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Short Communication

Developing a collaborative network for cystic fibrosis in Africa: A call to action

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ABSTRACT

Background: Cystic fibrosis (CF) is a genetic disorder that remains underrecognized across Africa, where limited diagnostic capacity, low awareness, and competing health priorities contribute to delayed or missed diagnoses [1–4]. Although increasing data suggests CF is more prevalent than previously believed in Africa, survival remains poor [1]. These challenges do not only affect people with CF (pwCF) in Africa but also have implications for global understanding of the disease, particularly among populations historically excluded from CF research and treatment advances.

Objective: This communication describes the formation of a Pan-African collaborative CF network aimed at addressing disparities in CF recognition, diagnosis, and care across the continent.

Methods: We launched an inclusive network of clinicians, researchers, and advocates by leveraging professional networks, longstanding partnerships, and regional expertise. Employing participatory methods, a 42-question REDCap survey was formulated in both English and French. The survey was disseminated via email and WhatsApp in December 2024, aiming to understand member priorities, communication preferences and data collection practices.

Results: As of August 2025, the network includes 44 members from 14 countries. Survey responses were received from 13 members across 8 countries. Five key themes emerged: transnational collaboration, advancing advocacy, establishing a Pan-African CF registry, strengthening capacity, and mobilizing funding.

Conclusion: This paper serves as a call to action to expand CF diagnosis, research, and care in Africa through an inclusive, decolonial, and equity-focused lens. We invite collaboration across disciplines and geographies to ensure that all people living with CF—including those long overlooked—receive the care they deserve.

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1. Introduction

Cystic fibrosis (CF), a life-threatening genetic disorder caused by pathogenic variants in the *CFTR* gene, remains critically underdiagnosed in Africa [1,2]. Despite increasing evidence of the prevalence of CF on the African continent, [2–4] and concurrent advancements in diagnosis and treatment in high-income countries (HICs), progress in CF care across Africa remains limited [5]. For the few confirmed cases, survival beyond infancy is uncommon [1]. In contrast, CF life expectancy in some HICs now approaches or exceeds 60 years, [6,7] highlighting an urgent disparity in CF-related care and outcomes. Addressing these gaps is crucial not only for people with CF (pwCF) in Africa but also for diaspora populations with *CFTR* pathogenic variants distinct from those seen in HICs [8–10].

2. Contextual barriers to CF diagnosis in Africa

CF has been recognized in African populations for over 60 years [11]. However, progress in understanding the disease remains slow and inconsistent due to multiple factors. Phenocopic conditions such as tuberculosis, malnutrition, chronic pulmonary infections, and HIV, which mimic CF symptoms, often confound CF diagnosis [1]. Second, CF is seldom emphasized in medical school curricula, as many medical educators have never encountered a case. Third, the persistent narrative that CF primarily affects white populations impedes awareness and research. [1] Lastly, the diagnostic challenge is exacerbated by the limited availability of the gold-standard sweat chloride test, which is costly and resource-intensive. In contrast, sweat conductivity testing offers a more affordable alternative and has shown promise in resource-limited settings [12–15]. Sweat conductivity testing, while not the "gold standard," provides a more accessible alternative in Low and Middle Income Countries (LMIC)s and has demonstrated utility in multiple African contexts [5].

3. Building a collaborative network

Recognizing the need for a unified approach to CF diagnosis and management in Africa, we initiated a collaborative network in September 2024, uniting researchers, clinicians, and advocates dedicated to improving CF-related care on the continent. This was done to foster multidisciplinary connections, share resources, and collectively address challenges in CF diagnosis and management.

4. Network formation and methodology

Initial outreach occurred through professional networks and long-standing collaborations. Dr. Marco Zampoli, who founded the first CF registry in Africa [16] and has trained numerous pediatric pulmonologists, led outreach efforts. Dr. Hugues Abriel (DRC and Morocco) and Dr. Samya Nasr (Egypt) [17,18] helped build engagement across Central and North Africa, respectively.

Our first network-wide symposium, held on 11 September 2024, included representatives from ten countries; each participant shared their experiences in identifying, diagnosing, and managing CF. During the initial meeting, the group agreed that the collaboration would encompass the entire African continent rather than distinguishing between Sub-Saharan and Northern Africa. While the network acknowledged regional and local differences, there was a strong consensus on the importance of fostering a Pan-African partnership.

