

PKD Foundation – Centers of Excellence Program

HRA Members Meeting
October 6th, 2022

Elise Hoover, MPH
Senior Director of Research



PKD FOUNDATION
Polycystic Kidney Disease

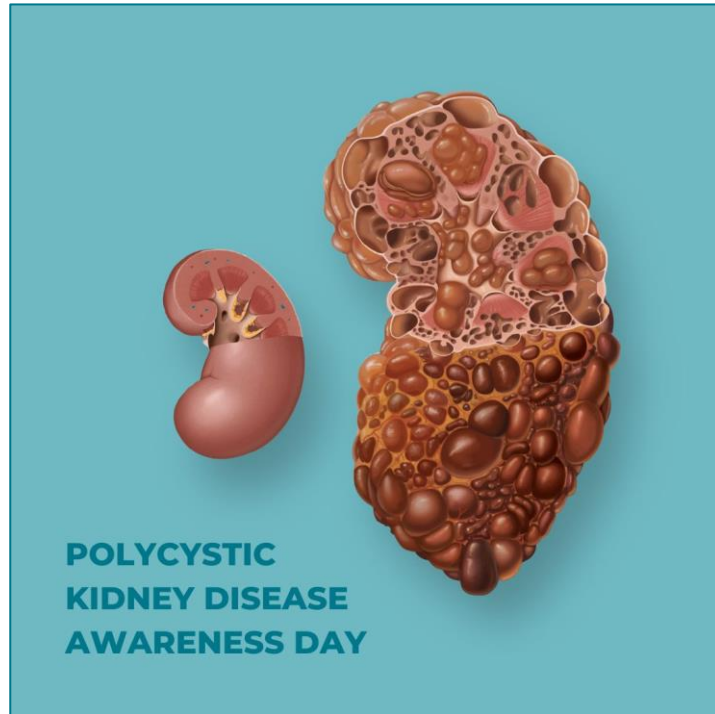


PKD FOUNDATION

Polycystic Kidney Disease



Polycystic Kidney Disease



ADPKD,
estimated to affect
**600,000
AMERICANS**
and
**12.4 MILLION
WORLDWIDE,**
is the 4th leading
cause of kidney failure.



