

# INITIATIVES TO FACILITATE RESEARCH RECRUITMENT IN UNDER-REPRESENTED GROUP

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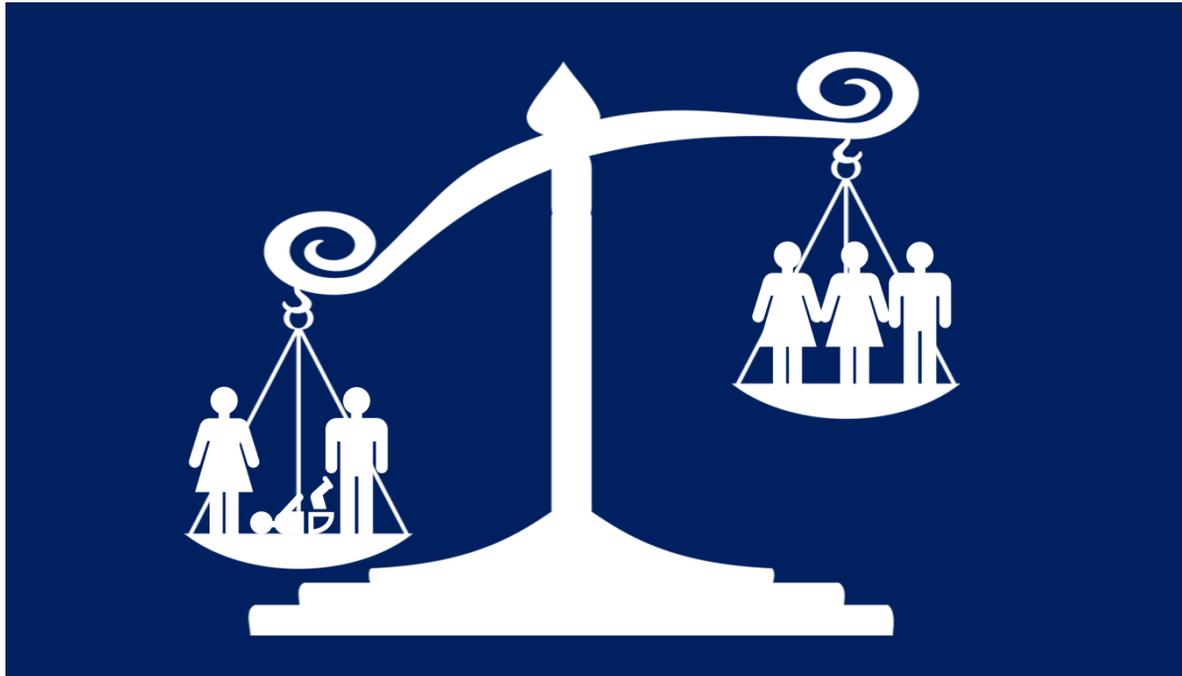
DEPUTY LEAD  
CLINICAL RESEARCH FACILITY,  
LEONARD WOLFSON EXPERIMENTAL NEUROLOGY CENTRE (LWENC)  
UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST



*(PRESENTATION BASED ON THE WORK AT  
KING'S COLLEGE HOSPITAL NHS FOUNDATION  
TRUST, LONDON - RENAL, EXERCISE &  
REHABILITATION RESEARCH UNIT)*

# BACKGROUND

## HEALTH RESEARCH **INEQUALITY**



- A disparity among different population groups in accessing essential research into new treatments.
- Patients from ethnic minority groups potentially miss out on valid treatment options, but under-enrolment may reduce the generalisability of any research findings

Diverse representation of minorities in clinical trials is essential to help researchers better understand patterns of difference in health and illness based on various racial, ethnic, and geographic backgrounds.

