ENSIGN GLOBAL UNIVERSITY, KPONG

EASTERN REGION, GHANA

FACULTY OF PUBLIC HEALTH

DEPARTMENT OF COMMUNITY HEALTH

EXPLORING THE PERCEPTIONS AND EFFECTIVENESS OF ENGAGE NOW AFRICA'S INTERVENTIONS FOR PERSONS LIVING WITH ALBINISM IN GHANA

BY

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A THESIS SUBMITTED TO THE DEPARTMENT OF COMMUNITY HEALTH, FACULTY OF PUBLIC HEALTH, ENSIGN GLOBAL COLLEGE IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE MASTER OF PUBLIC HEALTH DEGREE

NOVEMBER, 2025

DECLARATION

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the award of any other degree or diploma at Ensign Global University, Kpong or any other educational institution, except where due acknowledgment is made in the thesis.

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DEDICATION

I dedicate this thesis to all persons living with albinism in Ghana and beyond, whose resilience and strength continue to inspire me. This work also goes to Engage Now Africa, for their tireless efforts in advocating and improving the lives of vulnerable groups.

ACKNOWLEDGMENTS

First and foremost, I give thanks to Almighty God for granting me life, strength, and wisdom throughout this academic journey. Without His guidance, this work would not have been possible.

I wish to express my deepest gratitude to my supervisor, Dr. Stephen Manortey, for the invaluable guidance, constructive feedback, and patience that greatly shaped this work. Your mentorship has been instrumental to both my academic and personal growth.

My sincere appreciation goes to Engage Now Africa (ENA) for their collaboration and the interventions that inspired this research.

I am especially thankful to all the persons with albinism who participated in this study, for sharing their lived experiences and perspectives with openness and courage. This work is, in many ways, a reflection of your voice.

Finally, I extend heartfelt thanks to my colleagues, friends, and all who supported me in diverse ways. Your contributions have enriched this journey beyond measure.

LIST OF ABBREVIATIONS

Abbreviation	Full Meaning
DAC	Development Assistance Committee (OECD)
ENA	Engage Now Africa
GHS	Ghana Health Service
MoH	Ministry of Health
NCPD	National Council on Persons with Disability
NHIS	National Health Insurance Scheme
NMSC	Non-Melanoma Skin Cancer
OCA	Oculocutaneous Albinism
OECD	Organization for Economic Co-operation and Development
PWA	Persons With Albinism
SDGs	Sustainable Development Goals
SPSS	Statistical Package for the Social Sciences
UN	United Nations
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
UV	Ultraviolet
WHO	World Health Organization

ABSTRACT

Background: Persons living with albinism (PLWA) in Ghana face complex challenges that go beyond genetic and medical vulnerabilities. Despite efforts by non-governmental organizations such as Engage Now Africa (ENA) to improve their quality of life through targeted interventions, little is known about how these initiatives are perceived by the beneficiaries themselves. Understanding these perceptions is crucial to ensuring that such interventions are relevant, empowering, and culturally appropriate. This study aims to explore the experiences and perspectives of PLWA regarding the relevance and effectiveness of ENA's interventions.

Methodology: Using an exploratory qualitative design, the study relies on secondary data drawn from a project evaluation conducted by ENA. The dataset includes 40in-depth interview transcripts involving PLWA and a few caregivers of children with albinism across the Northern, Upper East, and Volta Regions of Ghana. For this study, the transcripts were reanalyzed using thematic analysis guided by Braun and Clarke's six-phase framework, using ATLAS.ti software. Deductive codes based on the Theory of Planned Behavior and inductive themes emerging from the narratives was used to identify patterns related to intervention relevance, access, empowerment, and social impact.

Results: The study found that interventions provided by Engage Now Africa (ENA) had a significant impact on the wellbeing of persons living with albinism (PLWA). Health-related support such as provision of sunscreen, skin care products, and access to healthcare services reduced vulnerability to skin cancer and improved health outcomes. Educational interventions, including scholarships, advocacy in schools, and awareness creation, enhanced enrolment and retention of PLWA in formal education. Livelihood empowerment programmes, particularly skills training and small business support, promoted economic independence and reduced dependency.

Advocacy and community sensitisation initiatives were instrumental in reducing stigma, improving social acceptance, and strengthening inclusion at the community level. Despite these positive outcomes, challenges such as limited coverage, sustainability concerns, and persistent social misconceptions were identified.

Conclusions: The study concludes that ENA's multifaceted interventions are relevant and effective in addressing the health, educational, and socio-economic needs of persons with albinism in Ghana. These interventions have contributed to improving quality of life and promoting social inclusion. However, sustaining these gains requires stronger governmental commitment, integration of albinism-related issues into national health and social protection policies, and continuous community engagement. Expanding partnerships between NGOs, state institutions, and international bodies is also necessary to ensure long-term impact and equity for PLWA.

Keywords

Albinism; Persons with Albinism (PWA); Engage Now Africa; Interventions; Livelihood Empowerment; Stigma; Inclusion

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CHAPTER ONE

1.0 INTRODUCTION

1.1 Background

Albinism is a heterogeneous genetic condition characterized by reduced or absent melanin in the skin, hair, and eyes, most commonly presenting as oculocutaneous albinism (OCA). Globally, OCA entails lifelong visual impairment (e.g., nystagmus, photophobia, reduced acuity) and heightened photosensitivity, with downstream risks for actinic damage and non-melanoma skin cancer (NMSC) if sun protection and regular skin surveillance are not accessible or affordable (Kromberg, Flynn and Kerr, 2023; Tomás-Velázquez *et al.,* 2024). A recent systematic review synthesizing epidemiological data across regions estimated a worldwide OCA prevalence of approximately 1 in 17,000, while underscoring marked variation by population and the concentration of evidence gaps in low- and middle-income countries (Kromberg, Flynn, and Kerr, 2023). In parallel, clinical literature from high-risk settings in Africa shows that squamous cell carcinoma is the dominant skin malignancy among people with albinism (PWA), that early lesions often appear at young ages, and that continuity of follow-up is essential to survival where health systems are overstretched (Tomás-Velázquez *et al.,* 2024; Kassang *et al.,* 2025). These biomedical realities intersect with social determinants of health: without sun-protective clothing, consistent sunscreen, low-vision aids and inclusive education and employment, the condition's preventable complications translate into avoidable morbidity, reduced quality of life, and premature mortality (Kromberg, Flynn and Kerr, 2023; Tomás-Velázquez *et al.,* 2024).