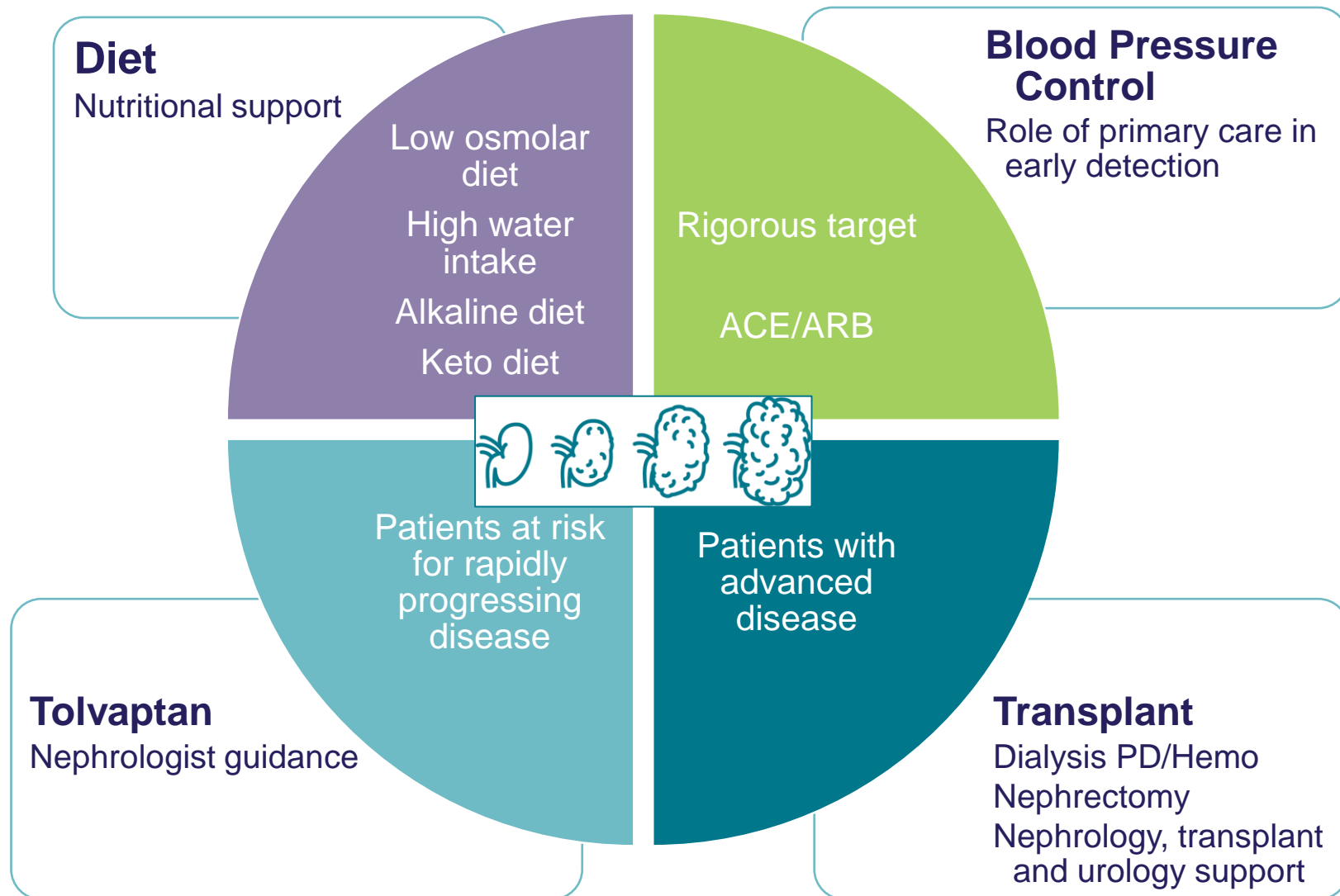
“

**When I was diagnosed, my
doctor told me to come
back when my kidneys
start to fail.**

”



Management of ADPKD



Modified from Osama Amro, MD – Swedish Medical Center, with permission



Engaging stakeholders

1

Clinicians

- What does excellent PKD care look like?
- What challenges are you experiencing?
- What could a valuable, centralized, national program look like?



What PKD clinicians told us:

Clinicians

- What does excellent PKD care look like?
- What challenges are you experiencing?
- What could a valuable, centralized, national program look like?

- Biggest challenges:
 - Management of patient needs as specialization increases
 - Referral gap from both primary care and community nephrologists
- Needs
 - Patient navigators
 - Mentoring relationships with PKD experts
 - Sharing of experience with case studies and new therapies
 - Structure/guidance to facilitate shared care (specialist referral)



Engaging stakeholders

1

Clinicians

- What does excellent PKD care look like?
- What challenges are you experiencing?
- What could a valuable, centralized, national program look like?

2

External Organizations

- What are your COE program goals?
- What barriers have you experienced?
- What's working?



What external organizations told us:

External Organizations

- What are your COE program goals?
- What barriers have you experienced?
- What's working?

- COE designation programs are important as care become more specialty-based (e.g., as more therapies become available)
- Tiered system recommended, especially with considerations of training/motivating next “generation” of clinicians
- COEs **need** Partner Clinics (time limitations, waiting list) and vice versa (training, education)



Engaging stakeholders

1

Clinicians

- What does excellent PKD care look like?
- What challenges are you experiencing?
- What could a valuable, centralized, national program look like?

2

External Organizations

- What are your COE program goals?
- What barriers have you experienced?
- What's working?

