taken in children with kidney diseases and their
862 families to enhance understanding of kidney care and cooperation.

863

864 **Conclusions**

865 Kidney diseases are associated with significant inequities that increase risk and
866 are imposed by the many social and structural factors, the relative invisibility of
867 the condition as a public health threat, and the time- and resource-intensive
868 therapies required for advanced disease, especially dialysis.

869 All professionals involved in kidney care should be alert for local inequities and
870 their impact on patient lives, as well as those occurring on a broader, regional,
871 national and international level. Recognition is the first step towards
872 developing actionable solutions.

873

874 Inequities include those specific to countries and regions, among social groups,
875 and those related to accessibility of preventive and therapeutic modalities. In
876 addition to adverse clinical outcomes, inequities also raise health economic and
877 ethical concerns, and are heavily compounded by non-medical social and

878 structural determinants such as poverty, social injustice, violence, racism, lack
879 of education, and cultural and religious barriers.

880 Solutions range from the individual to the global level. Awareness of potential
881 solutions is important to encourage advocacy and action by all stakeholders.

882 Although not all solutions may be universally applicable or implemented, there
883 is a collective need to develop and implement innovative strategies to tackle
884 barriers to equitable kidney health and kidney care. All nephrology
885 professionals should have the conviction to advocate within their communities,
886 armed with local and international data, and to engage with policy makers,
887 administrators and insurers, to raise awareness about inequities in kidney
888 health and to improve kidney care across the globe.

889

890 Keypoints:

- 891 - Insufficient investment across the spectrum of kidney health and kidney
892 care (from awareness raising, to prevention, diagnosis and treatment) is
893 a fundamental source of inequity. This affects all people at risk of, or
894 living with, kidney diseases.
- 895 - Social and structural inequities are major risk factors for, and contribute
896 to, poorer outcomes in kidney diseases both within and between
897 countries.
- 898 - There is insufficient accessibility of essential diagnostics and medications
899 to treat kidney diseases and to track their burden. This disadvantages
900 patients in low- and middle-income countries from the very beginning of
901 their disease course.
- 902 - Ability to access the entire spectrum of kidney care (from basic
903 medication to dialysis and transplantation) without experiencing
904 financial hardship is very inequitable across the globe. Transplantation is
905 the most equitable form of kidney replacement therapy, but is highly
906 unaccessible in lower income settings. This results in vastly different
907 outcomes and life courses for patients with the same diseases living
908 under different circumstances.
- 909 - Novel therapies for rare (orphan) diseases are often only available at
910 extremely high prices, which frequently affects or excludes children and
911 adolescents.
- 912 - All nephrology professionals should become skilled at advocating on
913 behalf of their patients to communities, policy makers, administrators
914 and insurers, to develop constructive strategies and collectively reach
915 optimal solutions to improve equity in accessibility of quality kidney care
916 locally and across the globe.

917

918 **CAPTIONS TO FIGURES**

919 **Figure 1:** Factors contributing to inequities by increasing risk and by affecting
920 accessibility of preventative measures, care and therapies. The description
921 considers global, national/regional, community-related, health system-related
922 and individual elements.

923 **Figure 2:** Ethical dilemmas in inequitable accessibility of kidney care: from
924 global to local.

925 **Figure 3:** The Universal Health Coverage cube: expanding universal healthcare
926 coverage for kidney diseases in low resource settings. The health needs of the
927 population are depicted by the larger transparent box, the funds available for
928 health financing are depicted in the blue box. In many high-income countries
929 the size of the blue and the transparent boxes are very similar (almost all
930 health needs are covered), whereas in low resource settings the blue box is
931 considerably smaller than the transparent box, meaning that many health
932 needs that do not fall within the blue box are not covered by the health system
933 and must be provided/paid for by individuals. As countries set health priorities
934 and expand their health coverage they must consider the impact across all 3
935 dimensions: who should be covered, which services should be provided and
936 how much of the costs can be covered by the health system. KRT falls outside
937 of the blue box in most low-resource settings. Suggestions here include how
938 accessibility of kidney care can be progressively expanded under universal
939 health coverage. Priority setting must consider prevalence of a condition, cost
940 of therapeutic options and available resources. AKI: acute kidney injury; CKD:
941 chronic kidney disease; KRT: kidney replacement therapy; CHE: catastrophic
942 health expenditure. *: data on disease burden missing in many places.

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944 “Making fair choices on the path to universal health coverage: final report of
945 the WHO consultative group on equity and universal health coverage.
946 [https://apps.who.int/iris/bitstream/handle/10665/112671/9789241507158_en](https://apps.who.int/iris/bitstream/handle/10665/112671/9789241507158_eng.pdf?sequence=1&isAllowed=y)
947 [g.pdf?sequence=1&isAllowed=y](https://apps.who.int/iris/bitstream/handle/10665/112671/9789241507158_eng.pdf?sequence=1&isAllowed=y) Figure 1.1, page 5, Copyright (2014).”

948

Box 1: Motivating scenarios for inequitable care specific groups of people

Social and economic position

"When you enter through the emergency department, you arrive in bad shape...you need to have a high potassium or they send you home even though you feel you are dying. Sometimes, you crawl out when they decide to not do dialysis. You eat a banana because it is high in potassium even though you may die and you go back and wait and hope that they will do dialysis so that you don't feel like you are drowning and so that the anxiety goes away."
(An undocumented immigrant in the USA receiving only emergency dialysis services)¹²³

"We have a population of about 30 million people and have less than 20 trained nephrologists. Unfortunately, due to lack of knowledge about kidney disease and its management, over 70% of patients report late to the teaching hospital with kidney failure and since care is not reimbursed by the National Health Insurance scheme, about a third of patients with kidney disease die on admission for which we have to sign death certificates and this does not include those who are stable enough to be discharged home with no hope of sustaining themselves on dialysis. It's really sad. Without money you die when you have kidney failure."

(A health professional's perspective on kidney care in Ghana)¹²⁶

Discrimination

"In my doctors they used to have this thing that when you signed in it was on a screen and you had to select in front of everyone in the waiting room whether you were male or female. Even that half a second just breaks my brain every time and I'm like, I kind of don't want to go to this appointment now".

(An LGBTQ+ patient on attending their appointment)¹²⁷

"My doctor[s]... be shocked when I asked them, well why is there so many Black people on dialysis and they don't have no real answer for me. I really don't like that. And so then on top of that he only spends ninety seconds with me... I'm like wow, I feel like cattle."

(A patient receiving dialysis discussing mistrust in their nephrologists connected with race)¹²²

Inequity within algorithms and guidelines

A 54 year old woman of mixed race is opportunistically found to have a low eGFR when attending hospital with a minor injury. She is advised that this is probably due to muscle mass and goes home. Several months later she reattends hospital in need of emergency dialysis.

"The insights about sexist and racist biases... are important because information organizations, from libraries to schools and universities to governmental agencies, are increasingly reliant on being displaced by a variety of web-based "tools" as if there are no political, social, or economic consequences of doing so."

(Safiya Umoja Noble, on reinforcing structural discrimination by use of algorithms)²⁹⁴

Health literacy

"I'd say about the hardest part was when he was on the prednisolone when he's on a high dosage, it's very lunatic. And then we went to the doctor to what's going on. Oh, it's the prednisolone. It causes anger and stress. So, more information and education of the carers as to what possible side effects could be and talk to you about this is what's going to happen."

