# The Chronic Kidney Disease-Personal Impact Index (CKD-PII): Analysis of the Global Day-to-Day Personal Impact of Disease on Patients With CKD

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### Background and Rationale

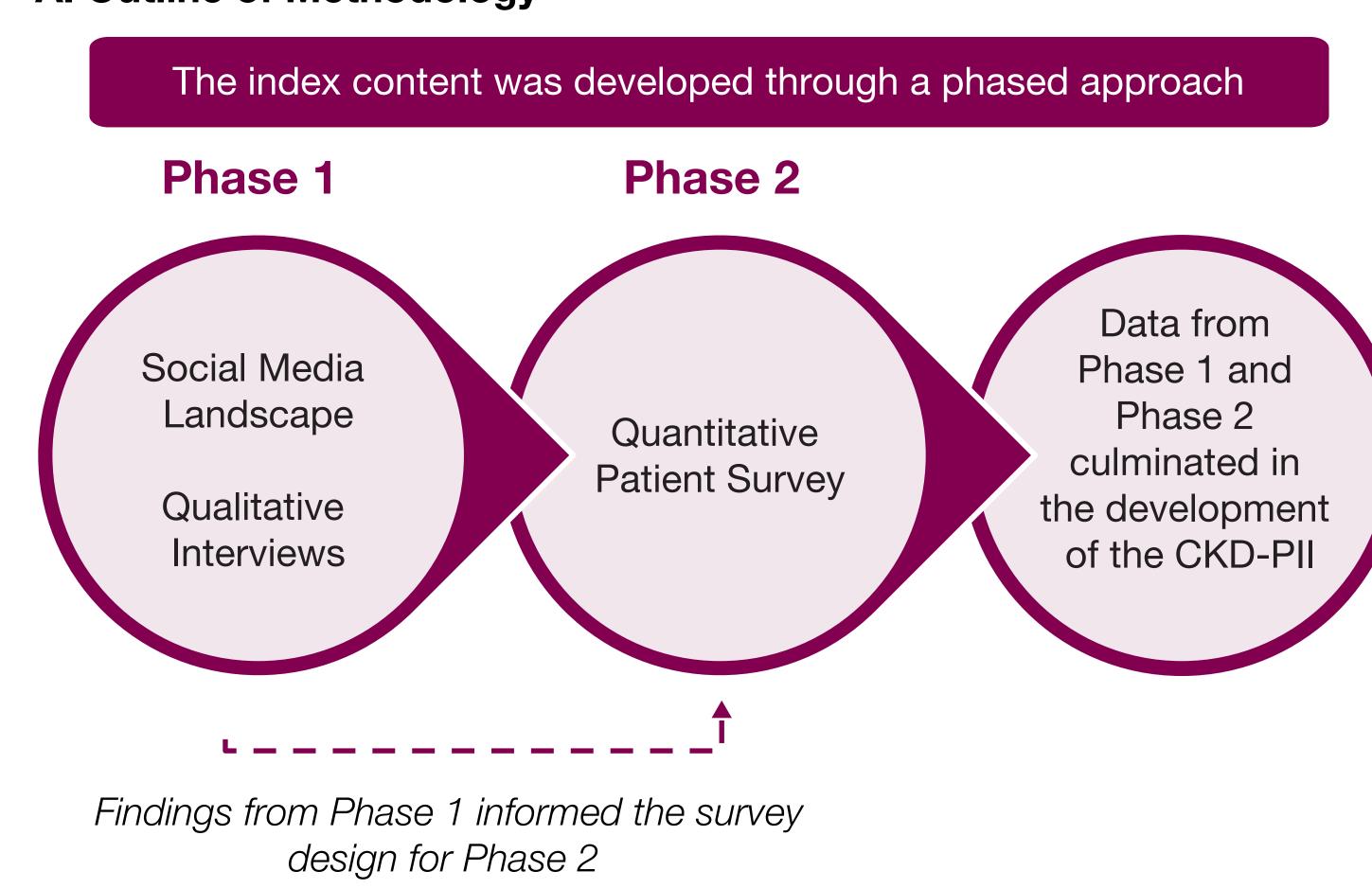
- Chronic kidney disease (CKD) affects >700 million people globally<sup>1</sup>.
- However, the daily personal impact of the disease on individuals diagnosed with CKD (and their families) has not been determined—either qualitatively or quantitatively.
- A global CKD-Personal Impact Index (PII) uncovering the direct and indirect impact of living with CKD on patients' activities of daily living and overall quality of life (QoL) is described here, which provides unique insights into the patient experience that other studies do not traditionally report.