Across sub-Saharan Africa, the prevalence of albinism is widely recognised to be higher than global averages, and the condition is entangled with entrenched stigma, myth and, in some

countries, targeted violence (Franklin *et al.,* 2018). Rights-based analyses document barriers "to being" (safety, dignity, psychosocial wellbeing) and "to doing" (education, employment, participation) that operate through discriminatory norms and institutional inattention, even where formal disability rights frameworks exist (Franklin *et al.,* 2018). Consistent regional evidence also highlights educational exclusion linked to low vision (lack of accommodation, assistive devices, teacher preparedness) and to safety concerns on the journey to school, which together depress attainment and narrow pathways into safer, indoor livelihoods (Franklin *et al.,* 2018). Complementing this, qualitative and mixed-methods studies from Botswana and other settings describe converging medical and psychosocial needs: routine skin/eye care, but also counselling, community sensitisation, and anti-stigma measures to address isolation, bullying, and employment discrimination (Anshelevich *et al.,* 2021; Franklin *et al.,* 2018).

In response, African and international institutions have articulated commitments and programmatic roadmaps. The African Commission on Human and Peoples' Rights endorsed the Regional Action Plan on Albinism in Africa (2017–2021), a framework structured around prevention, protection, accountability, and equality/non-discrimination, and subsequent AU/UN processes have maintained focus on ending attacks and enabling inclusion (African Commission on Human and Peoples' Rights, 2017; OHCHR, 2017; Reimer-Kirkham *et al.,* 2024). While uptake is uneven, these platforms provide continental guidance for states, civil society and development partners on coordinated action, from public education and legal enforcement to sunscreen access and data systems that monitor PWA (African Commission on Human and Peoples' Rights, 2017; Reimer-Kirkham *et al.,* 2024).

Ghana reflects many of these broader dynamics. Peer-reviewed Ghanaian studies demonstrate that social stigma significantly erodes the subjective well-being of PWA, with social support only

partially buffering harms (Affram, Teye-Kwadjo and Gyasi-Gyamerah, 2019). Recent qualitative work on contemporary accounts of exclusion, including housing denials, school drop-out linked to bullying or poverty, and precarious outdoor work with high sun exposure (Daklo and Obadire, 2024). Alongside day-to-day discrimination, context-specific harmful practices persist: civil society reporting to UN bodies has documented ritual banishment of PWA and the absence of disaggregated official data, which together obscure needs and impede service planning (Africa Albinism Network, 2024). These Ghana-specific insights echo the continental evidence: without sustained access to sunscreen and protective clothing, low-vision services, and school/workplace accommodations, health and life chances diverge sharply from what is achievable with basic supports (Affram, Teye-Kwadjo and Gyasi-Gyamerah, 2019; Daklo and Obadire, 2024; Africa Albinism Network, 2024).

Non-governmental actors have stepped into the existing critical gaps. Engage Now Africa (ENA) has implemented multi-component programmes aligned with the regional plan's pillars: community and school sensitisation durbars, mass awareness events, targeted support (e.g., sunscreen, wide-brimmed hats, long-sleeve clothing, sunglasses), scholarships and skills training, and limited clinical support for advanced skin cancers. ENA also piloted local sunscreen production using shea-butter–based formulations to address affordability and supply constraints (Engage Now Africa, 2022). Such initiatives aim simultaneously at risk reduction (skin health), empowerment (education and livelihoods), and norm change (public attitudes). They illustrate the country's emergent, multi-stakeholder response, and underline why rigorous evaluation is needed to determine relevance to context, effectiveness in shifting outcomes, impact on health and inclusion, and sustainability beyond project cycles in line with OECD-DAC criteria.

Taken together, the global, regional, and Ghana-specific literature converge on a clear background problem: PWA face a predictable mix of clinical risks and social exclusion that are highly modifiable through low-cost public health and inclusion measures, yet delivery remains inconsistent. In Ghana, promising NGO-led models exist, and continental policy commitments set a supportive frame; however, gaps in official data, uneven access to skin/eye care and accommodations, and persistent stigma limit progress. This context justifies a focused evaluation of ENA's albinism interventions using the OECD framework to generate actionable evidence on what works, for whom, and at what cost in Ghana's real-world conditions (Kromberg, Flynn and Kerr, 2023; African Commission on Human and Peoples' Rights, 2017; Engage Now Africa, 2022; Daklo and Obadire, 2024).

1.2 Problem Statement

Persons with albinism (PWA) in Ghana continue to experience severe forms of social, health, and economic marginalisation despite increasing advocacy and global awareness. Their unique biological condition exposes them to heightened risks of ultraviolet (UV) damage, vision impairment, and discrimination. The World Health Organization (2017) identifies skin cancer as a leading cause of early mortality among PWA in sub-Saharan Africa, with squamous cell carcinoma often developing before the age of 30 due to prolonged UV exposure without protection. