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Meeting report: The Systemic Lupus International Collaborating Clinics (SLICC) World Lupus Seminar on Africa

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ABSTRACT

The Systemic Lupus International Collaborating Clinics (SLICC) is an international research group dedicated to promoting collaboration among scientific investigators in the study of systemic lupus erythematosus (SLE). Currently, most SLICC members are based in North America and Europe, with limited representation from other regions. SLICC recognises the importance of expanding its global collaborations and representation to ensure that its research accurately reflects the global burden of SLE and provides equal benefit to all patients with SLE worldwide. Given that SLICC currently lacks representation from the African continent, an opportunity was identified to convene a meeting bringing together lupus physicians with experience providing clinical care and conducting lupus research in Africa, along with members of the SLICC group. The purpose of the meeting was to share information regarding SLE in Africa, to discuss recent innovations and current challenges in the region and to explore future collaborations between SLICC members and colleagues in Africa in the areas of SLE clinical care, research and education. This meeting report highlights information presented during the seminar as well as a discussion of next steps moving forward.

INTRODUCTION

This report summarises the presentations and discussion of a meeting titled 'SLICC World Lupus—Seminar on Africa' which was held in San Diego, California and hosted by the Systemic Lupus International Collaborating Clinics (SLICC) on 11 November 2023. This seminar brought together lupus physicians with experience providing clinical care and conducting lupus research in Africa, along with members of the SLICC group. The purpose of the meeting was to share information regarding systemic lupus erythematosus (SLE) in Africa, to discuss recent innovations and current challenges in the region and to explore future collaborations between SLICC members and colleagues in Africa in the areas of clinical care, research and education that could be mutually beneficial. The meeting featured presentations by SLE clinician investigators working in Africa and a facilitated discussion of how the group can work together moving forward to improve outcomes for the global SLE community.

BACKGROUND

Originally established in 1991, SLICC is an international research group of rheumatologists and immunologists dedicated to promoting collaboration among scientific investigators in the study of SLE.[1] Over the years, SLICC has made numerous important contributions in this realm, including the development of classification criteria[2] and a standardised measure of organ damage[3] as well as the establishment of the SLICC inception cohort.[4 5] Currently, SLICC includes members from over 40 academic medical centres in 18 countries across five continents. However, the majority of SLICC members are based in North America and Europe, with less representation from other regions of the world.

It has been increasingly recognised that such gaps in representation can lead to negative impacts, including contributing to SLE-related health disparities for those in under-represented communities. For SLICC to be one of the global leaders in SLE research moving forward, there is a need to expand its global collaborations and representation to ensure that its research accurately reflects the global burden of SLE and provides equal benefit to all people with SLE worldwide. To address this, SLICC has established the World Lupus Committee, whose mission is to lead and foster a global view of SLE to inform patient care, conduct research and develop educational programmes.

The charge of the SLICC World Lupus Committee is to (1) promote bidirectional sharing among members of SLICC and other

colleagues around the world on universal needs in SLE care, research and education and (2) leverage existing SLE research networks and develop new opportunities for collaboration between SLICC members and other colleagues on global issues in SLE. As an initial step towards achieving these goals, a seminar on SLE in Africa was organised and held in conjunction with the annual general meeting of the SLICC membership in November 2023. The focus on Africa was selected, as this is a region that has been historically overlooked by the broader SLE research community, with no current representation within SLICC.

Africa is the second largest and second most populous continent in the world. At over 30 million square kilometres, it accounts for approximately 20% of the earth's land area, which is more than the USA, Canada and China combined.[6] As of 2024, its population exceeds 1.5 billion people and is expected to climb to 2.5 billion by 2050, at which point it is projected that Africa will account for one-quarter of the world's population.[7] Consisting of 54 independent states and approximately 2000 ethnolinguistic groups,[7 8] Africa is also a continent of tremendous social and cultural heterogeneity. Finally, the incredible genetic diversity that exists within Africa exceeds that of all other continents,[9 10] though this remains largely unexplored, with individuals of African ancestry comprising only 2% of all data used in genome-wide association studies.[11 12] Together, these factors highlight both the complexity and the importance of collaborative efforts to advance SLE research, education and clinical care in this vast and diverse region.