#### Methods

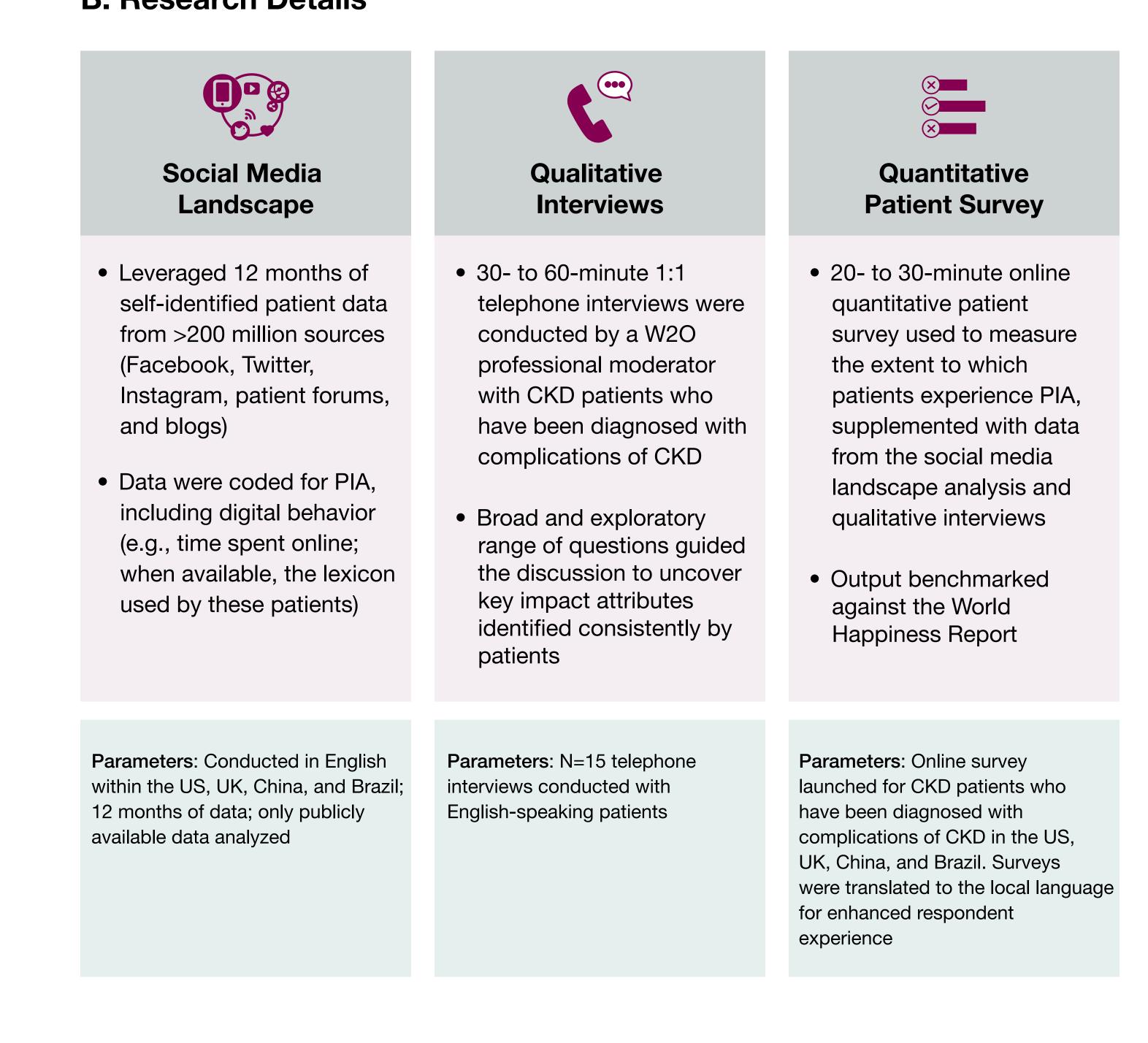
- We outline a multiphase, collective analysis of aggregate data from a geographically diverse cohort of patients living with CKD (Figure 1A).
- As part of the research recruitment criteria, patients whose activities of daily living or overall QoL were impacted by their diagnosis of CKD were included. Any patients who reported no impact were excluded.
- Online social media landscape analysis (>200 million internet sources), qualitative telephone interviews (N=15), and an online quantitative patient survey (N=443) determined the personal impact attributes (PIA) and quantified the extent of patients' experience of PIA (Figure 1B).
- The PIA that were assessed as part of this study are outlined in **Figure 1C**.