Using participatory methods [19] to identify our theory of change[20], we developed a 42-question REDCap survey designed to establish a shared vision. The survey was distributed over two months in late 2024. The survey covered demographic data, preferred communication methods, leadership and decision-making preferences, and data collection practices for CF registries. To improve accessibility, the survey was translated into French and English and disseminated via email and WhatsApp. Simultaneously, network leadership began spreading the word about the network through professional circles, foundations, rare-disease networks, non-governmental organizations and academic societies to garner financial support and interest.

Table 1
Barriers to Participation (Frequency of mentions).

What (if any) could the network do to support your participation/overcome any of these barriers?	Mentions (frequency)
Funding	8
Registry Development	5
Dedicated time	1
Mentorship	3
Collaborative Research	1
Equipment/Diagnostics	2

5. Survey findings and network growth

As of August 2025, the network has 44 active members from 14 countries, including Ghana, Ethiopia, Rwanda, Egypt, Morocco, Tunisia, Libya, Democratic Republic of the Congo, South Africa, Nigeria, Kenya, United States, United Kingdom, and Switzerland. However, at the time of the survey there were 28 active members, of those there were 13 respondents (from 8 countries) who completed the survey.

Key survey findings include:

- **Professional Backgrounds:** (N=7) are pediatric pulmonologists, but the network also includes general pediatricians and internists, PhD researchers, medical trainees, and clinical geneticists.
- **Preferred Communication:** WhatsApp was the most favored platform (N=12), especially among LMIC members.
- **Barriers to Participation:** The most cited barrier was workload constraints, with suggestions for flexible meeting schedules and academic recognition for participation. (Table 1)
- **Network Priorities:** Participants highlighted the need for collaboration, resource sharing, advocacy, and registry development. (Table 2)
- **Registry Development:** Five countries are actively collecting CF-related patient data.

6. Advancing CF research and care in Africa

Five key themes that emerged from the survey, which have informed the structure and goals of our network (Fig. 1).

- **Collaboration:** Strengthening multidisciplinary and multinational partnerships to foster knowledge exchange tailored to local contexts.
- **Advocacy:** Raising awareness about CF, developing culturally relevant patient and family resources, and influencing international and national policies to improve equity in CF-related care.
- **Registry Development:** Establishing a Pan-African CF registry, hosted on the continent of Africa, to generate region-specific data, standardize diagnostic practices, and facilitate research.
- **Capacity Strengthening:** Expanding training for healthcare providers, improving diagnostic infrastructure, and increasing access to essential CF therapies.
- **Funding and Research:** Writing collaborative grants and promoting equitable resource distribution.

7. Call to action

We hope this can plant the seeds for a sustainable, inclusive network with a low barrier to participation, recognizing that healthcare professionals globally, and especially across the African continent, are already overstretched. Progress hinges on the ability to make timely and accurate diagnoses. A critical first step is expanding access to reliable,

Table 2
When Asked About Priorities and Goals for the Network (Responses with Frequency of Mentions).

Code	Sub-Code	Frequency *If mentioned more than 1 time, numerical value noted below*	Associated Proposed Solution /Needs *If mentioned more than 1 time, numerical value noted below*
Collaboration	• What makes successful partnerships • Multidisciplinary connections / Collaborations • Knowledge exchange relevant to local context • Combining forces	Collaboration (Mentioned 15 times) Learn from others (Mentioned 4 times) Partnerships/Connection (Mentioned 3 times) Multidisciplinary connections Sharing Resources	• Collaborate on funding (grants)/ research
Improve Understanding of CF	• Gain resources for CF diagnosis • Improve education around the disease • Improve my personal practice	Knowledge exchange (Mentioned 2 times) Improve own understanding/practice (Mentioned 4 times) Improve education for other clinicians Context appropriate learning	• Create CF specific trainings (Mentioned 2 times) • Case conference(s)
Support CF Diagnosis (and Care)	• Gain resources/support with diagnosis • Build good clinical structures	Gain resources (Mentioned 2 times) Build clinical structures Build capacity around locally appropriate care	
Advocacy	• Creation of resources for patients and families specific to the continent • Collectively be a voice on international stage	Creation of resources for families Collectively be a voice Bring awareness	• Newsletters for families (Mentioned 2 times) • Work with Right to Breathe campaign • Write grants together • Support groups • Understand patient stories
Registry Development	• Generate context-specific data • Creation of shared registry	Context specific data (Mentioned 2 times) Creation of shared registry (Mentioned 2 times) Standardize data collection	• Pan-African CF registry • African CF Conferences
Build Research Infrastructure	• Learn research skills • Collaborate on research topics/agendas	Build research collaboration (Mentioned 3 times) Improve research (Mentioned 2 times)	
Capacity Strengthening around CF	• Build infrastructure	Improve/gain resources in diagnostics (Mentioned 5 times) Capacity strengthening (Mentioned 2 times)	
Improve/gain resources for CF care (diagnostics, management, etc)	• Gain resources in diagnostics • Gain resources in Medication • Improve CFTR modulator access	Locally relevant care (Mentioned 2 times)	