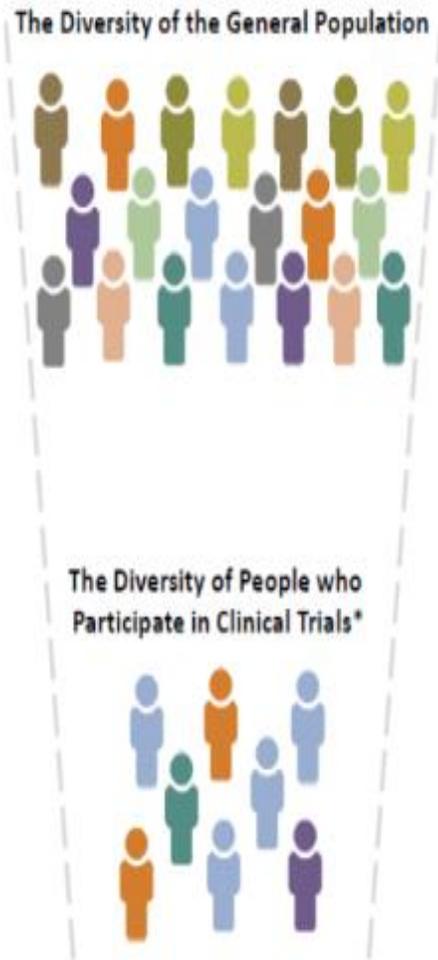
Enrolling diverse people in clinical trials helps make sure treatments are safe and work well for different communities. Different people may have different reactions to the same treatment, based on their age, gender, weight, race, ethnicity and other factors.

## DIVERSITY IN CLINICAL RESEARCH— WHY IT IS IMPORTANT?



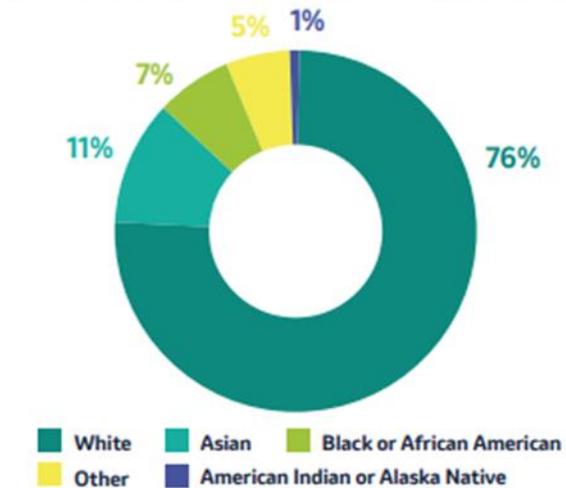
Participants in clinical trials should reflect our diverse population.