#### Figure 1. CKD-PII Development

#### A. Outline of Methodology



#### B. Research Details



#### C. Personal Impact Attributes (PIA) assessed in patients with CKD

Personal Impact Attributes	
<ul> <li>Mental well-being</li> <li>Sleep schedule</li> <li>Planning of life events/holidays/trips</li> <li>Management of meals/dieting</li> <li>Employment status</li> <li>Time for medical appointments</li> <li>Managing the family</li> </ul>	<ul> <li>Finances</li> <li>Personal time</li> <li>Personal relationships</li> <li>Exercise schedule</li> <li>Household responsibilities</li> <li>Personal mobility</li> <li>Professional time</li> <li>Managing insurance</li> </ul>

CKD, chronic kidney disease; CKD-PII, CKD-Personal Impact Index; PIA, personal impact attributes; UK, United Kingdom; US, United States.

#### Results

#### Impact on Overall QoL

- The burden of CKD was profound and rapid; globally, 56% of patients living with CKD highlighted an extremely negative impact on overall QoL, and 13% felt an impact almost immediately after diagnosis (**Figures 2 and 3**).
- A total of 25% of the survey respondents reported an impact on overall QoL within the first 3 months of their diagnosis, and 22%, within 4–6 months (**Figure 3**).
- The impact on QoL was more pronounced for patients on dialysis (dialysis, 61% vs. non-dialysis, 50%) and those who underwent a kidney transplant (transplant, 73% vs. no transplant, 52%).