OVERVIEW OF MEETING CONTENT

The meeting featured presentations by four SLE clinician investigators with experience providing clinical care and conducting research on the African continent. Each presenter shared their experiences, described their SLE patient cohorts, highlighted some of their recent research findings and discussed current barriers and facilitators to their work. Following all the presentations, meeting attendees participated in a facilitated discussion, which is summarised below.

APOLIPOPROTEIN L1 IN SLE: A WEST AFRICAN DIASPORA STORY

Dr Ashira Blazer

(University of Maryland, Baltimore, Maryland, USA)

Dr Blazer began her presentation by discussing the increased incidence and prevalence of SLE among Black individuals in the USA.[13 14] She highlighted several key challenges in comparing epidemiological data for SLE between the USA and Africa. This includes physician shortages, particularly a lack of rheumatologists in many African countries, as well as differences in diagnostic practices and infrastructural challenges, leading to limited availability of serologic testing and access to SLE pharmacotherapies. Data generated in African SLE cohorts are also subjected to publication bias. These factors have contributed to the epidemiology and pathogenesis of SLE in Africa being understudied, under-reported and misrepresented.[15]

Dr Blazer presented data from the Ancestrally African SLE Cohort as an exemplary collaborative study between centres in the USA and West Africa, comprising patients from New York City in the USA, Accra in Ghana and Lagos in Nigeria. The first participants were recruited in 2015, and this is now the longest-running international African ancestry cohort in rheumatology. Longitudinal clinical and serologic biomarker data were collected once every 6 months between 2015 and 2019, and over 350 participants have been recruited to date. Characteristics of the SLE cohort in Accra, Ghana are shown in table 1.

This cohort has demonstrated key differences in genetic, serological and clinical features between patients with SLE in the USA and in Ghana. For example, Ghanaian

Table 1 Demographic, clinical and laboratory characteristics of patients with systemic lupus erythematosus followed in the outpatient rheumatology clinic at the Korlebu Teaching Hospital in Accra, Ghana (n=100)

Demographic features	
Age (years), mean (SD)	32.4 (9.4)
Female, n (%)	99 (99)
Disease duration (years), mean (SD)	2.3 (2.3)
Symptom duration at diagnosis (months), mean (SD)	8.5 (15.8)
Clinical features	
Malar rash, n (%)	49 (49)
Discoid rash, n (%)	41 (41)
Photosensitivity, n (%)	39 (39)
Mucosal ulcers, n (%)	48 (48)
Arthritis, n (%)	77 (77)
Serositis, n (%)	50 (50)
Renal disease, n (%)	53 (53)
Neurologic disease, n (%)	13 (13)
Laboratory features	
ANA positivity, n (%)	93 (93)
Anti-dsDNA positivity, n (%)	63 (63)
Anti-Sm positivity, n (%)	54 (54)
Medication use	
Corticosteroids, n (%)	92 (92)
Prednisolone dose (mg), mean (SD)	12.8 (9.6)
Hydroxychloroquine, n (%)	87 (87)
Methotrexate, n (%)	10 (10)
Azathioprine, n (%)	37 (37)
Cyclophosphamide, n (%)	13 (13)

Adapted from Blazer A *et al*.[16]
ANA, antinuclear antibodies.

SLE patients demonstrated increased prevalence of autoantibodies including anti-Ro/SSA, anti-Smith and anti-RNP as well as a higher frequency of specific SLE disease manifestations, notably discoid lesions, serositis and arthritis.[16] There may be key differences in the pathogenesis of SLE in Africa, as several cytokines associated with SLE disease flare in African ancestry patients in the USA, did not show similar associations in Ghanaian patients with SLE.[16] The reasons for these discrepancies require further investigation.