cost-effective screening methods like sweat conductivity testing.

At the same time, we must name and reckon with the historical colonial legacies that continue to shape disparities in global health research, funding, and care delivery. Addressing these structural inequities is essential to achieving equity in CF care. We aim to advance with intentionality—centering health justice, decoloniality, and contextualized care. While allyship is inherently complex and evolving, we believe there is a meaningful role for collaborators both on and off the continent. Those from HICs can contribute time and funding and—most importantly—amplify the voices, ideas, and lived experiences of those working and living in African settings.

We invite researchers, clinicians, and advocates to join us in:

- Establishing and expanding CF diagnosis in Africa using appropriate, accessible, and affordable screening tools. We have two funded studies within the network, which aim to expand capacity for genetic diagnostics as well as the implementation of sweat conductivity testing.
- Building a Pan-African CF registry in REDCap, based on the existing South African CF patient registry and hosted at University of Cape Town, to understand the disease burden better and improve care strategies. This will be implemented with staged onboarding (i.e. pilot countries) and implemented with the support of IT specialists in the network.
- Addressing stigma surrounding chronic, life-altering illnesses in many LMICs where spiritual beliefs are often central to understanding disease causation and progression—as identified by members as a common challenge.
- Applying for grants and finding other sustainable funding sources to support CF research and healthcare infrastructure. We have currently applied for and successfully been awarded funding by both the Cystic Fibrosis Foundation and the Swiss National Science Foundation. We are in the process of submitting applications across other diverse funding streams.
- Ensuring equitable access to training, diagnostics, multidisciplinary specialist care, and basic treatments and modulator therapies. We have begun running a monthly case conference, run by a network member, open to all members, to help collaborate on challenging cases and support those who have less experience with the disease.