#### Figure 2. Impact on Overall Quality of Life

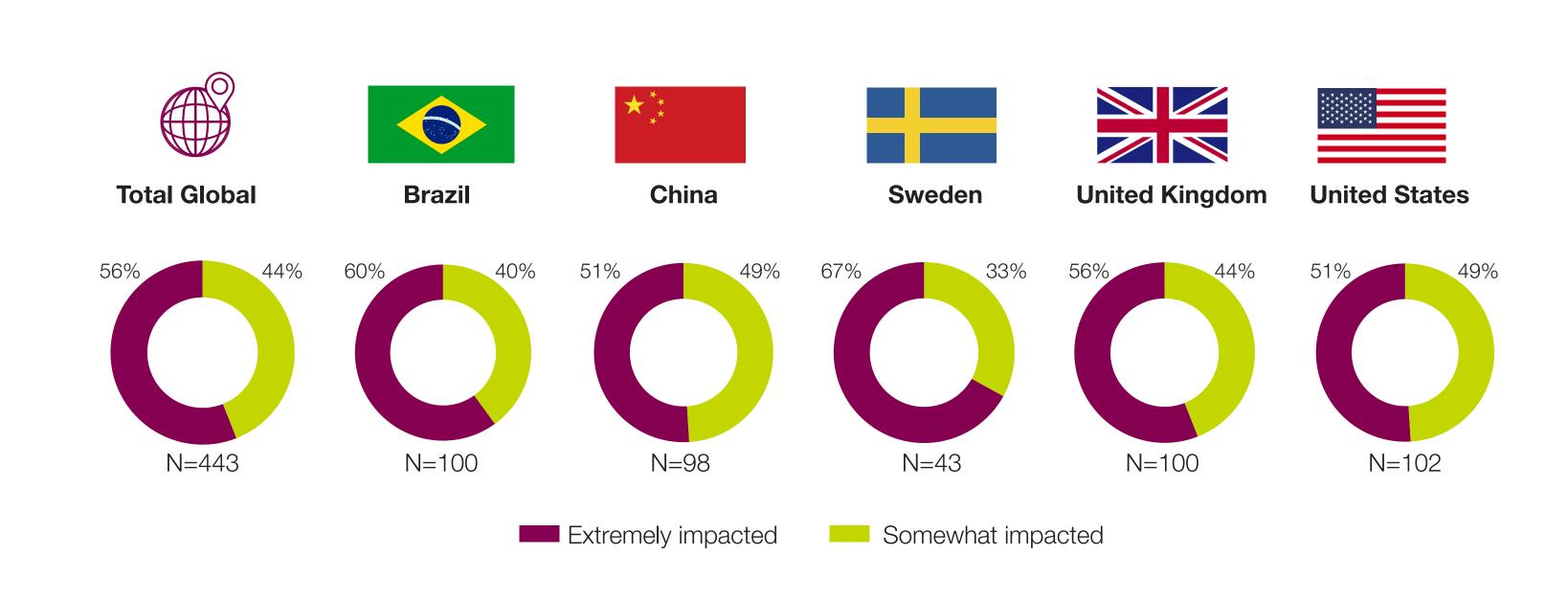
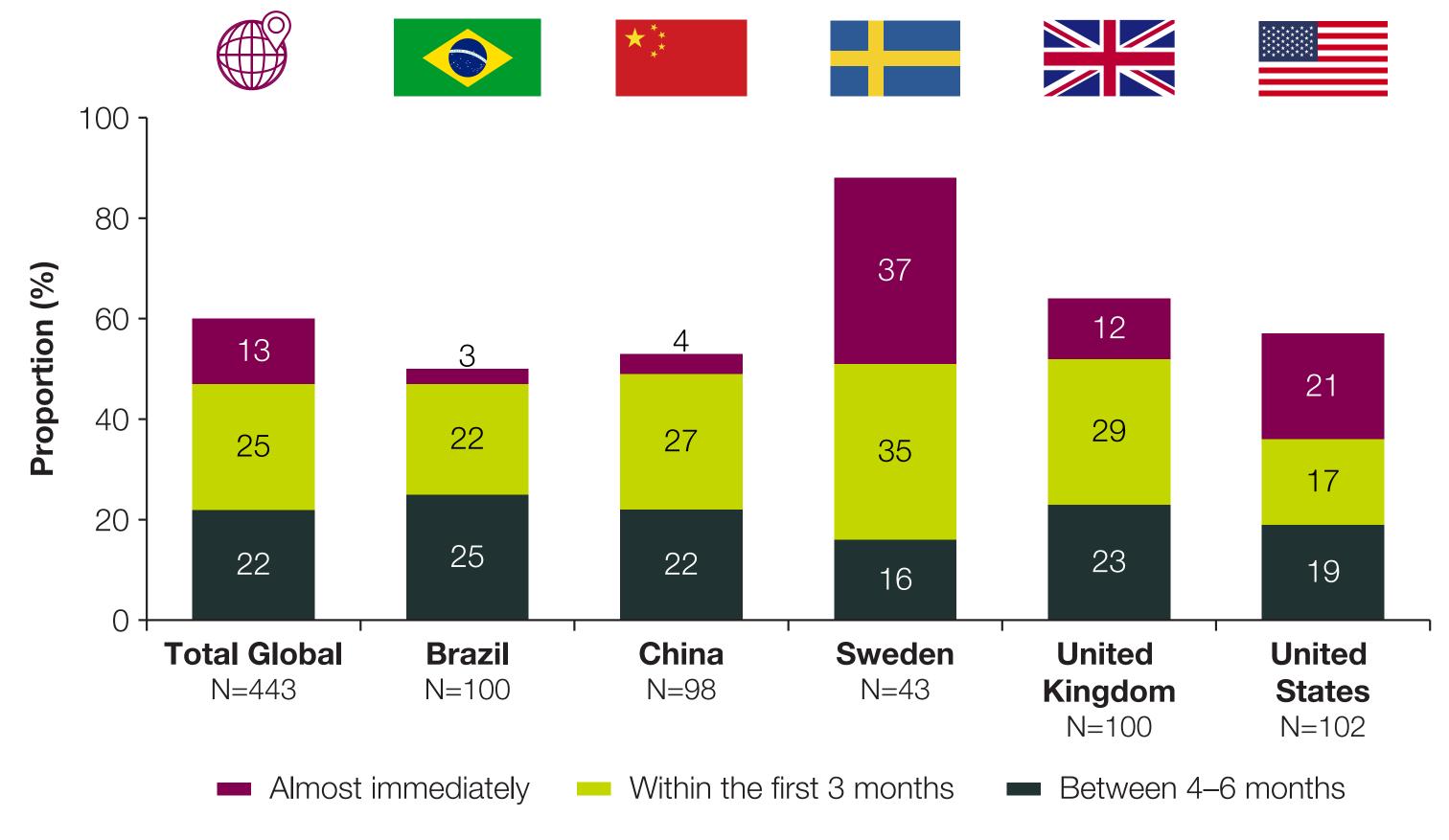