Using data from the Ancestrally African SLE Cohort, Dr Blazer has also been studying the impact of risk variants in the apolipoprotein L1 (*APOL1*) gene on health outcomes in SLE. Mutations in *APOL1* confer evolutionary advantage via resistance to African trypanosomiasis.[17] The allelic frequency of these genetic variants is high in Ghana and Nigeria where trypanosomiasis has previously been endemic as well as among African Americans of recent West African heritage. In non-SLE populations with chronic kidney disease, these *APOL1* polymorphisms have been shown to be associated with adverse renal and vascular outcomes.[18] Among African American SLE patients with nephritis, individuals who are homozygous for these *APOL1* risk variants are at increased risk for end-stage kidney disease, despite lower activity and chronicity scores on renal biopsy. This raises the question of whether SLE inflammatory pathways may increase *APOL1* expression and the burden of toxic protein in variant-carrying endothelium, leading to adverse health outcomes.[19] Dr Blazer has investigated this hypothesis further in a Ghanaian cohort of 100 patients with SLE, where *APOL1* risk variants were found to be associated with increased risk of organ damage and higher mortality risk, with end-stage kidney disease and congestive heart failure as the leading causes.[16]

Dr Blazer concluded her presentation by sharing some early findings from an ongoing pilot study that aims to use urine cell epigenetics to help differentiate between active lupus nephritis and *APOL1*-related nephropathy.[20] This work has the potential to offer non-invasive alternatives to kidney biopsy for the diagnosis and monitoring of nephritis in SLE and could be particularly useful in under-resourced areas where access to renal biopsies is limited.

LUPUS IN NIGERIANS

Dr Olufemi Adelowo

(Lagos State University Teaching Hospital & Lagos University Teaching Hospital, Lagos, Nigeria)

Dr Adelowo emphasised that SLE remains understudied and under-reported in Africa. Although the last two decades have seen increased efforts to report clinical and epidemiologic data on SLE in Africa,[21] there is still a relative paucity of data from West Africa and East Africa. However, a recent systematic review and meta-analysis including a total of 28 375 individuals admitted to hospitals revealed a prevalence of SLE of 1.7% (95% CI 0.8 to 2.9%) across general medicine and rheumatology units,[22] suggesting that SLE is much more common in sub-Saharan Africa than previously thought. While the mean age of patients with SLE at presentation appears similar across Africa and comparable to global estimates, the women–men ratio among East and West African patients with SLE appears exaggerated (21:1-32:1)[23 24] when compared with data from North America and Europe. The reasons for this observation remain poorly understood and require further investigation.

In a study of patients attending a rheumatology clinic in an urban area of Nigeria, SLE was found to account for 5.3% of all rheumatic disease cases. Conversely, there appears to be a paucity of SLE in rural communities. Two studies conducted in rural Northern and Southern Nigerian populations using the Community Oriented Program for the Control of Rheumatic Diseases (COPCORD) survey methodology, with 2454 and 3056 respondents respectively, did not identify a single SLE patient.[25 26] One limitation of these studies is the potential for under-ascertainment of SLE in individuals without prominent musculoskeletal symptoms, which are required as part of the COPCORD entry criteria for classifying cases as being potentially rheumatic in nature. Another possible explanation for the rarity of SLE in rural communities could be the absence of environmental pollution when compared with urban communities. Further research is required to identify potential genetic differences as well as specific pollutants and other environmental factors.

Across the African continent, the clinical phenotype of SLE varies; for example, photosensitivity is more common in North and South Africans, while discoid disease is less common in North Africa and malar rash may be less common in Nigeria.[21] Regional variations in serology are also observed, with higher frequency of anti-Smith antibodies in West Africa[23] but higher frequency of anti-dsDNA antibodies in North Africa.[27] In particular, Dr Adelowo highlighted the important contributions of the Lupus Registry in Nigeria (LURIN) study, a cohort of nearly 900 patients with SLE recruited from across the six geopolitical zones in Nigeria, in generating key data to advance our understanding of the prevalence, clinical phenotype and serologic characteristics of patients with SLE in West Africa (table 2).[28]

Dr Adelowo discussed some of the challenges facing patients with SLE in Nigeria. He noted a lack of awareness of SLE among general practitioners, particularly in more rural areas. Due to the presence of constitutional symptoms, many patients are initially diagnosed and treated for infectious diseases, such as malaria and tuberculosis, in areas where these diseases are endemic.[23] Certain religious and cultural beliefs may also lead to reluctance or delay in seeking conventional medical care, with some patients preferring to seek help from traditional healers or alternative care practitioners. These factors contribute to significant diagnostic delays. For example, in a cross-sectional survey of 245 patients with SLE in Nigeria, many had sought care from multiple healthcare professionals

Table 2 Demographic, clinical and laboratory features of patients with systemic lupus erythematosus in a multicentre hospital-based study in Nigeria (n=896)

Demographic features	
Age (years), mean (SD)	34.5 (11.7)
Female, n (%)	798 (89.1)
Clinical features	
Malar rash, n (%)	309 (34.5)
Discoid rash, n (%)	178 (19.9)
Photosensitivity, n (%)	372 (41.5)
Oral ulcers, n (%)	427 (47.7)
Alopecia, n (%)	403 (45.0)
Serositis, n (%)	292 (32.6)
Renal disease, n (%)	270 (30.1)
Neurologic symptoms, n (%)	303 (33.8)
Laboratory features	
Antinuclear antibodies (ANA)	
Test performed, n (%)	742 (82.8)
Positive result, n (%)	727/742 (98.0)
Anti-dsDNA antibodies	
Test performed, n (%)	616 (68.8)
Positive result, n (%)	369/616 (59.9)
Anti-Sm antibodies	
Test performed, n (%)	375 (41.9)
Positive result, n (%)	141/375 (37.6)
Medications	
Prednisolone, n (%)	705 (78.7)
Hydroxychloroquine, n (%)	781 (87.2)
Azathioprine, n (%)	394 (44.0)
Methotrexate, n (%)	117 (13.1)
Mycophenolate mofetil, n (%)	194 (21.7)
Cyclophosphamide, n (%)	113 (12.6)
Rituximab, n (%)	42 (4.7)
Belimumab, n (%)	0 (0)

Adapted from Osaze O, *et al*.[28]

before receiving their diagnosis and nearly 40% of patients had symptoms for over 5 years prior to seeing a rheumatologist. This can result in patients presenting at an advanced stage of disease with irreversible organ damage.

Lack of human resources and infrastructure also plays a role. There is a severe lack of rheumatologists, estimated at only one rheumatologist per 4 million population. Access to serologic testing is limited, particularly in rural areas. ANA and ENA tests are processed outside of the country, leading to prolonged wait times for results. Critical investigations such as renal biopsies are unaffordable to many patients. While therapies like prednisolone and antimalarials are relatively accessible, immunosuppressives may be prohibitively expensive for some patients, and biologic therapies, such as rituximab and belimumab, are not typically available.[21]

Dr Adelowo shared his vision for the path forward to address the current barriers to optimal care for patients with SLE in Africa. He called for additional rheumatology training for medical trainees, nurses and general practitioners to increase awareness of SLE, especially in more rural settings, as well as for more local rheumatology training programmes in African countries to bolster the rheumatology workforce. For example, Nigeria presently has two, 6-year curriculum-based rheumatology residency training programmes, leading to the award of Fellowship certificates in rheumatology. The country has thus been able to produce more than 60 rheumatologists. Citing the success of LURIN,[28] Dr Adelowo urged that more clinical SLE registries are needed to demonstrate the burden of SLE in Africa, as such data are critical for effective advocacy work. Finally, he emphasised the need for SLE clinical practice guidelines that are relevant to the African context, and the importance of including representation from Africa in the development of classification criteria and outcome measures for SLE.

LUPUS IN GHANA

Dr Dzifa Dey
(University of Ghana Medical School, Korlebu Teaching Hospital, Accra, Ghana)

Dr Dey described SLE as a significant healthcare challenge in Ghana. For many years, it was an unrecognised disease hiding in the shadows. The first dedicated clinic providing organised care to patients with SLE in Ghana was established in Accra in 2010 and has served an estimated 871 patients with SLE to date.