(A caregiver's perspectives on kidney transplant aftercare and education)¹¹⁵

"I would have really liked to have sat and talked with somebody who had gone the journey before me, and to give me a heads up on about what I'm going to experience from the importance of taking the medication, understanding what the kidney function is in my body, understanding about my fluids, my nutrition, all of those coming together of the importance, because as a primary school teacher, you're having to say it at least 20 times before it clicks."

(A care partner)¹²⁵

"All the patient navigators that I've met, have been on dialysis and going through transplant and their second transplant. They know exactly what it's like to sit in that chair, and have treatment for hours on end, the restrictions that you're on, the medications that your body must handle after transplant. And although someone can sit and tell you about this importance, I think it comes at another level with someone else who's experienced that and been successful, and that you can draw on and build a relationship with, and it's kind of upskilling."

(A patient's perspective of lay navigators)¹²⁸

Geography and accessibility of care

J lives in a town with no dialysis services, the closest is 175kms away. He is ineligible for a transplant or home dialysis. His only choice is to move or receive conservative care.

"Just the understanding, like if you're having a transplant, you've got to deal with the city hospital and they say, "Okay, I'll book you in 8:00 in the morning, tomorrow morning, can you make it?" Well, I live in XXX. All right, well can you travel? Well, it's six hours away and I've got a family to organize and I'm on dialysis so it's like they don't get it. And then they'll say, "Come back next week and see me." Like, you're kidding. Can't you have

the one stop thing?”
(A patient experience of lack of accessible care due to remoteness)¹²⁵

950

951 Abbreviations: LGBTQ+, lesbian, gay, bisexual, transgender, queer, and other

952

953

954

955

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977

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Table 1 – Barriers to optimal kidney care

	Patient level (inherent to kidney diseases and care)	Health system level (inherent to organisation of healthcare)	Population level (inherent to environment)
Chronic Kidney Disease*	<ul style="list-style-type: none"> • Lack of symptoms in early stage kidney diseases • Lack of awareness of symptoms of kidney diseases • Late diagnosis of kidney disease due to lack of appropriate screening of those at risk • Late diagnosis of kidney disease due to long asymptomatic phase • Late start of measures to prevent kidney disease progression • Inadequate monitoring, surveillance and treatment • Poor health literacy associated with lower concordance with medications, clinical plans, dietary requirements • Instability of living environment (financial resources, housing, recreation facilities, freedom of persecution or war) 	<ul style="list-style-type: none"> • Inadequate screening for kidney disease in at risk populations • Lack of funding of prevention • Unavailability or lack of reimbursement of kidney function tests • Shortage and brain drain of nephrologists and shortage of kidney centres • Lack of healthcare funding for expensive drugs • Limitation of healthcare provision or reimbursement to certain groups or certain therapeutic options • Lack of education of primary and secondary healthcare professionals regarding early signs of kidney disease and when to refer to specialist teams • No consideration of priorities and outcomes that matter to patients 	<ul style="list-style-type: none"> • Lack of accessibility of healthy food, clean water, health facilities • Healthy diet and lifestyle may be unaffordable for some people • No financial incentives to stimulate healthy diet and lifestyle • Unhealthy or polluted living areas or working conditions • Working conditions in conflict with health needs (e.g. to attend check-up appointments) • Population burden of diabetes, obesity and hypertension is exacerbated by social determinants of health • Inadequate dietary information for population, e.g., on salt intake • Religion, culture or tradition may interfere with optimal solutions for kidney health • Discrimination of race or minorities

	<ul style="list-style-type: none">• Distrust, fear and misunderstanding of health professionals• Language barriers• Follow-up by (too) many healthcare providers due to multimorbidity• Competing complications and outcomes may disturb decision making• Difficult to treat symptoms (fatigue, itching) may disturb confidence in care providers• Chronic stress without sufficient adaptive coping strategies• Cognitive dysfunction, visual and hearing impairment, learning difficulties, mental illness) hamper decision making• Inability to pay for drugs• Expensive special diets• Potential loss of income attending outpatient clinics• Complexity of required decisions• Distrust of healthcare system• Fear of stigmatisation• Unavailability of personal health insurance	<ul style="list-style-type: none">• Lack of training of healthcare professionals on how to provide culturally appropriate care and how to deal with discrimination, unconscious bias or health illiteracy• Lack of research and research funding on kidney health and care• Unavailability of structural health insurance (universal health insurance coverage)	<ul style="list-style-type: none">• Lack of education of general population on kidney health and care
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	<ul style="list-style-type: none"> • Non-adherence augmented in adolescents • Stigmatization 		
Dialysis	<ul style="list-style-type: none"> • Inadequate accessibility of pre-dialysis nephrology care • Inability to engage in decision making regarding choices / health illiteracy • Ageing and frailty • Dependence on family and social support which is not always available • Inability to pay out-of-pocket expenses • Distance from kidney centre • Certain options (home hemodialysis, peritoneal dialysis, self-care) not available • Long-term dependence on life-saving treatment as cause of lack of adherence • Accesibility problems in humanitarian crises (wars, refugees, undocumented migrants) • Child size limits dialysis possibilities 	<ul style="list-style-type: none"> • Availability of dialysis facilities • Government funding • Education of healthcare providers about dialysis options • Number of nephrologists and specialist dialysis nurses • Availability of multi-professional teams for psychosocial support • Availability of dialysis-related drugs e.g., erythropoietin • Insufficient possibilities to diagnose, prevent and treat acute kidney injury • Unconscious/structural biases of healthcare providers, favouring patients of their own age, sex, and social and ethnic background • Limitation in availability of dialysis modalities – PD and HD variably accessible 	<ul style="list-style-type: none"> • Lack of awareness of dialysis options • Lack of medical support for comorbidities • Lack of welfare support for patients • Urban vs. rural living area • Geographic distribution of dialysis centers

Conservative care	<ul style="list-style-type: none"> • Inadequate accessibility of pre-dialysis nephrology care • Inability to engage in decision making regarding choices / health literacy • Dependence on family and social support which is not always available • Cultural / religious beliefs perturbing decision making • Lack of training of health care workers 	<ul style="list-style-type: none"> • Lack of respect for patient autonomy and shared decision making • Lack of government funding • Lack of training in decision making related to frailty • Lack of vision or know-how on person-centred care • Unavailability of palliative care • Unavailability of community / primary care 	<ul style="list-style-type: none"> • Skewed healthcare beliefs regarding end-of-life decision • Religion, philosophy, culture or tradition interfere with decision making • Family members or acquaintances may impose their views
Transplantation	<ul style="list-style-type: none"> • Perturbing inaccurate knowledge and beliefs • Socio-economic situation and inability to afford long-term medications • Racial/ ethnic/gender/ cultural inequities and differences • Concern for living donor (hesitancy to ask) • Dependence of caregivers and family support • Co-morbidities • Risk of recurrence of primary disease (e.g. aHUS) • Availability limited by need for matching • Child size limits transplantation possibilities 	<ul style="list-style-type: none"> • Lack of government funding • Unavailability of transplant program • Unavailability of immunosuppression • Delayed nephrology referral and referral for transplantation • Lack of health literacy support for education regarding transplantation • Systemic racism • Lack of transplantation workup tests and protocols • Certain options (e.g. pediatric transplantation, living donation, organ exchange programs, cross-over 	<ul style="list-style-type: none"> • Lack of awareness and community education regarding organ donation • Opt-in versus opt-out deceased organ donation policy • Inadequate organ allocation algorithms • Population disease burden • Centralisation of transplantation services to major metropolitan areas. • Government policies for financial support of living donors and recipients insufficient • Unavailability of transplantation registry • Cultural and legal restrictions