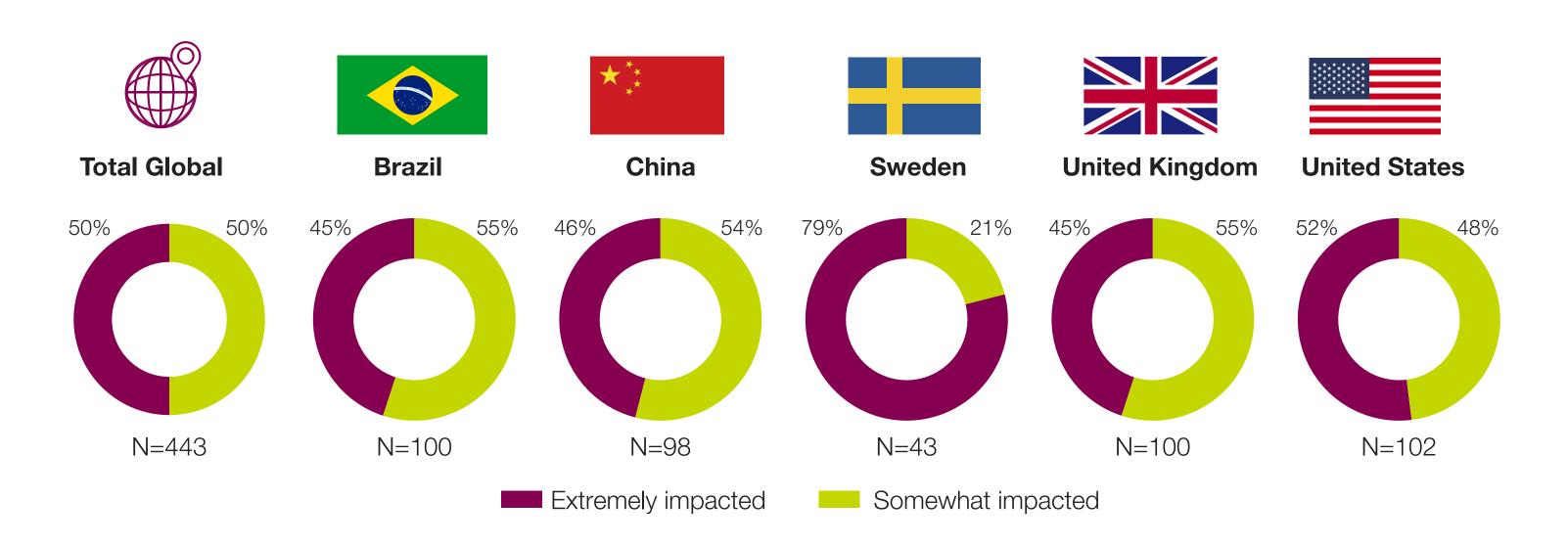
Figure 3. Timeline of Impact on Overall Quality of Life