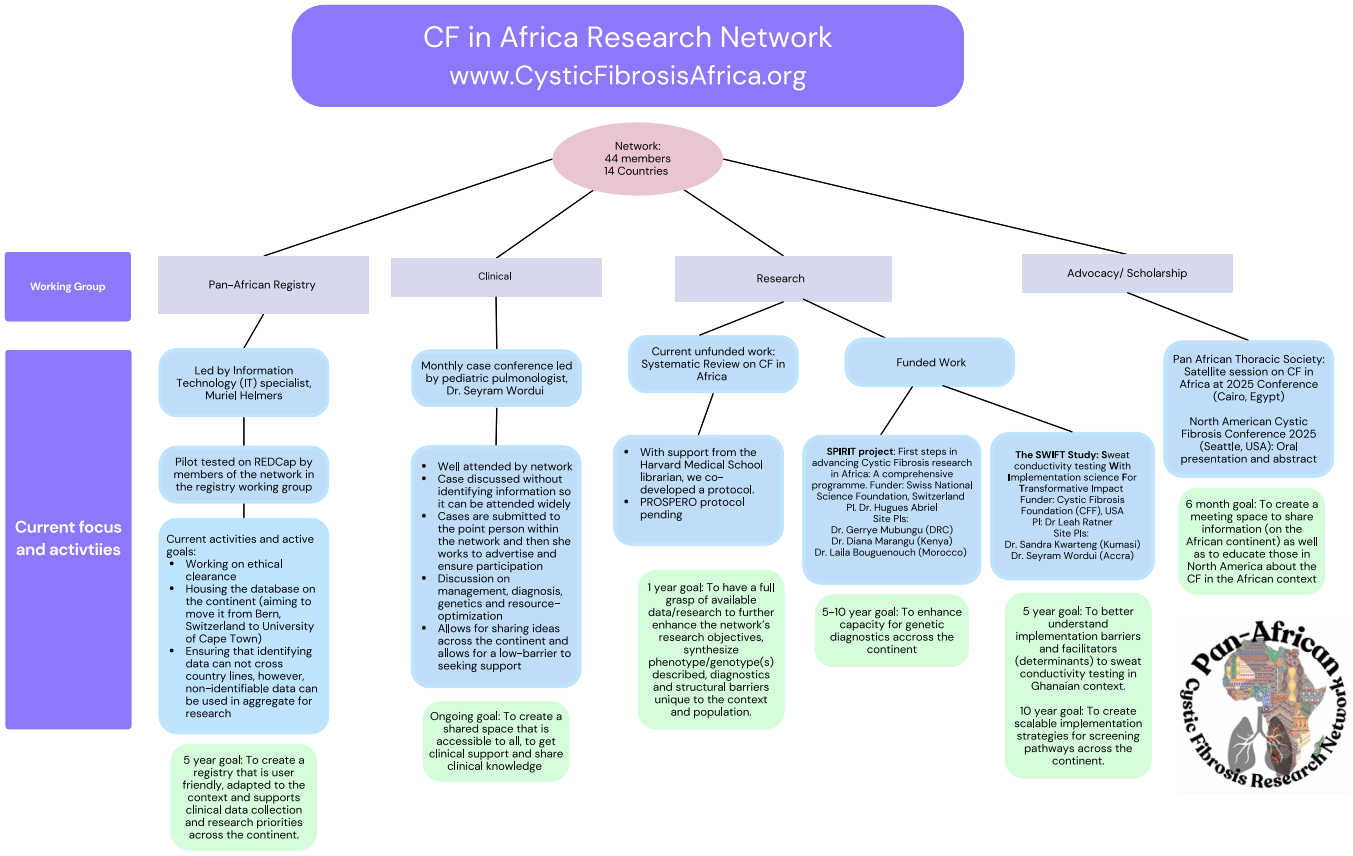

Fig. 1. Network structure, current activities and goals.

- Recognizing and valuing the contributions of all network participants, including pathways for academic credit and funding leadership roles. We are presenting several pieces on the network at the North American Cystic Fibrosis Conference in October 2025, as well as at the Pan African Thoracic Society Conference in 2025 in Cairo, Egypt.

Each goal and activity has accompanying process and outcome metrics that we are using to guide our success. As a network, we have also engaged local stakeholders, including distributors of diagnostics and pharmaceuticals. By workingtogether, both on and off the continent, to improve access to diagnostics and treatments for CF in Africa, we can drive meaningful advancements in care and ultimately improve the lives of those living with this underrecognized disease in this context. By collectively addressing the barriers to CF recognition and treatment, we can work toward a future where care is accessible and equitable across Africa and beyond. Tremendous progress has been made in CF over the past decade, yet many have been left behind—let this be our call to action to ensure that all pwCF receive the support and care they deserve. Join us – www.CysticFibrosisAfrica.org

Credit author statement

LR conceptualized and designed the survey as well as wrote the first draft of the manuscript. MH implemented and piloted the survey. HA, AU, REC, CS, GH, AYW, SAO, NEM, SKO, SMW, AU, SZN and MZ provided feedback and edits. MZ, SN and HA provided senior level mentorship.

Declaration of competing interest

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References

[1] Stewart C, Pepper MS. Cystic fibrosis on the African continent. Genet Med 2016;18 (7):653–62. https://doi.org/10.1038/gim.2015.157.
[2] Abubakar Bobbo K, Ahmad U, Chau DM, Nordin N, Abdullah S. A comprehensive review of cystic fibrosis in Africa and Asia. Saudi J Biol Sci 2023;30(7):103685. https://doi.org/10.1016/j.sjbs.2023.103685.
[3] Owusu SK, Obeng-Koranteng G, Odai SL, et al. Cystic fibrosis in two Ghanaian Children. J Pan Afr Thorac Soc 2021;2:167–70. https://doi.org/10.25259/JPATS_10_2021.
[4] El Makhzen N, Daimi H, Bouguenouch L, Abriel H. The burden of cystic fibrosis in North Africa. Front Genet 2024;14:1295008. https://doi.org/10.3389/fgene.2023.1295008.
[5] Fuhrer M, Zampoli M, Abriel H. Diagnosing cystic fibrosis in low- and middle-income countries: challenges and strategies. Orphanet J Rare Dis 2024;19(1):482. https://doi.org/10.1186/s13023-024-03506-1.
[6] Cystic fibrosis Canada. 2021 Annual Data Report: Canadian Cystic Fibrosis Registry 2022. *Retrieved from*, *Https://Www.Cysticfibrosis.ca/Our-Programs/Cf-Registry/2021-Registry-Annual-Data-Report*.
[7] UK Cystic fibrosis trust. UK Cystic Fibrosis Registry Annual Data Report 2022 2023. *Retrieved from*, *Https://Www.Cysticfibrosis.Org.Uk/News/Registry-2022-Data-Now-Available*.

[8] Zampoli; On behalf of the Msac M. cystic fibrosis: what's new in South Africa in 2019. S Afr Med J 2018;109(1):16. https://doi.org/10.7196/SAMJ.2018.v109i1.13415.
[9] McGarry ME, McColley SA. Cystic fibrosis patients of minority race and ethnicity less likely eligible for CFTR modulators based on *CFTR* genotype. Pediatr Pulmonol 2021;56(6):1496–503. https://doi.org/10.1002/ppul.25285.
[10] Wu M, Davis JD, Zhao C, Daley T, Oliver KE. Racial inequities and rare CFTR variants: Impact on cystic fibrosis diagnosis and treatment. J Clin Transl Endocrinol 2024;36:100344. https://doi.org/10.1016/j.jcte.2024.100344.
[11] Grove SS. Fibrocystic disease of the pancreas in the Bantu. South Afr J Lab Clin Med Suid-Afr Tydskr Vir Lab- En Kliniekw 1959;5(2):113–9.
[12] Barben J, Ammann RA, Metlagel A, Schoeni MH. Conductivity determined by a new sweat analyzer compared with chloride concentrations for the diagnosis of cystic fibrosis. J Pediatr 2005;146(2):183–8. https://doi.org/10.1016/j.jpeds.2004.08.085.
[13] Bedran RM, Alvim CG, Sader OG, et al. Sweat conductivity for diagnosing cystic fibrosis after positive newborn screening: prospective, diagnostic test accuracy study. Arch Dis Child 2023;108(7):538. https://doi.org/10.1136/archdischild-2022-324723.
[14] Mattar ACV, Leone C, Rodrigues JC, Adde FV. Sweat conductivity: An accurate diagnostic test for cystic fibrosis? J Cyst Fibros 2014;13(5):528–33. https://doi.org/10.1016/j.jcf.2014.01.002.
[15] Sezer RG, Aydemir G, Akcan AB, et al. Nanoduct sweat conductivity measurements in 2664 patients: relationship to age, arterial blood gas, serum electrolyte profiles and clinical diagnosis. J Clin Med Res 2013;5(1):34–41. https://doi.org/10.4021/jocmr1191w.
[16] Fleifil S, Widmer A, Hart-Johnson T, et al. Nationwide survey of cystic fibrosis knowledge and resource accessibility in Egypt. Sch 2024;5(3):386–91. https://doi.org/10.34197/ats-scholar.2023-0156BR.
[17] Nasr SZ, Gökdemir Y, Erdem E, et al. Collaboration between two CF centers; one in USA and one in Turkey before and during CoV2 pandemic. Pediatr Pulmonol 2022;57(10):2553–7. https://doi.org/10.1002/ppul.26041.
[18] Bartels WL, Furman CA. Building community for participatory modeling: network composition, trust, and adaptive process design. Soc Nat Resour 2023;36(3):326–46. https://doi.org/10.1080/08941920.2023.2177916.
[19] Review of the use of 'theory of change in international development I vogel - London. DFID; 2012.