Dr Dey reported on the clinical and serologic characteristics of 392 patients with SLE in their cohort. The most common manifestations were musculoskeletal (77.6%) and skin disease (70.2%), although over 40% of patients had neuropsychiatric disease, most frequently depression, seizures and psychosis. Lupus nephritis was present in 56% of patients and was identified at the time of SLE diagnosis in the majority (76%). Dr Dey reported improved outcomes among Ghanaian patients with SLE in their cohort compared with previous eras, with 95.4% of patients in their cohort remaining alive after a mean follow-up of 8 years. Mortality risk was highest among patients with SLE with nephritis and/or neuropsychiatric disease.

In the Ghanaian SLE cohort, ANA positivity was noted in approximately 90% of patients with SLE in whom testing was available, which was approximately 70% of the overall cohort. While less than 40% patients demonstrated positivity for anti-dsDNA antibodies, over 80% of patients had antibodies against extractable nuclear antigens. Dr Dey presented data from a study conducted in collaboration with Dr Blazer and Dr Adelowo among others, which assessed the performance of various SLE

classification criteria in two West African SLE cohorts in Ghana (n=110) and Nigeria (n=94) compared with the NYU Langone-African American cohort (n=151).[29] While 95% of patients in the NYU cohort met the 2019 ACR/EULAR classification criteria for SLE, these criteria were only met by 62% of patients in the Ghana cohort and 61% of the Nigerian cohort.[29] This was largely due to missing ANA values in the West African cohorts, which impacted 26% of the Ghanaian patients and 33% of the Nigerian patients.[29] This study demonstrated how the ANA entry criterion may diminish the diagnostic utility of the ACR/EULAR criteria in under-resourced settings where access to laboratory testing may be limited. Limitations in laboratory testing, access to kidney biopsies and prohibitive costs of emerging treatment options highlight the need to include voices from regions such as Africa in the development of such tools to ensure that they are broadly applicable to the global SLE community and to avoid exacerbating existing health disparities.[30]

Dr Dey identified several barriers to clinical SLE care in Ghana. Diagnostic delays and lack of awareness about SLE are common issues. In particular, Dr Dey shared data on health-seeking behaviour among patients with autoimmune rheumatic diseases in Ghana demonstrating that many individuals seek care at pharmacies, churches, prayer camps and traditional healers and may be less likely to access specialist care, such as from a rheumatologist.[31] Access to medications is also limited.[21 32] In the SLE cohort in Accra, Ghana, the most commonly used medications were corticosteroids (94.9%), antimalarials (87.8%) and azathioprine (54.8%). Cyclophosphamide (16.6%) was used in severe cases, while access to mycophenolate (7.7%), tacrolimus (0.3%) and biologics (0.5%) was very limited. Finally, Dr Dey highlighted the costliness of haemodialysis as a major barrier to accessing renal replacement therapy for lupus nephritis patients, with very few individuals being able to afford long-term dialysis for more than 1 year. There is a need to implement projects that would aid in early SLE diagnosis and characterise unique features of African patients with SLE to enable tailored management strategies.

Table 3 Clinical and laboratory characteristics of patients with systemic lupus erythematosus in Nairobi, Kenya (n=100)

	Number/per cent of cases
Clinical features	
Malar rash	54
Discoid rash	22
Photosensitivity	44
Oral ulcers	36
Arthritis	90
Serositis	28
Renal disease	24
Neurologic disease	19
Haematologic manifestations	67
Laboratory features	
Antinuclear antibodies (ANA)	
Positive	82
Negative	8
Not performed	10
Anti-dsDNA antibodies	
Positive	56
Negative	10
Not performed	34
Medication use	
Corticosteroids	84
<10 mg/day	32
10–20 mg/day	45
>20 mg/day	7
Hydroxychloroquine	77
Methotrexate	15
Azathioprine	27
Mycophenolate mofetil	12

Adapted from Genga E, *et al*.[33]

LUPUS IN KENYA

Dr Omondi Oyoo and Dr Eunice Omondi
(University of Nairobi, Kenya)

Dr Oyoo discussed that the incidence and prevalence of SLE in Kenya are unknown due to a lack of epidemiological studies. In Kenya, there are only 12 rheumatologists and one rheumatology specialist nurse, for a population of 55 million people. He indicated that this falls well short of the WHO recommendations of at least one rheumatologist per 100 000 people. Furthermore, 9 of the 12 rheumatologists in Kenya are based in Nairobi, and therefore access is even more limited in rural areas. For these reasons, patients with SLE may be managed in general medical or dermatology clinics, in addition to rheumatology services.