DIVERSITY IN  
CLINICAL TRIALS  
BENEFITS EVERYONE



## RACE and ETHNICITY DISTRIBUTION IN CLINICAL TRIALS

Global Race  
Global race distribution for clinical trials

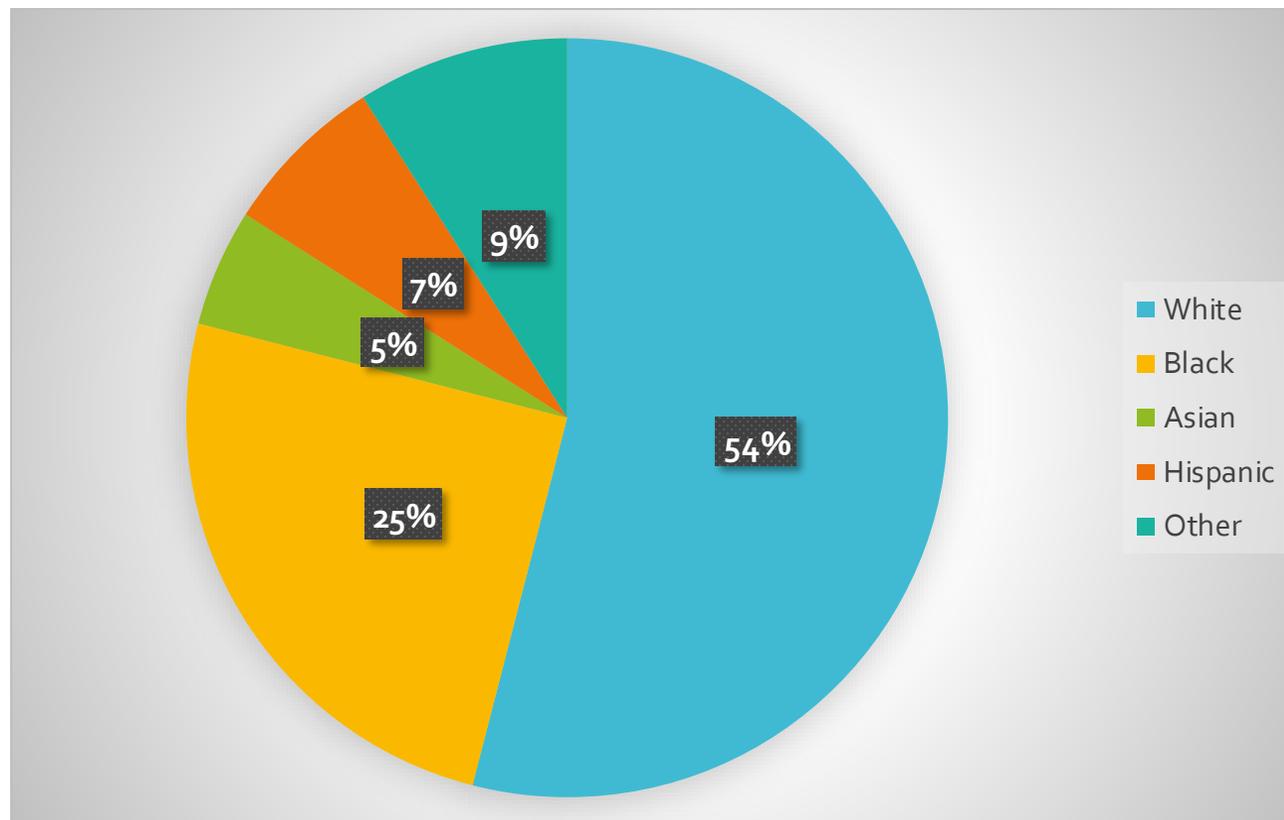


\*Source: FDA 2015-2019 Drug Trials Snapshots Summary Report

### In the UK

- Only 5% of respondents from ethnic minorities have ever participated in a clinical trials (A. Smart and E. Harrison, 2017)
- In 2020, of almost 300K individuals recruited for COVID-19 Vaccine Trials, only 7% were ethnic minorities. ([www.gov.uk](http://www.gov.uk))

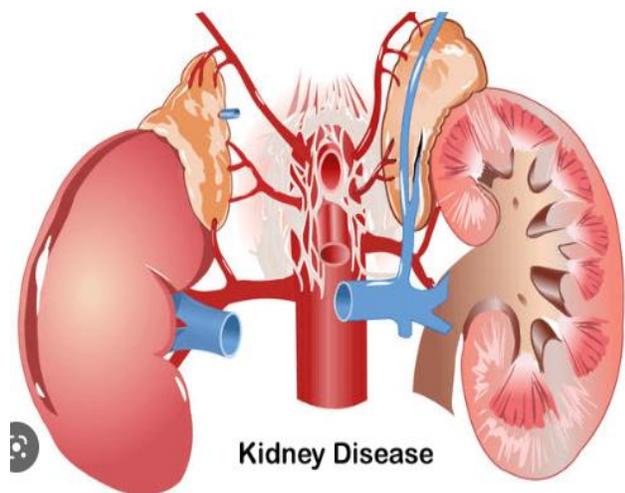
## PARTICIPATION OF UNDER-REPRESENTED GROUP IN RENAL RESEARCH?



Registered Kidney Disease Trials: 532  
Total Participants: 214,702  
Years covered: 2000-2021

Source: [www.ClinicalTrial.gov](http://www.ClinicalTrial.gov)

# KIDNEY DISEASE IN ETHNIC MINORITIES – WHAT DOES THE DATA SHOW?



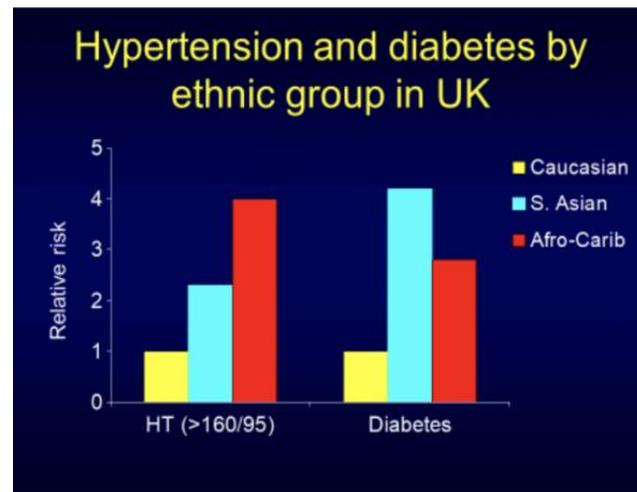
**5x** more common in

Kidney Research UK



## Two Main Causes of Kidney Disease

#1: Diabetes #2: High Blood Pressure



London Cardiovascular Clinics

SOUTH ASIAN & BLACK PEOPLE ARE  
**2-4x** MORE LIKELY  
TO DEVELOP

[www.nhsrho.org](http://www.nhsrho.org)