		<p>programs, altruistic donation) not available</p> <ul style="list-style-type: none">• Presence of co-payments• Lack of transparent centralised organ allocation service• Unconscious/structural biases of healthcare providers, favouring patients of their own age, sex, and social and ethnic background	
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*: Applies to all CKD care (also dialysis, transplantation, conservative care)

Table 2: Health-economic sources of inequity, depending on the country's financial status

Higher income countries*	Lower income countries
Selection bias in favor of health literate for home dialysis and transplantation leaving those remaining in-center at high risk of certain complications (e.g. COVID-19)	Countries with lower incomes invest proportionally more of their healthcare budget in (in-center) hemodialysis, making less funds available for measures that would benefit more people (e.g. prevention of CKD)
Higher uptake of peritoneal dialysis and home hemodialysis in wealthier countries	Unavailability of the therapeutic options with the lowest societal or out-of-pocket cost (prevention, transplantation, home dialysis) because of organizational or infrastructural problems
Lack of adequate screening and prevention programs creates a disadvantage for the deprived, health illiterate and minoritized communities who face barriers in obtaining health care	No or inadequate screening and prevention and no or inadequate education will cause large groups or regions to be missed out
Educational initiatives, if any, are not adapted to health illiteracy, culture, language	Educational initiatives, if any, are not adapted to health illiteracy, culture, language
Higher risk for employment loss and financial disadvantage for less educated and deprived if they suffer from NCDs including CKD	High risk of employment loss and financial disadvantage for less educated and deprived if they suffer from NCDs including CKD
Even if KRT is fully reimbursed, if there are remaining out-of-pocket costs these will be more problematic for the deprived (e.g. for transportation, medication co-payments) potentially leading to abandoning KRT	If KRT is not reimbursed, risk of impoverishment for patients and their families until all resources are exhausted and treatment must be abandoned
Even if KRT is fully reimbursed, if there is no global educational and financial support for approaches for early diagnosis and prevention of progression towards kidney failure, including preventive	Insufficient resources to pay or reimburse basic preventive medication (antihypertensives, antidiabetics) will especially harm the deprived

medication. Accordingly, deprived populations may be at higher risk of progression, because of fewer opportunities to make healthy choices	
Shortage of workforce for delivery of care will especially be felt by financially deprived	Shortage of workforce for delivery of care may be more substantial in lower income countries
	Medical technology (dialysis) not adapted to local conditions (heat, humidity), no possibilities for repair, no financial resources
	Two-tiered health care systems (public for the poor and private for the rich) are a basic form of inequity although not necessarily resulting in unequal quality of therapy)
	If no universal health care insurance, only the rich, the employed and certain classes (e.g. government officials) will be covered
	Money invested in reimbursement of dialysis cannot be invested in prevention
	The poor in lower income countries may be forced to sell their kidneys, and as a consequence may be victim of criminal, unethical or harmful practices

*: the dichotomy between higher and lower income country is artificial and only for illustrative reasons. There may also be exceptions to these general principles.

NCDs: non-communicable diseases; CKD: chronic kidney disease; KRT: kidney replacement therapy

Table 3: Examples of ethical dilemmas caused by structural inequities in nephrology

Case – by Level of Care	Sources of Inequity	Ethical Dilemmas Arising from Inequity
<p style="text-align: center;">Primary Level</p> <p><u>Poor accesibility of primary care and preventative kidney care</u> A 35-year-old mother of 3 from a poor rural farming background in a LIC was diagnosed with gestational diabetes, pre-eclampsia and proteinuria during her third pregnancy. At her postnatal check fingerstick blood glucose and BP were still elevated. She was advised to get HbA1c, urine albumin creatinine ratio and kidney function testing but these were not available in the primary healthcare center nearby. The woman’s family, not wanting to spend money on travel to a nearby city for care, instead took her to a traditional medicine practitioner. When the woman became too fatigued to carry out her household duties, she was brought to a referral hospital where diabetes, hypertension and proteinuria were confirmed. In addition to ACE inhibitors, SGLT2 inhibitors were considered. The medical team contemplated on enrolling her in a clinical trial of SGLT2 inhibitors but all studies required frequent clinic visits that were considered too burdensome for the family. The woman’s family decided to continue whatever care was available at the primary care center and in addition resumed traditional medicine.</p>	<ul style="list-style-type: none"> • Poverty • Poor primary healthcare • Low health literacy • Discrimination against women • Effective medications too expensive • Inequitable inclusion in clinical trials • Cultural mistrust of regular medicine • Lack of universal health care 	<p><u>Adverse effect of Social Determinants of Health on Outcomes and the principle of Justice:</u></p> <ul style="list-style-type: none"> • The woman’s social determinants of health (low socioeconomic status, sex and geographic location) very likely affected her possibilities to obtain primary care and prevention of progression of kidney disease. • Are these differences avoidable through better governance or change in circumstances (would a woman with the same disease living in a wealthy urban educated family have had better possibilities to obtain preventative care?). If yes, then the inequality in outcome is unfair, and addressing this inequity is a moral imperative. <p><u>Gender Discrimination</u></p> <ul style="list-style-type: none"> • inclusion into clinical research and thus determination of efficacy of important preventive medications are unfairly biased against women who are pregnant or breastfeeding. This inequity must be addressed to improve outcomes.
<p style="text-align: center;">Secondary Level</p> <p><u>Poor accesibility of early diagnosis and treatment</u></p>		<p><u>Poor prioritization of pediatric kidney disease</u></p>

<p>During an antenatal ultrasound of a 20-year-old woman's first pregnancy in an LMIC, a kidney and bladder anomaly of the fetus was suspected. Unable to travel to the maternal-fetal referral center 250 km away, she delivered a low birth weight male at home. The infant did not feed well, had a poor urinary stream and became progressively lethargic. At the primary health center, he received some antibiotics, improved and was discharged. After multiple similar admissions and persistent failure to thrive, at the age of one, he was referred to a private pediatric nephrology center 300 km away where the parents had to pay out-of-pocket for care. The possibilities for an effective treatment in the private center in that country were considered minimal.</p> <p>By this time the child already had growth failure, rickets, blood urea of 200mg/dL and a serum creatinine of 4mg/dL. At work-up a diagnosis of posterior urthelial valves (PUV) was made. The family was told about the need for expensive surgery to treat the PUV to salvage some kidney function and possibility of dialysis. Unable to afford care, they left against medical advice.</p>	<ul style="list-style-type: none"> • Geographic remoteness • Poverty • Inadequate accessibility of effective maternal screening • Low awareness of pediatric kidney disease • Inadequate pediatric kidney care services • Poor public-private partnership rendering treatment unaffordable • Poor social services support for children • No accessibility of UHC 	<ul style="list-style-type: none"> • In low resource settings, funding pediatric kidney disease detection (by good perinatal follow-up of structural anomalies) is of low priority for governments. Thus accessible public sector care is inadequate, resulting in late diagnosis, high morbidity and poor outcomes. <p><u>Where UHC is absent, ability to pay determines outcomes</u></p> <ul style="list-style-type: none"> • When specialized pediatric care is only available in the private sector, life-saving therapy is accessible only for those who can afford to pay. This violates the ethical principle of justice <p><u>Parental refusal of treatment</u></p> <ul style="list-style-type: none"> • Refusal of treatment by the parents is undoubtedly against the best interest of the child. However, given the expense to family should we consider the interests of the family as well? Patient families in LIC and LMIC often exhaust all their financial resources without reaching positive outcomes (no cure and no transplantation). This morally distressing question results from inequitable accessibility of care.
Tertiary Level		
<p><u>Case 1: Rationing Dialysis</u></p> <p>A 50-year-old father of 3 with kidney failure due to type 2 diabetes in a MIC was assessed by the healthcare team for eligibility for the single remaining spot for government-funded maintenance dialysis. He was not considered a candidate for kidney transplantation due to his diabetes complications and was denied dialysis.</p>	<ul style="list-style-type: none"> • Rationed availability of free or low cost dialysis • Age-based discrimination • Disease-based discrimination • Rationing policies favoring those with 	<p><u>Ethical challenges of rationing life-saving therapy</u></p> <ul style="list-style-type: none"> • Rationing access to dialysis may result in biased unethical decisions based on prejudices related to age, sex, race or socioeconomic status • The patient's ability to exercise his autonomy to make treatment choices is constrained by (lack of) policy