In virtual attendance at the meeting was Dr Sheilla Achieng, a rheumatology global health research fellow based in Liverpool, United Kingdom. In collaboration with the University of Liverpool and the University of Manchester in the United Kingdom, Dr Achieng has secured research funding to support the initial development of an SLE registry in Kenya, with data collection already underway. This marks a significant milestone in advancing research in this area and the data will help us better understand the clinical characteristics and outcomes of patients living with SLE in Kenya.

The emerging data suggest that, similar to other cohorts, arthritis and skin disease are the most common clinical manifestations of SLE (table 3).[33] In contrast to West Africa, there is good access to diagnostic tests. In

a cohort of 100 patients from Nairobi, ANA was positive in 82% of patients and anti-dsDNA antibodies detected in 52%.[33] Some smaller studies on SLE in Kenya have suggested a high prevalence of peripheral neuropathy (60%) and cardiac manifestations (89%), including pericardial thickening, valvular disease and pulmonary hypertension.[34] Depression (73%) and fibromyalgia (65%) are prevalent and contribute to the reduced health-related quality of life observed among Kenyan patients with SLE,[35] along with disease-related factors such as renal involvement and high disease activity. Corticosteroids are a mainstay of treatment, with reported use in 84%–100% of patients with SLE across studies.[33]

Dr Oyoo identified many challenges in the management of SLE in Kenya. Non-adherence to medication is common, reported in 46% of patients with SLE in one series, due to a combination of factors including poor access to medication, lack of care continuity, perceptions about medication, use of alternative therapies and a lack of understanding of the illness. Accompanying Dr Oyoo at the meeting was Dr Eunice Omondi, a rheumatology specialist nurse and PhD researcher based in Nairobi, Kenya. Dr Omondi has conducted qualitative work with patients with SLE and healthcare providers to better understand the burden and impact of SLE in Kenya as well as facilitators and barriers to improving care.[36] This work is crucial for informing the development of effective programmes and strategies to meet the unique health needs of Kenyan patients with SLE.

Dr Oyoo further highlighted the significant challenges in accessing appropriate therapy for patients with SLE in Kenya, noting that the cost of SLE care is high, and there is currently no government support for therapies for patients with SLE. It is anticipated that data from the SLE registry could be used to advocate for improved access to care for patients with SLE in Kenya. Dr Oyoo concluded his presentation with several proposed initiatives to increase clinical research capacity and to better educate clinicians in Kenya regarding SLE, including sponsored rheumatology fellowship programmes, provision of dedicated research training and educational short courses in rheumatology for general practitioners and other healthcare providers.

SUMMARY OF DISCUSSION

At the end of the meeting, participants joined in a facilitated discussion about the current obstacles to optimising SLE care in Africa as well as opportunities for future collaboration between SLICC and colleagues in Africa in the areas of clinical care, research and education.

One of the main issues identified by multiple participants with experience working in Africa was a lack of awareness about SLE among non-rheumatology healthcare providers and the public. To reduce this gap, several programmes are needed, including educational programmes for patients and families as well as for primary care physicians. Educational programmes have proven to be effective in other parts of the world, such as in Latin America and Asia.[37–39] Such programmes could be adapted to the local context in African countries.[40] The advantage of these programmes is that they could be implemented via social media platforms and other smartphone apps, with short but clear messages for both patients and their families. Remote, virtual education could be useful for primary care physicians working together with rheumatologists who may support them on their diagnostic and therapeutic endeavours using digital health technologies.