3

Patient Community

- What does your PKD care look like?
- What barriers are you experiencing?
- Would this program solve any of these barriers for you or your family?



What PKD patients and caregivers told us:

Patient Community

- What does your PKD care look like?
- What barriers are you experiencing?
- Would this program solve any of these barriers for you or your family?

- Patients see inconsistent care between family members receiving care at different clinics
- Access to and awareness of research opportunities is essential part of clinical care
- Simplifying the referral process would address a lot of barriers experienced in the clinic – a patient navigator could be a solution
- Cultivating Partner Clinics (community nephrologists in rural areas) had the most perceived value



PKD FOUNDATION

CENTERS *of* EXCELLENCE

Select clinical centers to drive improvement in PKD patient care and research excellence

Why

- Improve patient care
- Means to understand clinical practice gaps, drive education and measure outcomes

What

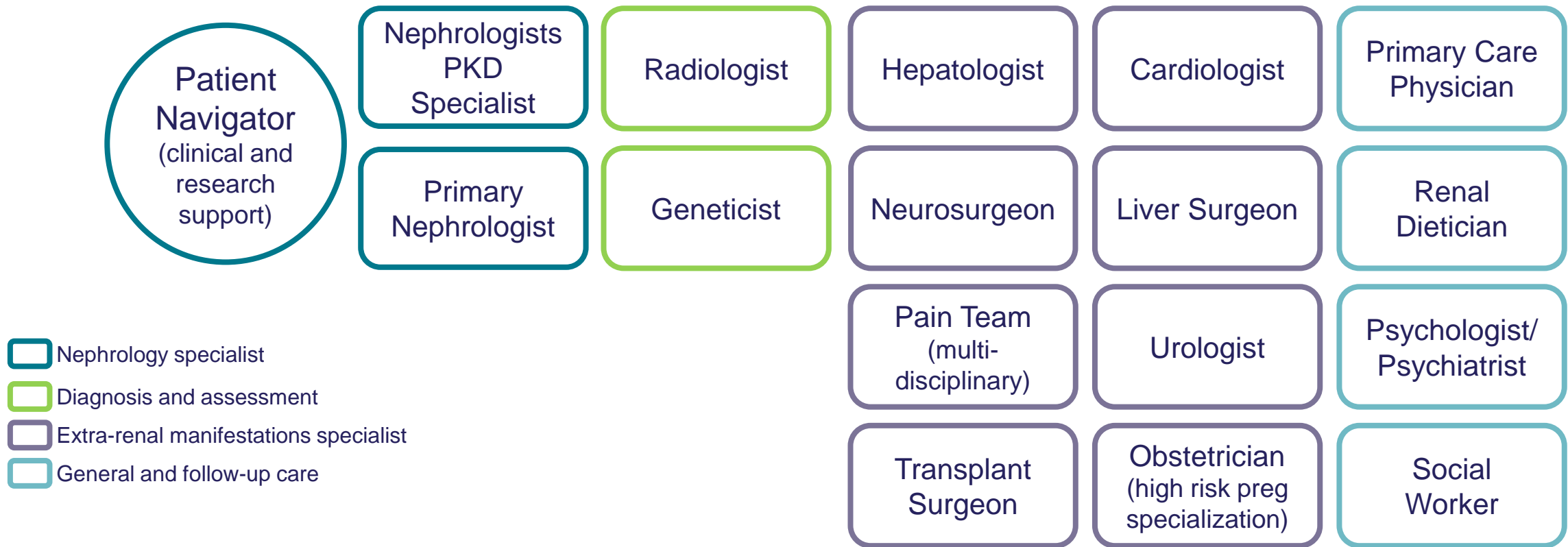
- Program based on clinical expertise and research participation
- Commitment to participate in and provide education

How

- Criteria based selection with focus on a care team model
- PKDF financial support for Patient Navigator and health equity initiatives



COE care team construct



COE Inception Conference



**CENTERS^{OF}
EXCELLENCE**

Connected ADPKD Care

March 31st, 2022

Goals:

- Present the program to the larger clinician community
- Encourage community to apply for the program
- Initiate the first annual meeting for the ADPKD COEs

Panelists:

- Provide feedback on not-yet final aspects of program
- Help create buy-in from the community – will this have an impact on barriers to care you experience in the clinic?