<p>Unable to pay for dialysis in the private sector, he was forced to accept palliative care. By policy, a younger patient with no comorbidities was deemed eligible instead.</p>	<p>highest likelihood of survival (utilitarianism)</p>	<ul style="list-style-type: none"> • Forced rationing decisions result in moral distress amongst physicians forced to deny life-saving care to patients • Ensuring distributive justice (a fair, transparent, equitable priority-setting process with stakeholder input) is essential for policy makers but is rarely applied
<p><u>Case 2: Inequitable global accessibility of transplantation</u> A 50-year-old wealthy man with kidney failure in a MIC desired kidney transplantation. There were no compatible living donors in his family and his native country had no deceased donor transplant program. He travelled to a private sector, for-profit hospital in a LMIC accompanied by a 50-year-old woman, from a lower socioeconomic background. The patient claimed she was a distant cousin. He requested living donor transplantation be performed and furnished a government certificate giving clearance for altruistic kidney donation. Communicating with the recipient and his donor was limited and required an interpreter. Paid donation was suspected but could not be proven. After the transplantation, the patient returned for care to his native country. The donor was never seen with the patient again and did not show up for follow-up care.</p>	<ul style="list-style-type: none"> • Poor accessibility of deceased donor transplantation • Necessity for physicians to rely on living donation as only option for transplantation • Inadequate surveillance process and legal framework to prevent organ trafficking 	<p><u>Inequitable accessibility of donor transplantation drives people to organ trade and unjustly exploits donors</u></p> <ul style="list-style-type: none"> • Without UHC, transplantation is largely inaccessible to the poor • Although paying for donor evaluation and surgery to ensure financial neutrality is acceptable, offering donors financial gain is unethical and illegal • Trafficked donors have poor health and economic outcomes • Trafficked donors are often unfairly exploited by intermediary persons Organ trafficking remains a serious and prevalent problem despite global condemnation. • Nations may have a moral obligation to provide deceased donor transplantation services to their citizens • Nations have a major obligation to combat paid donation via legal and judiciary means, but this is often neglected • Preventing organ trafficking is a global responsibility but the burden of decision making unfairly falls most on healthcare providers.

Case 3: Caregiver burden

A 15-year-old boy with PUV in a rural area of a HIC was initiated on PD in a city 450 km from his home. The indigenous family had owned a farm for 3 generations. His parents incurred high out-of-pocket costs for travel to a pediatric nephro-urology centre and lost income during monthly clinic visits. When his mother initiated work-up for a living donor transplantation, the hospital visits became more frequent. The family decided to sell their farm to move closer to the city where they had no family or friends. The mother stayed home to be the primary caregiver. The father relied on daily odd jobs, the family's income plunged and the existence of all centered around keeping the boy alive.

- Inadequate accessibility of pediatric focused KRT
- Geographic remoteness reduces accessibility of care
- Poor support for living donor indirect costs
- Caregivers not provided with enough social support

Caregiver burden worsened by socioeconomic and demographic factors

- Patients in remote areas face unfair obstacles to accessing care and a greater financial burden.
- It is unfair that caregivers of kidney failure patients be expected to shoulder these burdens
- To satisfy the principle of justice and non-maleficence, clinicians might consider discussing these burdens with caregivers before beginning dialysis but this may lead to a difficult and uneasy conversation
- The inequitable accessibility of care unfairly burdens indigenous populations, minorities and immigrants

HIC: high income country; LIC: Low income country; LMIC: low middle income country; MIC: middle income country; BP: blood pressure; HbA1C: hemoglobin A1C; PUV: posterior urethral valves; UHC: universal health care; PD: peritoneal dialysis; KRT: kidney replacement therapy
Case stories are based on the clinical experience of the authors.

Table 4: Opportunities for stakeholders to mitigate inequities

STAKEHOLDER GROUP	ATTENTION POINTS
Patients, patient organizations	<ul style="list-style-type: none"> - Raise patient voices - Raise awareness of CKD - Advocate for fair therapeutic price setting - Advocate to combat inequities - Facilitate empowerment and communication training - Include people from all origins and social classes in their activities
Nephrology professionals	<ul style="list-style-type: none"> - Self-awareness of own socio-cultural knowledge/communication limitations - Listen to patient voices - Favour patient empowerment - Increase advocacy efforts to draw appropriate attention to kidney diseases - Embed structural competency in the training process, including inequities and their mechanisms, and apply approaches to avoid those, e.g. by shunning racism and paying special attention to health illiteracy - Steer clear of therapeutic cherry picking - Use language translation - Increase diversity among nephrology work force - Share equipment and expertise with emerging countries
Nephrology societies	<ul style="list-style-type: none"> - Lead by example, ensure diverse and equitable global representation - Include local experts in guideline committees, decision-making, research calls - Include sessions devoted to equity in their meetings and congresses - Collect reliable data on disease burden, costs and inequities related to CKD - Generate a shift of mind from cure to screening and prevention, by engaging with policy makers, those involved in healthcare design, and funders - Achieve harmonization among countries by support and exchange of information - Create patient education materials adapted for language and culture - Advocate at regional and global level
General educators	<ul style="list-style-type: none"> - Ensure all children, both boys and girls, have access to quality education - Include health in education - Promote healthy lifestyle through education about food, exercise, smoking, alcohol etc - Provide healthful food and sport opportunities in schools

Medical educators	<ul style="list-style-type: none"> - Ensure diversity among educators - Include inequities in the educational curricula - Improve teaching about kidney diseases and especially their diagnosis and prevention - Consciously act as role models
Researchers, developers	<ul style="list-style-type: none"> - Develop therapeutic options that are affordable for all - Ensure that newly promoted approaches are made available and evaluated across subsets where inequities may occur - Prioritize research that focuses on equity and accessibility of kidney care in disadvantaged populations - Prioritize research on health illiteracy - Develop and study approaches to prevent CKD or progression of CKD - Be conscious of the risks of research in exacerbating inequities - Include patients with kidney diseases in clinical trials, including in non-kidney areas (e.g. cardiology, oncology) - Ensure diverse representation of patients included in clinical trials - Consider ethnic and sex/gender aspects in clinical trials, drug metabolism, patient reported outcomes
Pharmacological and medical technology sectors	<ul style="list-style-type: none"> - Develop therapeutic options that are affordable for all - Develop and study approaches to prevent CKD or progression of CKD - Being transparent on investments in therapy development and real cost of therapies - Apply fair prices and fair profit principles - Register and distribute therapeutic products (e.g. peritoneal dialysis fluids) in all countries
Governments, administrations, insurers	<ul style="list-style-type: none"> - Acknowledge CKD as a public health problem - Collect reliable data on disease burden, costs and inequities related to CKD to support priority setting - Negotiate fair price setting of medications - Favour affordable therapies and therapies with high value-for-money, without further exacerbation of inequities - Aim for progressive expansion of universal health coverage - Generate a shift of paradigm from focus on cure towards focus on screening and prevention - Achieve harmonization among countries by support and exchange of information - Apply reimbursement models that disincentivize cherry picking - Stimulate and finance research on health inequities and health illiteracy