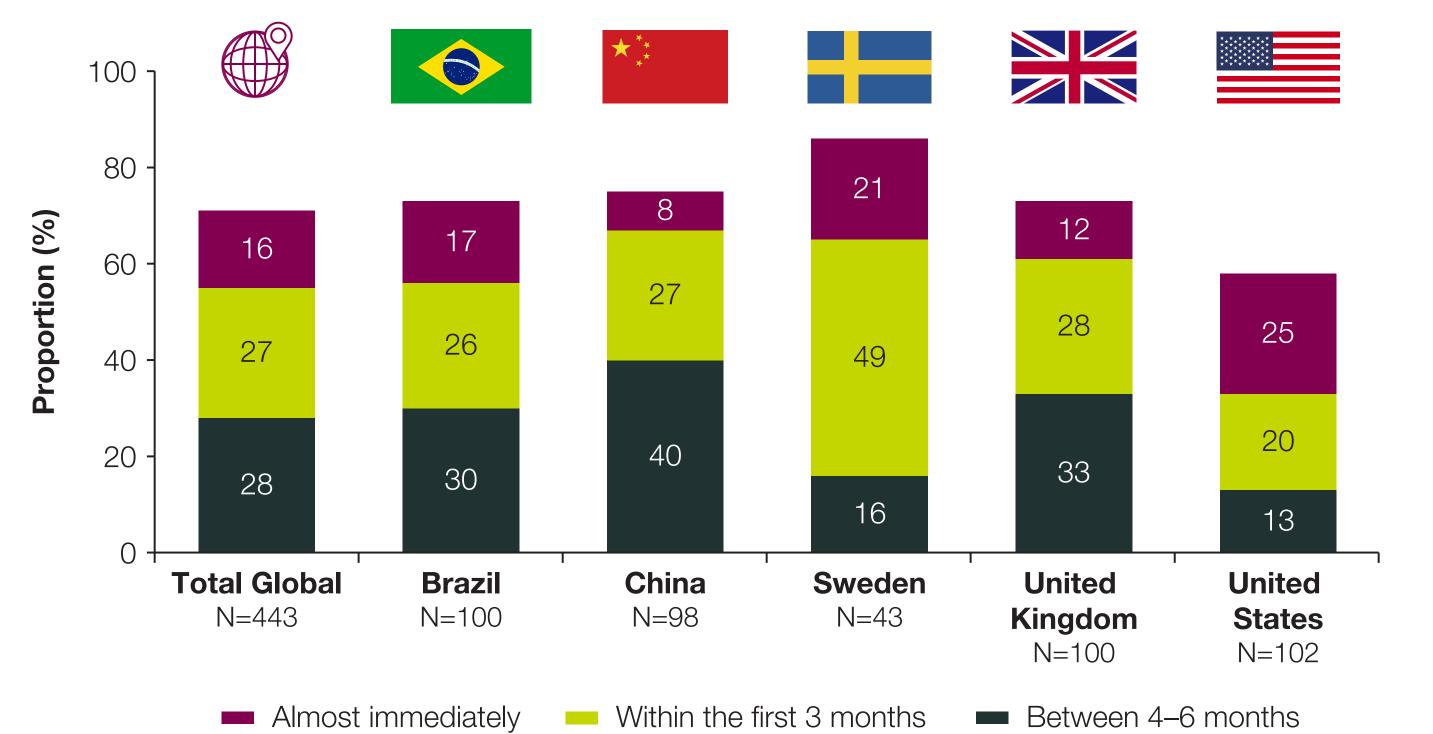
#### Impact on Activities of Daily Living

- The impact of CKD on patients' activities of daily living was severe. Patients were either extremely or somewhat impacted; 16%, 27%, and 28% of patients noticed an impact almost immediately after diagnosis, within 3 months of diagnosis, and between 4–6 months of diagnosis, respectively (**Figures 4 and 5**).
- The impact of CKD on activities of daily living was the most severe for patients aged 41–50 years, those with full-time employment, and those earning between (or market equivalents); this suggests that the burden of CKD is compounded by familial, professional, and financial responsibilities.