## THE RESEARCH STUDY

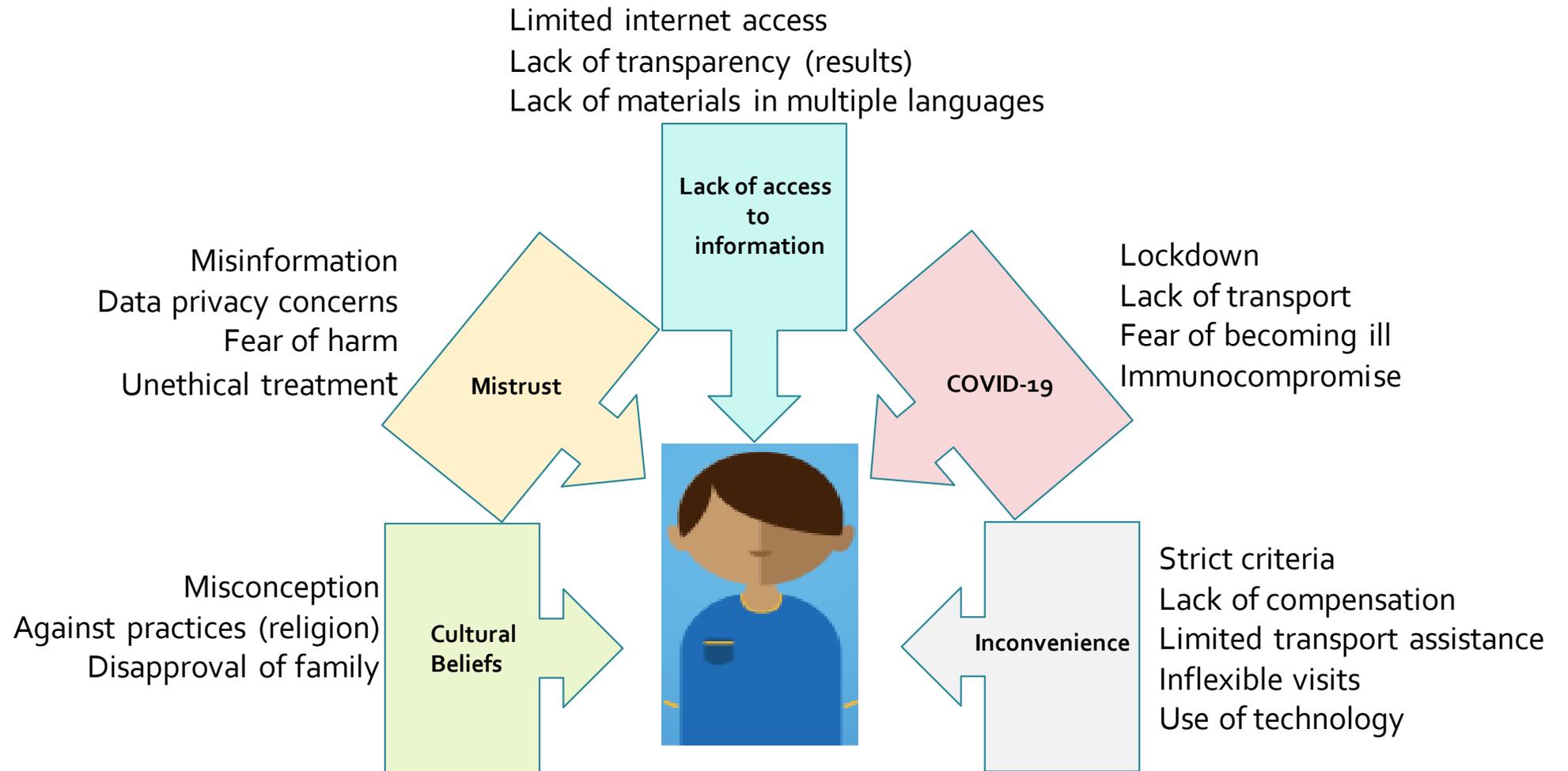
- In late 2020 - A commercial study, sponsored by a Pharmaceutical Company based in the United States was initiated in King's College Hospital