Table 1 – Barriers to optimal kidney care

	Patient level (inherent to kidney diseases and care)	Health system level (inherent to organisation of healthcare)	Population level (inherent to environment)
Chronic Kidney Disease*	<ul style="list-style-type: none"> • Lack of symptoms in early stage kidney diseases • Lack of awareness of symptoms of kidney diseases • Late diagnosis of kidney disease due to lack of appropriate screening of those at risk • Late diagnosis of kidney disease due to long asymptomatic phase • Late start of measures to prevent kidney disease progression • Inadequate monitoring, surveillance and treatment • Poor health literacy associated with lower concordance with medications, clinical plans, dietary requirements • Instability of living environment (financial resources, housing, recreation facilities, freedom of persecution or war) 	<ul style="list-style-type: none"> • Inadequate screening for kidney disease in at risk populations • Lack of funding of prevention • Unavailability or lack of reimbursement of kidney function tests • Shortage and brain drain of nephrologists and shortage of kidney centres • Lack of healthcare funding for expensive drugs • Limitation of healthcare provision or reimbursement to certain groups or certain therapeutic options • Lack of education of primary and secondary healthcare professionals regarding early signs of kidney disease and when to refer to specialist teams • No consideration of priorities and outcomes that matter to patients 	<ul style="list-style-type: none"> • Lack of accessibility of healthy food, clean water, health facilities • Healthy diet and lifestyle may be unaffordable for some people • No financial incentives to stimulate healthy diet and lifestyle • Unhealthy or polluted living areas or working conditions • Working conditions in conflict with health needs (e.g. to attend check-up appointments) • Population burden of diabetes, obesity and hypertension is exacerbated by social determinants of health • Inadequate dietary information for population, e.g., on salt intake • Religion, culture or tradition may interfere with optimal solutions for kidney health • Discrimination of race or minorities

	<ul style="list-style-type: none">• Distrust, fear and misunderstanding of health professionals• Language barriers• Follow-up by (too) many healthcare providers due to multimorbidity• Competing complications and outcomes may disturb decision making• Difficult to treat symptoms (fatigue, itching) may disturb confidence in care providers• Chronic stress without sufficient adaptive coping strategies• Cognitive dysfunction, visual and hearing impairment, learning difficulties, mental illness) hamper decision making• Inability to pay for drugs• Expensive special diets• Potential loss of income attending outpatient clinics• Complexity of required decisions• Distrust of healthcare system• Fear of stigmatisation• Unavailability of personal health insurance	<ul style="list-style-type: none">• Lack of training of healthcare professionals on how to provide culturally appropriate care and how to deal with discrimination, unconscious bias or health illiteracy• Lack of research and research funding on kidney health and care• Unavailability of structural health insurance (universal health insurance coverage)	<ul style="list-style-type: none">• Lack of education of general population on kidney health and care
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	<ul style="list-style-type: none"> • Non-adherence augmented in adolescents • Stigmatization 		
Dialysis	<ul style="list-style-type: none"> • Inadequate accessibility of pre-dialysis nephrology care • Inability to engage in decision making regarding choices / health illiteracy • Ageing and frailty • Dependence on family and social support which is not always available • Inability to pay out-of-pocket expenses • Distance from kidney centre • Certain options (home hemodialysis, peritoneal dialysis, self-care) not available • Long-term dependence on life-saving treatment as cause of lack of adherence • Accesibility problems in humanitarian crises (wars, refugees, undocumented migrants) • Child size limits dialysis possibilities 	<ul style="list-style-type: none"> • Availability of dialysis facilities • Government funding • Education of healthcare providers about dialysis options • Number of nephrologists and specialist dialysis nurses • Availability of multi-professional teams for psychosocial support • Availability of dialysis-related drugs e.g., erythropoietin • Insufficient possibilities to diagnose, prevent and treat acute kidney injury • Unconscious/structural biases of healthcare providers, favouring patients of their own age, sex, and social and ethnic background • Limitation in availability of dialysis modalities – PD and HD variably accessible 	<ul style="list-style-type: none"> • Lack of awareness of dialysis options • Lack of medical support for comorbidities • Lack of welfare support for patients • Urban vs. rural living area • Geographic distribution of dialysis centers

Conservative care	<ul style="list-style-type: none"> • Inadequate accessibility of pre-dialysis nephrology care • Inability to engage in decision making regarding choices / health literacy • Dependence on family and social support which is not always available • Cultural / religious beliefs perturbing decision making • Lack of training of health care workers 	<ul style="list-style-type: none"> • Lack of respect for patient autonomy and shared decision making • Lack of government funding • Lack of training in decision making related to frailty • Lack of vision or know-how on person-centred care • Unavailability of palliative care • Unavailability of community / primary care 	<ul style="list-style-type: none"> • Skewed healthcare beliefs regarding end-of-life decision • Religion, philosophy, culture or tradition interfere with decision making • Family members or acquaintances may impose their views
Transplantation	<ul style="list-style-type: none"> • Perturbing inaccurate knowledge and beliefs • Socio-economic situation and inability to afford long-term medications • Racial/ ethnic/gender/ cultural inequities and differences • Concern for living donor (hesitancy to ask) • Dependence of caregivers and family support • Co-morbidities • Risk of recurrence of primary disease (e.g. aHUS) • Availability limited by need for matching • Child size limits transplantation possibilities 	<ul style="list-style-type: none"> • Lack of government funding • Unavailability of transplant program • Unavailability of immunosuppression • Delayed nephrology referral and referral for transplantation • Lack of health literacy support for education regarding transplantation • Systemic racism • Lack of transplantation workup tests and protocols • Certain options (e.g. pediatric transplantation, living donation, organ exchange programs, cross-over 	<ul style="list-style-type: none"> • Lack of awareness and community education regarding organ donation • Opt-in versus opt-out deceased organ donation policy • Inadequate organ allocation algorithms • Population disease burden • Centralisation of transplantation services to major metropolitan areas. • Government policies for financial support of living donors and recipients insufficient • Unavailability of transplantation registry • Cultural and legal restrictions

		<p>programs, altruistic donation) not available</p> <ul style="list-style-type: none">• Presence of co-payments• Lack of transparent centralised organ allocation service• Unconscious/structural biases of healthcare providers, favouring patients of their own age, sex, and social and ethnic background	
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*: Applies to all CKD care (also dialysis, transplantation, conservative care)

Table 2: Health-economic sources of inequity, depending on the country's financial status

