

Role of Patients and Patient Advocates in Research:

A Kenyan Perspective

*Presented by: Christine Mutena
On Behalf of: Rare Disease Kenya
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Rare Disease Kenya



- ▶ Umbrella body that creates awareness and advocates for rare diseases in Kenya
- ▶ Plan to engage the government

to develop a national plan for rare diseases and develop a national registry

Some of the Rare Diseases in Kenya

- ▶ Albinism
- ▶ Alagille Syndrome
- ▶ Behcet's syndrome
- ▶ Congenital Central Hypoventilation Syndrome (CCHS)
- ▶ Conn's Syndrome
- ▶ Eosinophilic Enterocolitis
- ▶ Gaucher
- ▶ Guillain-Barré Syndrome
- ▶ Hereditary Angioedema
- ▶ Idiopathic Hypogonadotropic Hypogonadism (IHH)
- ▶ Joubert Syndrome
- ▶ Marfan Syndrome
- ▶ Megalencephaly – Capillary Malformation (MCM)
- ▶ Multiple Sclerosis
- ▶ Muscular Dystrophy: Duchenne, Limb Girdle and Spinal Muscular Atrophy
- ▶ Myasthenia Gravis
- ▶ Narcolepsy
- ▶ Parkinson
- ▶ Primary Immunodeficiency Disorder
- ▶ Ring 18 Chromosome
- ▶ Spinocerebellar Ataxia (SCA)
- ▶ Very Early Onset-Inflammatory Bowel Disease (VEO-IBD)



christina mutena 🇰🇪
@cmutena



Patient-Centricity

Do you think the current stakeholders in the health industry in Kenya embrace this ?

Yes, Patient is key!	6%
No, Patient for who?	35%
Some stakeholders do!	26%
What's patient-centricity	32%

31 votes • Final results

14:22 · 23 Apr 19 · [Twitter Web App](#)

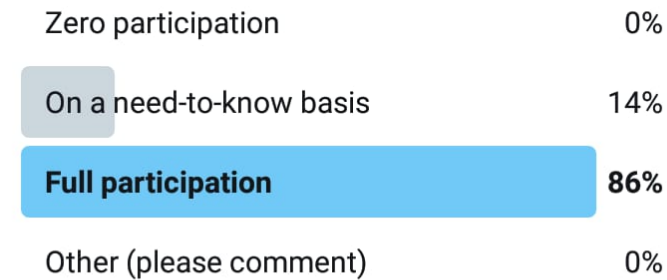
A poll taken on Twitter to try and see if Kenyans understood patient centricity & their role in research.

What do you think is the role of a patient and patient advocate in (medical) research when it comes to medication and overall treatment of their condition?

(This is in reference to drug companies)

cc: [@RareDiseaseKE](#)

Please RT



21 votes • Final results

A poll taken on Twitter to try and see what Kenyans opinion on the importance of patient role in drug development is.

Current Situation

- * Lack of a patient registry
- * Few patient organizations established
- * Lack of public education
- * Lack of trust in clinical trials ... “guinea pig” mentality
- * Few to zero experts in the field of genetics
- * Patients look for clinical trials and not the other way round
- * Social culture doesn't give patients the voice they deserve



Rare Disease Kenya (RDK)

KCB Building, Rm. 207,
Garage Road, Off Dar es Salam Road,
Nairobi, Kenya
Tel : +254 701 025 753

info@rarediseasekenya.org
www.rarediseasekenya.org
Twitter: @RareDiseaseKE
Facebook: @RareDiseaseKE
YouTube: RareDiseaseKE