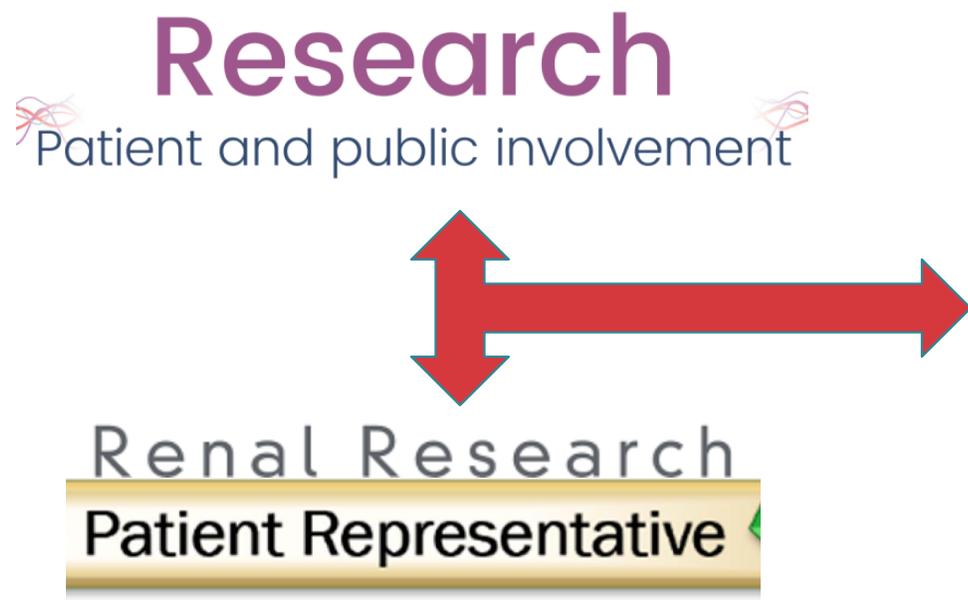
VX19-NEN-801 Study

- A genotype study looking into the Prevalence of Apolipoprotein L1 (APO L1) Alleles Among Individuals With Proteinuric Kidney Disease
- Main criterion: people with kidney disease caused by the Focal Segmental Glomerulosclerosis (FSGS)
- Target population: African ancestry or geographic origin (which may include but is not limited to people who identify as Black, Caribbean, African American, or LatinX)
- Recruitment target: 5 patients