#### Figure 4. Impact on Activities of Daily Living



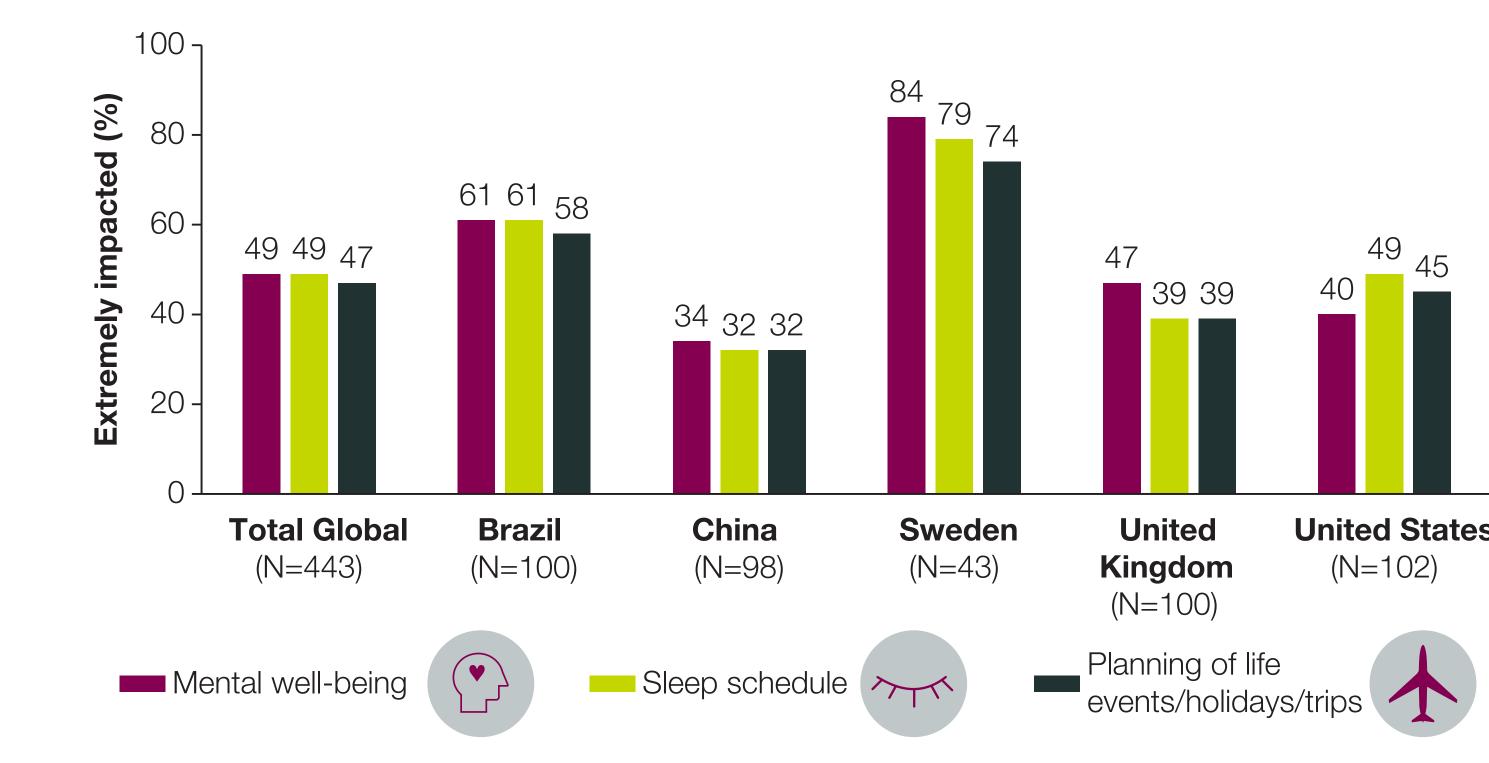
#### Figure 5. Timeline of Impact on Activities of Daily Living



## Individual Attribute Analysis: Burden of Impact of Living With CKD

- Specific personal attributes that were the most severely impacted by CKD were mental well-being (49%) and sleep schedule (49%) (**Figure 6**).
- Secondary attributes included planning of life events/holidays/trips (47%) and diet/meal management, exercise schedule, and time for medical appointments (45% each).
- Patients in Sweden reported the highest levels of impact on mental well-being, sleep schedule, and planning of life events/ holidays/trips, followed by patients in Brazil (Figure 6). Patients in China reported the lowest levels of impact on mental well-being, sleep schedule, and planning of life events/holidays/trips.

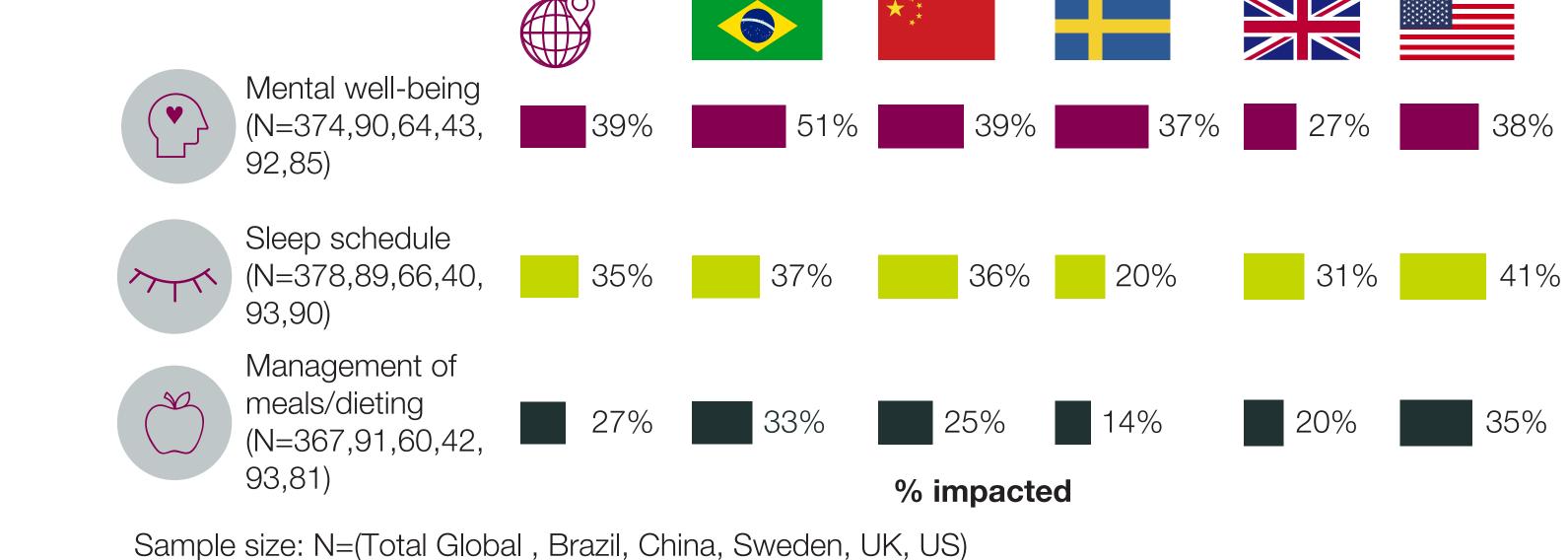
#### Figure 6. Personal Impact Attributes