Additionally, new strategies are needed to increase the access to diagnostic tests and treatments across Africa. Participants raised the possibility of using previous and ongoing health promotion initiatives targeting HIV infection in Africa as a model for similar programmes in SLE. The support given by the international community to individuals living with HIV in Africa and to their healthcare providers includes access to antiretroviral therapy, laboratory tests, home care, nutritional support and educational programmes. Such programmes could not only improve access to essential SLE therapies but also the local knowledge about the disease and adherence to treatment.[41]

This session also reinforced the need for more robust epidemiological information about SLE in Africa, as the available information comes from only a few countries[42]; however, its prevalence and severity appear to be higher than in other parts of the world.[22] These data refute past assertions that lupus was rare in Africa (ie, 'the lupus gradient hypothesis'), when in fact that is not the case: it has historically been under recognised and thus inadequately treated.[43] Epidemiological data are critical to effective advocacy for increased funding and other resources to support the clinical care of rheumatic diseases in Africa, including SLE.

Additionally, genetic studies to determine the genomic and epigenetic characteristics of African patients with SLE are needed. Previous experiences of the Human Heredity and Health in Africa programmes (H3Africa) in other diseases like malaria, tuberculosis and HIV, among others, suggest that these initiatives are feasible and could help improve our understanding of the distinctive characteristics of SLE in Africa.[44] Furthermore, by harnessing the tremendous genetic diversity of the African continent, such studies could provide new insights into the pathophysiology of SLE that could benefit the global lupus community through the identification of novel disease mechanisms and therapeutic targets.

NEXT STEPS

Moving forward, SLICC wants to position itself as a catalyst and is committed to working closely and collaboratively with our colleagues in Africa to address current challenges in SLE clinical care, research and education. Historically, representation from Africa has been missing from international SLE initiatives, such as the

development of clinical practice guidelines, outcome measures and classification criteria. In addition, Africa has often been overlooked in genetic studies and drug development in SLE. This can lead to unintended negative impacts for patients with SLE in under-resourced settings, where such tools often are not applicable. This seminar has highlighted the urgent need to include voices from Africa in such efforts, to facilitate shared learning and to ensure that the entire global SLE community can benefit from the outputs. SLICC will advocate for the inclusion of our African colleagues in future initiatives, starting with the ongoing revision of the SLICC/Lupus Foundation of America Damage Index and the planned update of the core outcome set for SLE that is currently being led by Outcome Measures in Rheumatology (OMERACT).

Improving knowledge of SLE through educational programmes for patients and primary care providers has also been identified as a priority. In collaboration with the Latin American Group for the Study of Lupus, SLICC will explore whether educational programmes that have been successful in Latin America can be adapted based on local contextual factors to meet the unique educational needs on the African continent.

As an international SLE research organisation, SLICC is well positioned to support the collection of more robust epidemiologic and clinical data on SLE in Africa, which our colleagues have told us is paramount to raising awareness of SLE in their countries, increasing funding and changing health policies. African centres must be included in international SLE registries, so that we can better understand the global burden of SLE. Such collaborations would facilitate sharing of resources and infrastructure to help build SLE research capacity on the continent. International research collaboration and mentorship can help generate funding to support local research infrastructure. SLICC will work with our colleagues in Africa towards the goal of including their centres in future multicentre observational cohort studies and will also explore strategies to promote the dissemination of SLE research findings from Africa to help address the current publication barriers that are faced by our African colleagues.

Finally, a key theme from this seminar was the need for our colleagues in Africa to be provided opportunities to speak for themselves, as opposed to others trying to tell their stories for them. Equal representation within international SLE research groups such as SLICC alongside their colleagues from other regions of the world is critical, long overdue and will only serve to strengthen these organisations and the work they produce.

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Contributors AL and RR-G conceived and planned the meeting agenda. OA, AB, DD, EO and OO contributed to the content of the meeting. AL, JAR, MFU-G and RR-G took the lead in outlining, writing and editing the manuscript. OA, AB, DD, EO and OO provided feedback and helped revise the manuscript. All authors approved the final manuscript. As corresponding author, AL is guarantor and takes responsibility for the integrity and accuracy of the information presented.

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