# REPORTED BARRIERS TO RESEARCH PARTICIPATION OF THE UNDER-REPRESENTED COMMUNITIES



# METHODOLOGY USED TO DEVELOP RECRUITMENT INITIATIVES

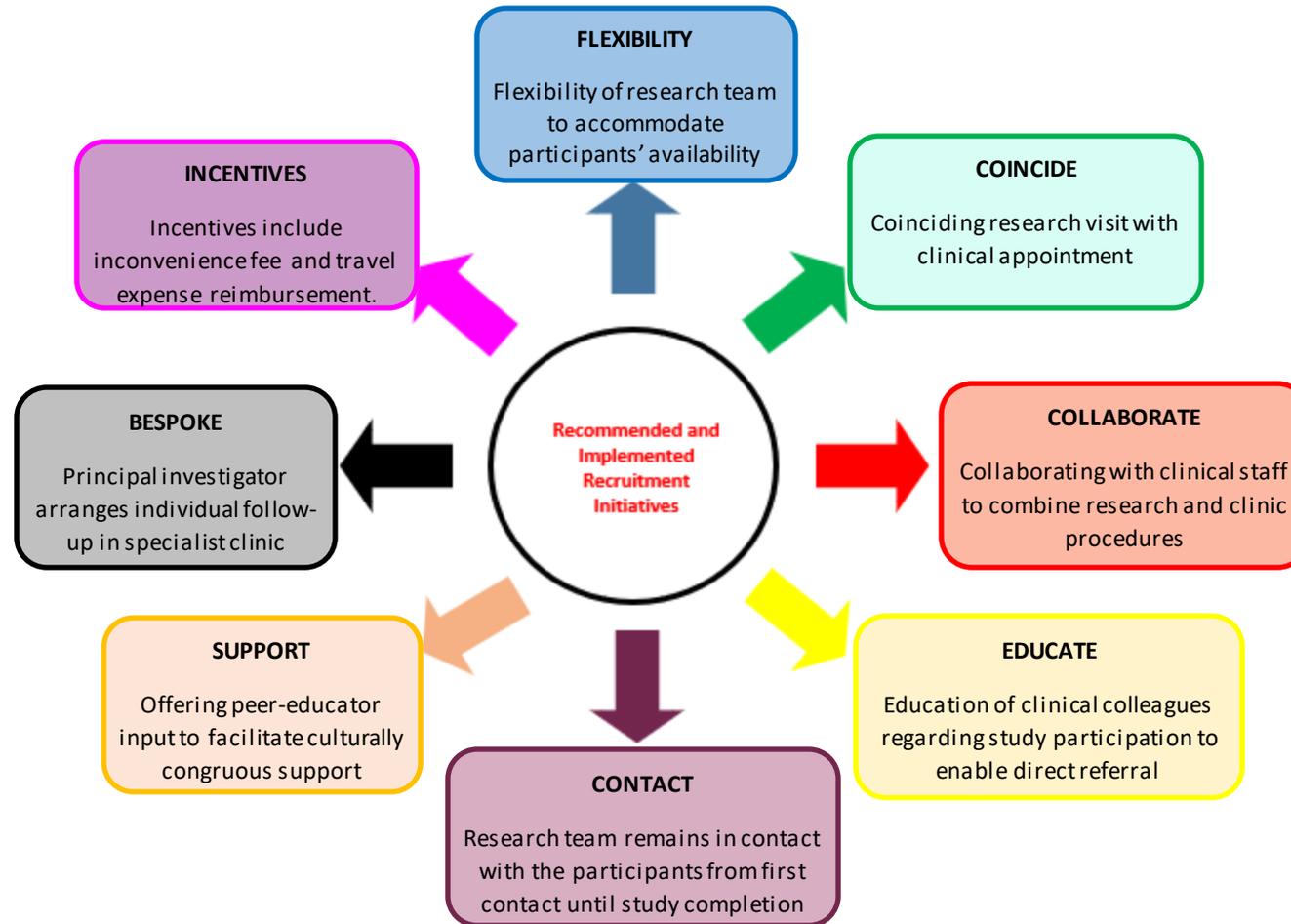


Fuel for innovation

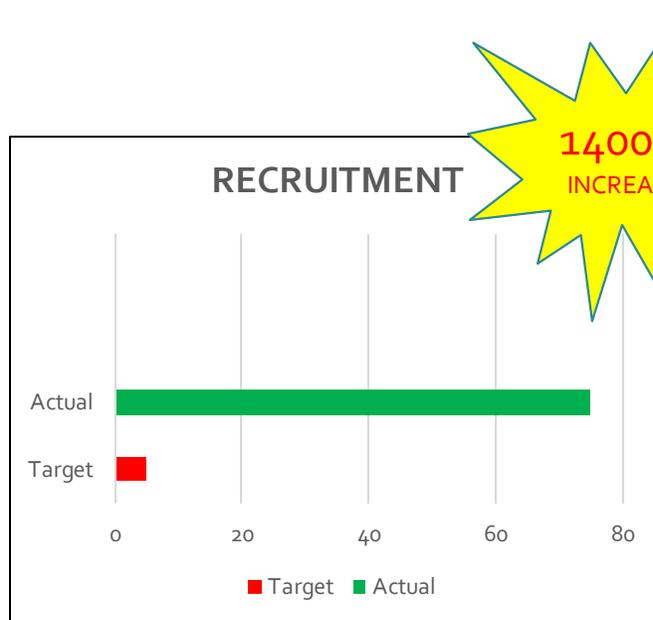
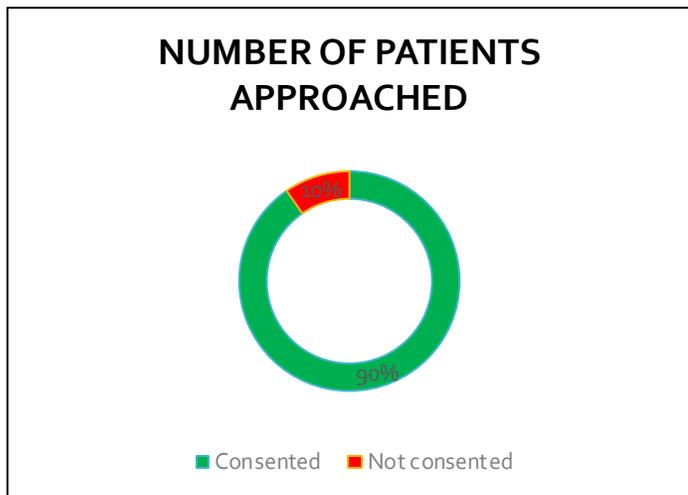
Explore drivers / barriers / perceptions / attitudes / brand perceptions

