

The patients left behind by HIV research

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People with HIV from BAME communities, women and heterosexual men are underrepresented in HIV studies—according to new research from the University of East Anglia and Western Sydney University.

Medication to manage HIV is now very effective at keeping people well.

But over half of people living with HIV do not take their [medication](#) as prescribed.

We are yet to find solutions that are routinely used by healthcare teams to successfully support people to take their medication as prescribed—despite many studies designed to investigate the problem.

New research published today reveals that the problem could be in the way that studies are designed in the first place—with BAME communities, women and straight men under-represented.

The research team say that this imbalance of representation needs to be fixed, in order to design solutions that suit the needs of a diverse population and keep people with HIV living longer, healthier lives.

Lead researcher Prof Debi Bhattacharya from UEA's School of Pharmacy said: "It's really important that people with HIV start taking medication as soon as possible and continue taking it as prescribed for life. While medication can't cure HIV, taking it correctly helps people live longer, healthier lives. Medication can also reduce the risk of HIV transmission.

The research team reviewed 80 studies designed to evaluate different approaches for supporting people to take their HIV medication correctly.

They found that people from ethnic minorities, women and [heterosexual men](#) were underrepresented for the country in which the study was taking place.

Prof Bhattacharya said: "We found that none of the 80 studies had a trial population that reflected the actual population of people living with HIV.

"For example in many cases, gay men were over-represented in studies,

compared with the amount of gay men living with HIV.

"In one American study not a single woman was included even though women represent around one in five people with HIV."

"This is a problem because we know that in several countries including America, HIV rates in men are falling more than they are for women."

"As these patient groups are being significantly underrepresented in these types of trials, their needs, beliefs and attitudes to treatment are not fully understood. This potentially leaves these populations without the support they need to live well with HIV.

"We also know that language profoundly affects the way patients understand their treatment routines—which impacts on how they engage with their disease and medication. Failure to take this into account seriously hinders people from getting the best clinical outcomes.

"We found that none of the studies used [research methods](#) to encourage people with differing languages and culture to contribute in the ways that are needed for the research to be successful.

"This may explain why we have seen few of these solutions that are shown to work in the studies then go on to be routinely used in healthcare.

"Over the years we have seen greater scrutiny over how research is conducted to ensure that people invited to participate in research are fully informed before they decide to participate. These changes, like making sure that we have written consent, have been very important for protecting the public.

"But, the changes have led to new problems, such as people with limited

literacy or those less fluent in the local language being excluded from studies. It is important that we continue to protect the public whilst also supporting people with differing needs to participate in research."

"The guidelines for carrying out research need to recognise that research methods must be adapted to support the wide range of people with differing needs that make up the diversity of people with a specific disease.

"The guidelines also need to communicate more strongly, the importance of properly involving people for whom the research is intended to help, at the earliest possible stage of the research otherwise these health inequalities may continue."

More information: 'Do interventions to improve adherence to antiretroviral therapy recognise diversity? A systematic review' is published in the journal *AIDS Care* on August 27, 2020.

Provided by University of East Anglia

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