Higher income countries*	Lower income countries
Selection bias in favor of health literate for home dialysis and transplantation leaving those remaining in-center at high risk of certain complications (e.g. COVID-19)	Countries with lower incomes invest proportionally more of their healthcare budget in (in-center) hemodialysis, making less funds available for measures that would benefit more people (e.g. prevention of CKD)
Higher uptake of peritoneal dialysis and home hemodialysis in wealthier countries	Unavailability of the therapeutic options with the lowest societal or out-of-pocket cost (prevention, transplantation, home dialysis) because of organizational or infrastructural problems
Lack of adequate screening and prevention programs creates a disadvantage for the deprived, health illiterate and minoritized communities who face barriers in obtaining health care	No or inadequate screening and prevention and no or inadequate education will cause large groups or regions to be missed out
Educational initiatives, if any, are not adapted to health illiteracy, culture, language	Educational initiatives, if any, are not adapted to health illiteracy, culture, language
Higher risk for employment loss and financial disadvantage for less educated and deprived if they suffer from NCDs including CKD	High risk of employment loss and financial disadvantage for less educated and deprived if they suffer from NCDs including CKD
Even if KRT is fully reimbursed, if there are remaining out-of-pocket costs these will be more problematic for the deprived (e.g. for transportation, medication co-payments) potentially leading to abandoning KRT	If KRT is not reimbursed, risk of impoverishment for patients and their families until all resources are exhausted and treatment must be abandoned
Even if KRT is fully reimbursed, if there is no global educational and financial support for approaches for early diagnosis and prevention of progression towards kidney failure, including preventive	Insufficient resources to pay or reimburse basic preventive medication (antihypertensives, antidiabetics) will especially harm the deprived

medication. Accordingly, deprived populations may be at higher risk of progression, because of fewer opportunities to make healthy choices	
Shortage of workforce for delivery of care will especially be felt by financially deprived	Shortage of workforce for delivery of care may be more substantial in lower income countries
	Medical technology (dialysis) not adapted to local conditions (heat, humidity), no possibilities for repair, no financial resources
	Two-tiered health care systems (public for the poor and private for the rich) are a basic form of inequity although not necessarily resulting in unequal quality of therapy)
	If no universal health care insurance, only the rich, the employed and certain classes (e.g. government officials) will be covered
	Money invested in reimbursement of dialysis cannot be invested in prevention
	The poor in lower income countries may be forced to sell their kidneys, and as a consequence may be victim of criminal, unethical or harmful practices

*: the dichotomy between higher and lower income country is artificial and only for illustrative reasons. There may also be exceptions to these general principles.

NCDs: non-communicable diseases; CKD: chronic kidney disease; KRT: kidney replacement therapy

Table 3: Examples of ethical dilemmas caused by structural inequities in nephrology

Case – by Level of Care	Sources of Inequity	Ethical Dilemmas Arising from Inequity
<p style="text-align: center;">Primary Level</p> <p><u>Poor accesibility of primary care and preventative kidney care</u> A 35-year-old mother of 3 from a poor rural farming background in a LIC was diagnosed with gestational diabetes, pre-eclampsia and proteinuria during her third pregnancy. At her postnatal check fingerstick blood glucose and BP were still elevated. She was advised to get HbA1c, urine albumin creatinine ratio and kidney function testing but these were not available in the primary healthcare center nearby. The woman’s family, not wanting to spend money on travel to a nearby city for care, instead took her to a traditional medicine practitioner. When the woman became too fatigued to carry out her household duties, she was brought to a referral hospital where diabetes, hypertension and proteinuria were confirmed. In addition to ACE inhibitors, SGLT2 inhibitors were considered. The medical team contemplated on enrolling her in a clinical trial of SGLT2 inhibitors but all studies required frequent clinic visits that were considered too burdensome for the family. The woman’s family decided to continue whatever care was available at the primary care center and in addition resumed traditional medicine.</p>	<ul style="list-style-type: none"> • Poverty • Poor primary healthcare • Low health literacy • Discrimination against women • Effective medications too expensive • Inequitable inclusion in clinical trials • Cultural mistrust of regular medicine • Lack of universal health care 	<p><u>Adverse effect of Social Determinants of Health on Outcomes and the principle of Justice:</u></p> <ul style="list-style-type: none"> • The woman’s social determinants of health (low socioeconomic status, sex and geographic location) very likely affected her possibilities to obtain primary care and prevention of progression of kidney disease. • Are these differences avoidable through better governance or change in circumstances (would a woman with the same disease living in a wealthy urban educated family have had better possibilities to obtain preventative care?). If yes, then the inequality in outcome is unfair, and addressing this inequity is a moral imperative. <p><u>Gender Discrimination</u></p> <ul style="list-style-type: none"> • inclusion into clinical research and thus determination of efficacy of important preventive medications are unfairly biased against women who are pregnant or breastfeeding. This inequity must be addressed to improve outcomes.
<p style="text-align: center;">Secondary Level</p> <p><u>Poor accesibility of early diagnosis and treatment</u></p>		<p><u>Poor prioritization of pediatric kidney disease</u></p>

<p>During an antenatal ultrasound of a 20-year-old woman's first pregnancy in an LMIC, a kidney and bladder anomaly of the fetus was suspected. Unable to travel to the maternal-fetal referral center 250 km away, she delivered a low birth weight male at home. The infant did not feed well, had a poor urinary stream and became progressively lethargic. At the primary health center, he received some antibiotics, improved and was discharged. After multiple similar admissions and persistent failure to thrive, at the age of one, he was referred to a private pediatric nephrology center 300 km away where the parents had to pay out-of-pocket for care. The possibilities for an effective treatment in the private center in that country were considered minimal.</p> <p>By this time the child already had growth failure, rickets, blood urea of 200mg/dL and a serum creatinine of 4mg/dL. At work-up a diagnosis of posterior urthelial valves (PUV) was made. The family was told about the need for expensive surgery to treat the PUV to salvage some kidney function and possibility of dialysis. Unable to afford care, they left against medical advice.</p>	<ul style="list-style-type: none"> • Geographic remoteness • Poverty • Inadequate accessibility of effective maternal screening • Low awareness of pediatric kidney disease • Inadequate pediatric kidney care services • Poor public-private partnership rendering treatment unaffordable • Poor social services support for children • No accessibility of UHC 	<ul style="list-style-type: none"> • In low resource settings, funding pediatric kidney disease detection (by good perinatal follow-up of structural anomalies) is of low priority for governments. Thus accessible public sector care is inadequate, resulting in late diagnosis, high morbidity and poor outcomes. <p><u>Where UHC is absent, ability to pay determines outcomes</u></p> <ul style="list-style-type: none"> • When specialized pediatric care is only available in the private sector, life-saving therapy is accessible only for those who can afford to pay. This violates the ethical principle of justice <p><u>Parental refusal of treatment</u></p> <ul style="list-style-type: none"> • Refusal of treatment by the parents is undoubtedly against the best interest of the child. However, given the expense to family should we consider the interests of the family as well? Patient families in LIC and LMIC often exhaust all their financial resources without reaching positive outcomes (no cure and no transplantation). This morally distressing question results from inequitable accessibility of care.
Tertiary Level		
<p><u>Case 1: Rationing Dialysis</u></p> <p>A 50-year-old father of 3 with kidney failure due to type 2 diabetes in a MIC was assessed by the healthcare team for eligibility for the single remaining spot for government-funded maintenance dialysis. He was not considered a candidate for kidney transplantation due to his diabetes complications and was denied dialysis.</p>	<ul style="list-style-type: none"> • Rationed availability of free or low cost dialysis • Age-based discrimination • Disease-based discrimination • Rationing policies favoring those with 	<p><u>Ethical challenges of rationing life-saving therapy</u></p> <ul style="list-style-type: none"> • Rationing access to dialysis may result in biased unethical decisions based on prejudices related to age, sex, race or socioeconomic status • The patient's ability to exercise his autonomy to make treatment choices is constrained by (lack of) policy