Understand behavior/decision drivers, longitudinal behaviors (reflective)

# INITIATIVES IMPLEMENTED TO FACILITATE RECRUITMENT (as recommended/suggested by the Focus Group)



# OUTCOME



Doctors' referrals increased by 4-fold in 5 months

Patients have opportunity to participate in Phase II and Phase III trials!

Initiatives to facilitate research recruitment in underrepresented communities



**50<sup>th</sup> EDTNA/ERCA International Conference**  
50 Years of the Multidisciplinary Commitment in Kidney Care

**deDoelenICC Rotterdam** de Doelen – the International Conference Centre in Rotterdam, the Netherlands

**SAVE THE DATE: September 10–13, 2022**

# OUTCOME – continued...



## TEAM ON SPOTLIGHT



### VX19-NEN-801 Study Bulletin

Top sites that genotyped patients

Sites	Principal Investigators	Institutions
182	Echeverri	South Florida Research Institute
136	Thomas	
135	Shahid	
164	Varallo	
026	Bramham	



### VX19-NEN-801 Study Bulletin

Top sites that genotyped patients

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026	Bramham	King's College Hospital NHS Foundation Trust

### VX19-NEN-801 Study Bulletin

#### Site Insight from Dr. Kate Bramham and her team at King's College London



We will aim to share insight from various NEN sites that are successful in genotyping patients. Please find the first insight below from Dr. Kate Bramham and her team at King's College London on their approach in identifying and recruiting patients in their large academic center site

### VX19-NEN-801 Study Bulletin

Top sites that genotyped patients

Site	Principal Investigator	Institution
129	Urena-Torres	AURA Nord
131	Powell	Columbia Nephrology Associates, PA
240	McLean	Brookview Hills Research Associates
026	Bramham	King's College Hospital NHS Foundation Trust

Top sites that genotyped patients

Sites	Principal Investigators	Institutions
131	Powell	Columbia Nephrology Associates, PA
141	Ruiz-Ramon	Elia
240	McLean	Brookview Hills Research Associates
026	Bramham	King's College Hospital NHS Foundation Trust
034	Luscy	Renal Associates of Baton Rouge

## OTHER RESEARCH PROJECT

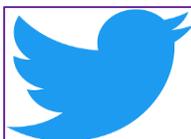


**A**Polipoprotein L1 in **P**eople of African ancestry **L**iving in the UK: **E**xploration of genetic and environmental factors associated with **C**hronic **K**idney **D**isease

A non-commercial, investigator's own study

Recruiting for the same population with the addition of healthy volunteers

### Additional Strategies Implemented:



Almost 400 interests registered within few days of tweet!

**Patient representative** actively involved with the recruitment drive

### Recruitment of healthy volunteers:

- Renal Nurse Representative
- Student Representative

## A Research Study Recruitment Stand at King's Atrium



An example of clinical research recruitment drive conducted by the Renal Research Team

Photo credit: Dr Kate Bramham

## CONCLUSION



Taking a proactive approach with co-development from community members to enhance recruitment of under-represented groups appears to be associated with successful recruitment



Carefully planned recruitment strategies to meet the demands of both the research studies and participants are crucial to maximise recruitment potentials by ensuring positive experience



Formal evaluation of these strategies is needed.



**THANKS FOR  
LISTENING**