#### Prioritization of Attributes

- When asked to rank the individual personal attributes, mental well-being (39%), sleep schedule (35%), and diet/meal management (27%) emerged as the top three most burdensome on patients' personal lives as a result of living with CKD and associated comorbidities (Figures 7 and 8).
- Patients on dialysis were more likely to rate the impact on meals and diet higher than those not on dialysis.
- Globally, managing insurance, professional time, personal relationships, and managing the family were the least burdensome on patients' personal lives.

#### Figure 7. Prioritization of Attributes



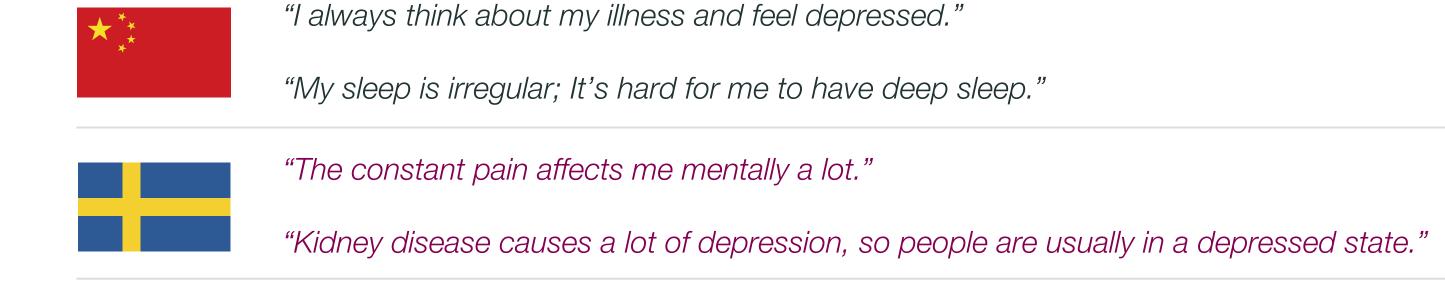
UK, United Kingdom; US, United States.

## Figure 8. Patient Perspectives Describing the Impact of Living With CKD

"My emotional health is impaired. You start thinking that you're giving everybody else a hard time, you feel weak and powerless."



"A daily change to my meals. Today I eat much better, I made some replacements, controlled my weight and, because of that, my sleeping habits have also improved. I try to eat at the right time and avoid ready snacks/fast food on the street on my way to work."



"Sometimes the pain makes it difficult for me to fall asleep and the amount of sleep I get is severely reduced."

nowing my kidneys have failed makes me somewhat depressed a lot of the time."



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#### Conclusions

- The results of the CKD-PII analysis raise awareness regarding the burden of living with CKD and could help identify patient cohorts whose activities of daily living and QoL may be severely impacted.
- To manage the negative impact of CKD on activities of daily living that are impacted profoundly and rapidly post-diagnosis, it is important to establish a multidisciplinary team comprising nephrologists, renal dieticians, nurses, and primary care physicians early in the CKD patient journey.
- The research highlights the most burdensome PIA, potentially facilitating the development of tangible and realistic solutions for both patients and healthcare providers.

#### References

1. Cockwell P, Fisher LA. The global burden of chronic kidney disease. Lancet. 2020;395(10225):662-664.

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