<p>Unable to pay for dialysis in the private sector, he was forced to accept palliative care. By policy, a younger patient with no comorbidities was deemed eligible instead.</p>	<p>highest likelihood of survival (utilitarianism)</p>	<ul style="list-style-type: none"> • Forced rationing decisions result in moral distress amongst physicians forced to deny life-saving care to patients • Ensuring distributive justice (a fair, transparent, equitable priority-setting process with stakeholder input) is essential for policy makers but is rarely applied
<p><u>Case 2: Inequitable global accessibility of transplantation</u> A 50-year-old wealthy man with kidney failure in a MIC desired kidney transplantation. There were no compatible living donors in his family and his native country had no deceased donor transplant program. He travelled to a private sector, for-profit hospital in a LMIC accompanied by a 50-year-old woman, from a lower socioeconomic background. The patient claimed she was a distant cousin. He requested living donor transplantation be performed and furnished a government certificate giving clearance for altruistic kidney donation. Communicating with the recipient and his donor was limited and required an interpreter. Paid donation was suspected but could not be proven. After the transplantation, the patient returned for care to his native country. The donor was never seen with the patient again and did not show up for follow-up care.</p>	<ul style="list-style-type: none"> • Poor accessibility of deceased donor transplantation • Necessity for physicians to rely on living donation as only option for transplantation • Inadequate surveillance process and legal framework to prevent organ trafficking 	<p><u>Inequitable accessibility of donor transplantation drives people to organ trade and unjustly exploits donors</u></p> <ul style="list-style-type: none"> • Without UHC, transplantation is largely inaccessible to the poor • Although paying for donor evaluation and surgery to ensure financial neutrality is acceptable, offering donors financial gain is unethical and illegal • Trafficked donors have poor health and economic outcomes • Trafficked donors are often unfairly exploited by intermediary persons Organ trafficking remains a serious and prevalent problem despite global condemnation. • Nations may have a moral obligation to provide deceased donor transplantation services to their citizens • Nations have a major obligation to combat paid donation via legal and judiciary means, but this is often neglected • Preventing organ trafficking is a global responsibility but the burden of decision making unfairly falls most on healthcare providers.

Case 3: Caregiver burden

A 15-year-old boy with PUV in a rural area of a HIC was initiated on PD in a city 450 km from his home. The indigenous family had owned a farm for 3 generations. His parents incurred high out-of-pocket costs for travel to a pediatric nephro-urology centre and lost income during monthly clinic visits. When his mother initiated work-up for a living donor transplantation, the hospital visits became more frequent. The family decided to sell their farm to move closer to the city where they had no family or friends. The mother stayed home to be the primary caregiver. The father relied on daily odd jobs, the family's income plunged and the existence of all centered around keeping the boy alive.

- Inadequate accessibility of pediatric focused KRT
- Geographic remoteness reduces accessibility of care
- Poor support for living donor indirect costs
- Caregivers not provided with enough social support

Caregiver burden worsened by socioeconomic and demographic factors

- Patients in remote areas face unfair obstacles to accessing care and a greater financial burden.
- It is unfair that caregivers of kidney failure patients be expected to shoulder these burdens
- To satisfy the principle of justice and non-maleficence, clinicians might consider discussing these burdens with caregivers before beginning dialysis but this may lead to a difficult and uneasy conversation
- The inequitable accessibility of care unfairly burdens indigenous populations, minorities and immigrants

HIC: high income country; LIC: Low income country; LMIC: low middle income country; MIC: middle income country; BP: blood pressure; HbA1C: hemoglobin A1C; PUV: posterior urethral valves; UHC: universal health care; PD: peritoneal dialysis; KRT: kidney replacement therapy
Case stories are based on the clinical experience of the authors.

Table 4: Opportunities for stakeholders to mitigate inequities

STAKEHOLDER GROUP	ATTENTION POINTS
Patients, patient organizations	<ul style="list-style-type: none"> - Raise patient voices - Raise awareness of CKD - Advocate for fair therapeutic price setting - Advocate to combat inequities - Facilitate empowerment and communication training - Include people from all origins and social classes in their activities
Nephrology professionals	<ul style="list-style-type: none"> - Self-awareness of own socio-cultural knowledge/communication limitations - Listen to patient voices - Favour patient empowerment - Increase advocacy efforts to draw appropriate attention to kidney diseases - Embed structural competency in the training process, including inequities and their mechanisms, and apply approaches to avoid those, e.g. by shunning racism and paying special attention to health illiteracy - Steer clear of therapeutic cherry picking - Use language translation - Increase diversity among nephrology work force - Share equipment and expertise with emerging countries
Nephrology societies	<ul style="list-style-type: none"> - Lead by example, ensure diverse and equitable global representation - Include local experts in guideline committees, decision-making, research calls - Include sessions devoted to equity in their meetings and congresses - Collect reliable data on disease burden, costs and inequities related to CKD - Generate a shift of mind from cure to screening and prevention, by engaging with policy makers, those involved in healthcare design, and funders - Achieve harmonization among countries by support and exchange of information - Create patient education materials adapted for language and culture - Advocate at regional and global level
General educators	<ul style="list-style-type: none"> - Ensure all children, both boys and girls, have access to quality education - Include health in education - Promote healthy lifestyle through education about food, exercise, smoking, alcohol etc - Provide healthful food and sport opportunities in schools

Medical educators	<ul style="list-style-type: none"> - Ensure diversity among educators - Include inequities in the educational curricula - Improve teaching about kidney diseases and especially their diagnosis and prevention - Consciously act as role models
Researchers, developers	<ul style="list-style-type: none"> - Develop therapeutic options that are affordable for all - Ensure that newly promoted approaches are made available and evaluated across subsets where inequities may occur - Prioritize research that focuses on equity and accessibility of kidney care in disadvantaged populations - Prioritize research on health illiteracy - Develop and study approaches to prevent CKD or progression of CKD - Be conscious of the risks of research in exacerbating inequities - Include patients with kidney diseases in clinical trials, including in non-kidney areas (e.g. cardiology, oncology) - Ensure diverse representation of patients included in clinical trials - Consider ethnic and sex/gender aspects in clinical trials, drug metabolism, patient reported outcomes
Pharmacological and medical technology sectors	<ul style="list-style-type: none"> - Develop therapeutic options that are affordable for all - Develop and study approaches to prevent CKD or progression of CKD - Being transparent on investments in therapy development and real cost of therapies - Apply fair prices and fair profit principles - Register and distribute therapeutic products (e.g. peritoneal dialysis fluids) in all countries
Governments, administrations, insurers	<ul style="list-style-type: none"> - Acknowledge CKD as a public health problem - Collect reliable data on disease burden, costs and inequities related to CKD to support priority setting - Negotiate fair price setting of medications - Favour affordable therapies and therapies with high value-for-money, without further exacerbation of inequities - Aim for progressive expansion of universal health coverage - Generate a shift of paradigm from focus on cure towards focus on screening and prevention - Achieve harmonization among countries by support and exchange of information - Apply reimbursement models that disincentivize cherry picking - Stimulate and finance research on health inequities and health illiteracy

GLOBAL

geography – standing – lack of solidarity - power –
industry – economics – false information –
leadership - trade-offs

