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## CENSUS 2019

# Why counting persons with albinism matters

*It is important that PWAs come out during this census to be counted for them to be fully included within the albinism agenda.*

by [ISAAC MWAURA](#)

News

31 August 2019 - 15:05



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## In Summary

- Many are asking why the exercise is taking too long. This is partly because of the new demographics as captured by some new questions such as question number 43 on albinism.
- The census will help in ascertaining amongst others, the genetic variability and occurrence of albinism within our population.

by [ISAAC MWAURA](#)

News

31 August 2019 - 15:05



COUNT: Abdhulhafidh Nassor with his mother Dor-bib Nassor register with Malalo Mwakazo in Mvita. Photo/Charles Mghenyi

Kenyans are currently being counted in our traditional 10-year census cycle that was last held in 2009.

Many are asking why the exercise is taking too long. This is partly because of the new demographics as captured by some new questions such as question number 43 on albinism.

PUBLICITÉ



For members of the Albinism Society of Kenya, this is a great milestone since for the first time in the history of this great republic; we are being counted to get a realistic estimate of how many we are.

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The census will help in ascertaining amongst others, the genetic variability and occurrence of albinism within our population. The clamour for our inclusion into the mainstream society hasn't been easy.

We officially started a campaign to be counted through a petition presented to Parliament on August 6, 2009, by Eugene Wamalwa, then MP for Saboti, and signed by more than 300 members of the society.

On August 31, 2010 Minister for Planning and Vision 2030 Wycliffe Oparanya invited members of ASK to his office for discussions with director general of the Kenya National Bureau of Statistics Anthony Kilele and later on for the launch of the results at KICC.

Later on in the afternoon, Oparanya officially responded to the petition by noting that while the 2009 census failed to capture persons with albinism's data, this was because the census' technical working group on disability didn't recommend for a special code on albinism and that the request by the society had come late, when materials had already been printed.

The ministry took note of the concerns and committed to looking into this in the future, together with ASK. The minister also suggested that a special census for PWAs be conducted through the provincial administration.

The government through the Ministry of Sports, Culture and Social services and the National Council for Persons with Disabilities were to ensure the Persons With Disabilities Act was amended to mainstream PWAs under the ambit of Persons With Disabilities.

On sunscreen and sunglasses, the minister committed to work with Uhuru Kenyatta, then Deputy Prime Minister and Minister for Finance, to ensure a tax waiver, in three months.

On representation, the minister advised that in view of the new Constitution, that political parties could nominate one of the PWAs to be among the 12 slots for special interest groups in the National Assembly, or amongst the two for PWDS in the Senate. He advised ASK to lobby parties to ensure this happens.

#### ATTEMPTED HEADCOUNT

Consequently, the Minister of Labour, Children and Social Services in conjunction with NCPWD attempted to a national headcount through the provisional administration in 2013.

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However, this exercise wasn't successful due to the manner in which it was conducted. Persons with albinism were supposed to report to the local administration to be counted, thus posing serious push-backs due to the distance covered and cost on the part of PWAs, and inadequate information, competence and facilitation on the part of the administration.

ASK was forced to go to court to stop the exercise, citing amongst others, lack of public participation.

Earlier in 2006, while serving as a board member of the NCPWD, I had managed to make albinism as a stand-alone type of disability within the organisation's registration policy and application form.

NCPWD had been given the mandate of registering all PWDs in Kenya under the act. It was not easy to convince my fellow board members we be removed from the category of visual impairment.

In fact, the terminology that found its way to the form is 'albino' but it served the purpose nevertheless.

Albinism has two major categories — ocular, that is characterised by lack of pigmentation in the eyes only, and oculocutaneous, which is lack of pigmentation in the eye, skin and hair.

The second category has a subtype also known as Rufus albinism, which is characterised by reddish-brown hair and yellow/bronze skin.

The majority of PWAs who have either ocular or Rufus albinism, aren't aware or don't identify as having albinism. It is, therefore, important that they come out during this exercise to be counted, for them to be fully included within the albinism agenda.

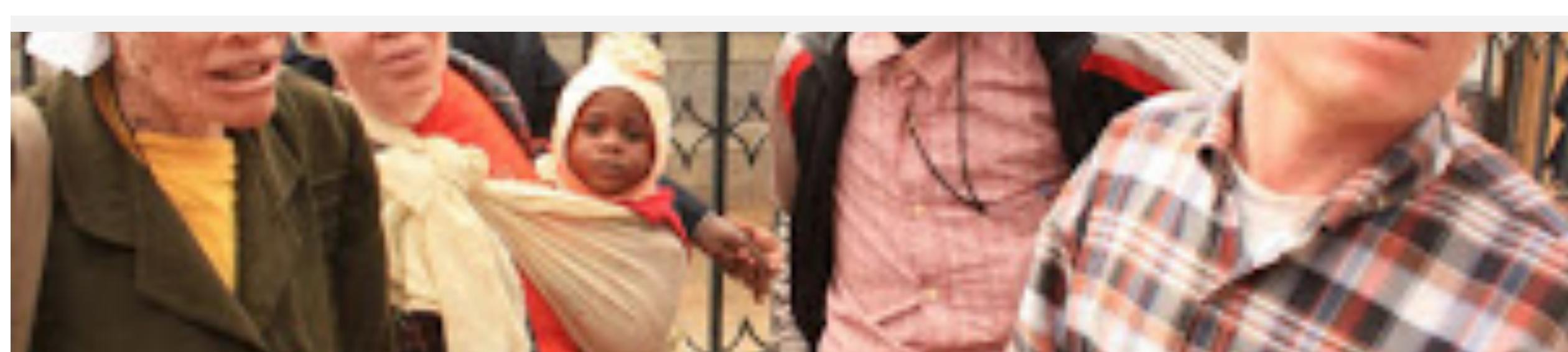
Enumerators as well shouldn't assume but ask the question openly and without shame or fear nor be hindered by terminology or political correctness. The terms "persons with albinism", albino person, or *ulemavu wa ngozi, mtu mwenye albinism*, are acceptable to many persons.

Persons with albinism must count in decision-making.

***The writer is the chairman of the albinism society of Kenya and the first MP and senator with albinism in Kenya.***

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**Warubuko Sokoke\_Khadzonzo** • 2 years ago • edited

Mother Nature has bequeathed Waafrika (weusi) with the willpower to accept ourselves as we are naturally, without ever feeling or seeming as very inadequate, because of the colour of our skins, texture of our hair, facial features, various accents, dietary habits, customs, traditions, names, and regions where we happen to be domiciled.

[ - ]

Unfortunately, Waafrika wengi have strayed far away from multiple natural ways of our once wonderful life on the African continent, that we should have acquainted ourselves with and fully embraced for decades, even after the disruptive series of arrival of 'outsiders' like Arabs, Asians and later Europeans.

[ - ]

We have now fated ourselves along destructive paths of self-inflicted inferiority complex, self-loathing and always seeking to be other people, like Europeans, Arabs, Asians and anything else other than ourselves as Waafrika wenye ngozi nyeusi from various cultural traditions.

[ - ]

But when Mother Nature issues a wake up call by presenting a child or adult in our midst who have ngozi 'nyeupe' ya kushangasha au isiofahamika like albinism (zeruzeru), we end up reacting negatively and also recoiling with immediate repulsion or shock. And yet we keep seeking 24/7 what Waafrika religiously and fanatically consider as superior ('advanced' or 'civilized') race just because it is of European origin, North American or Australian. Shida yetu kubwa ni nini!!

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