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Dialogue: commentary on 'Engaging African-ancestry participants in systemic lupus erythematosus clinic trials'

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In the review entitled *Engaging African-Ancestry Participants in Systemic Lupus Erythematosus Clinic Trials*, Anjorin and Lipsky[1] sought to (1) summarise the extensive body of literature demonstrating differences in genetics and health impact in African American (AA) patients with SLE compared with European American (EA) counterparts, and (2) describe challenges in recruiting AA for clinical trials. Several facts in their comprehensive review are indisputable: systemic lupus disproportionately affects individuals of African ancestry (and probably other racial/ethnic groups such as Hispanics and Asians) compared with Caucasians; the clinical and immunological manifestations, damage accrual and morbidity of SLE tend to be more severe in those of African ancestry; and such individuals are often more socioeconomically disadvantaged, which may lead to problems with access to medical care, at least in countries that do not have universal healthcare. They further point out the well-recognised observation that, despite higher overall disease prevalence, African–American patients with lupus are significantly under-represented in clinical trials of new therapies. The importance of this fact is not lost when one considers that response to therapy may be linked to genetic differences in racial/ethnic groups. On the other hand, one cannot discount sociocultural differences, in that a delay in seeking medical care, even when it is ultimately of cutting-edge quality, is likely to influence the eventual outcome.

The authors point out that enrolling minority patients in clinical trials has been a significant challenge for a number of reasons, including African–American distrust of clinical trials because of bad historical experiences and poor communication with healthcare professionals. Despite this they acknowledge that others have noted that AA subjects were as willing as their non-minority counterparts to participate in clinical trials.[2] Many of the potential remedies suggested by the authors are certainly relevant for clinical trials in many diseases and involving numerous new medications. They conclude that 'the various stakeholders involved in clinical research could act within their own realms to develop new paradigms and policies to bolster the inclusion of AA in the development of new therapies'.

Perhaps the need is to increase the involvement of underinvolved stakeholders in communities of colour. To borrow a phrase from Willie Sutton, we should 'go where the money is'. The healthcare professional participants in most clinical trials are the 'usual suspects'. Because of financial constraints, investigator-generated studies are rarely large enough to result in data acceptable to the Food and Drug Administration. Pharmaceutical and biotech-sponsored studies dominate the landscape. With their databases of likely trial sites, they rarely seek out small practices in geographical locations that cater to minority populations. This is not surprising, since individual office practices are unlikely to have the funds necessary to manage patients in clinical trials. Furthermore, rheumatologists in such practices may not be informed of the existence of relevant clinical trials at a stage early enough to refer patients to established clinical trial sites. The easy answer is MORE FUNDING! If it is not forthcoming from the National Institutes of Health or other agencies, perhaps the pharmaceutical industry could be induced to set up a collaborative funding source with grants to small practices or groups to set up and publicise clinical trials in minority-dominated neighbourhoods. The will is there; we need to pave the way.

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