COUNTRY

Income group - leadership - healthcare policies –
affordability/accessibility of quality therapeutics –
transparency – data collection/reporting – neglect

COMMUNITY

neighbourhoods – transportation – social networks –
public health – distance to health facilities – home
support – mistrust – lack of solidarity – discrimination –
minoritization – prejudices – food deserts

HEALTH SYSTEM

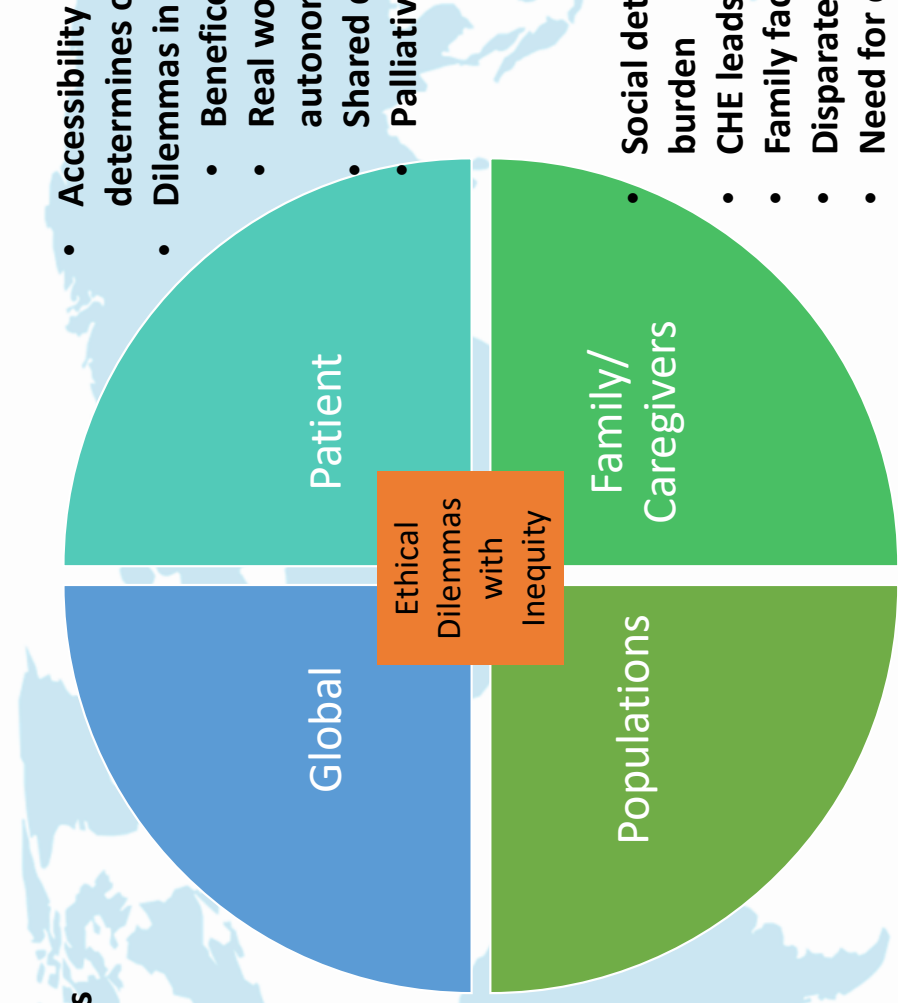
Universal health coverage - availability –
accessibility – acceptability - capacity -
prioritization strategies - triage – funding – public
health strategies – logistics – outreach – health
care worker burnout – public - private

INDIVIDUAL

race/ethnicity - age – birth weight/gestational age
- genetic predisposition – immunological
reactivity – propensity to infection – lifestyle
adherence - comorbidities - poverty – food
insecurity - employment/type - education - family
structure - isolation - citizenship - migrant status -
language - culture – sex/gender – insurance –
health illiteracy
In-centre haemodialysis - home dialysis –
transplantation – conservative management

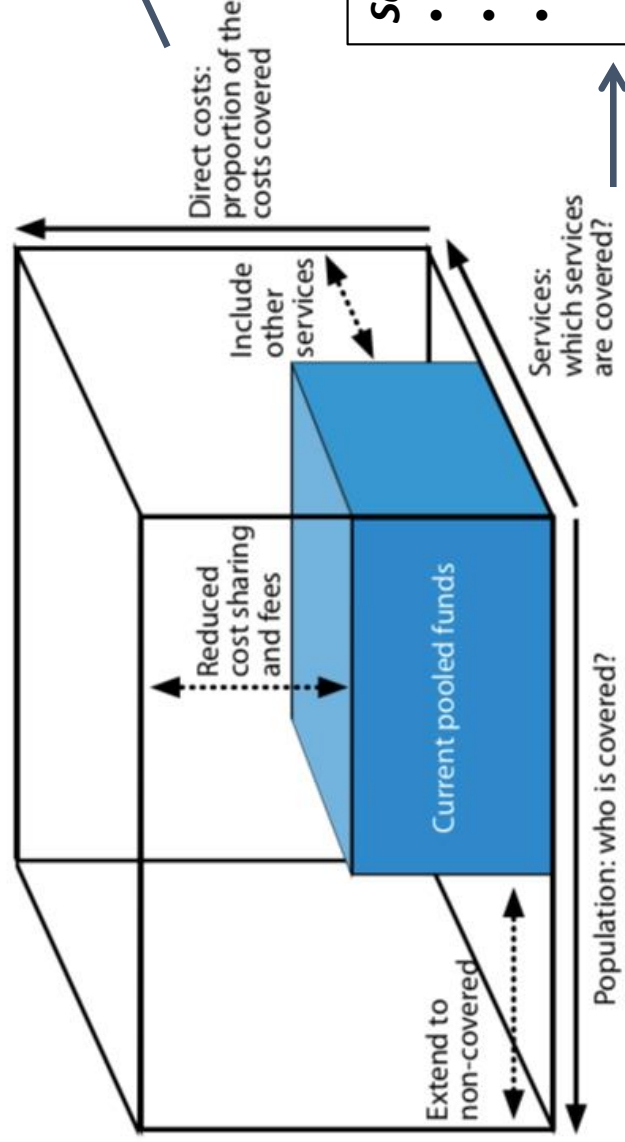
- Recognition of kidney disease as important NCD
- Need for moral responsibility
 - Global solidarity amongst patients and providers
 - Prevent brain drain
 - Develop a 'global' moral theory of kidney care?

- Accessibility determines C
- Dilemmas in
 - Benefic
 - Real wo
 - Shared auton
 - Shared
 - Palliativ



- Inequitable distribution of risk factors for kidney disease
- Decision-making driven by healthcare systems
 - National expenditure on health
 - Social, distributive justice
 - Moral Distress with rationing

- Social det
- burden
- CHE leads
- Family fac
- Disparate
- Need for



Financing?

- **Priority setting**
- **Transparency**
- **Accountability**
- **Sustainability**
- **Quality of care**

Services to be provided?

- **Prevention - YES**
- **Primary care – YES**
- **Dialysis – YES/NO?**
 - Moral dilemmas
 - AKI vs. CKD
 - Adult vs. Child
 - No comorbidities
 - Employed or unemployed
 - Transplantable or not
 - Transparent or not
- **Transplantation -**
 - If financially

Is kidney disease a priority*?

- **AKI – probably**
- **CKD not on KRT - probably**
- **KRT – if sustainable, yes, but currently expensive and technically difficult; risk of CHE high if not reimbursed**