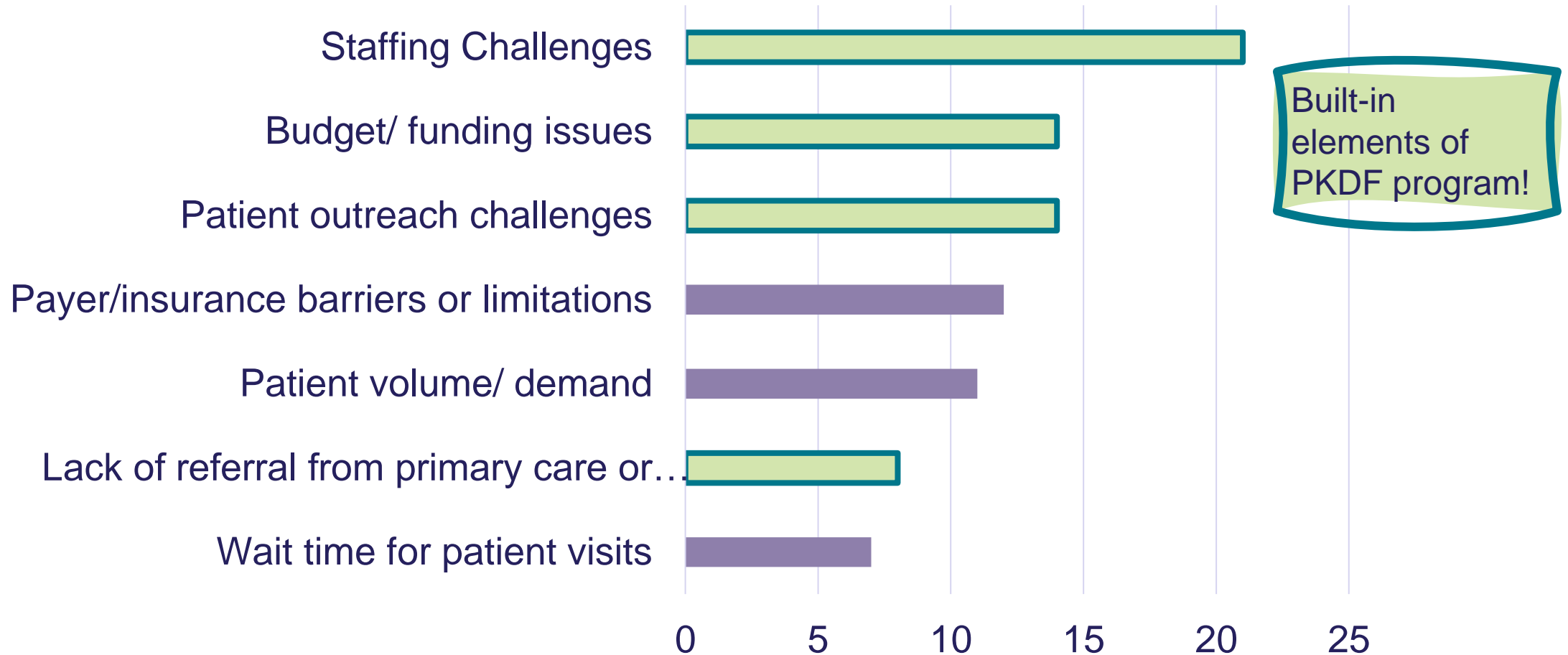
45 clinics applied for the program



Select the top two challenges that impact your clinic's service delivery



Select the top two challenges that impact your clinic's service delivery



Acknowledgements

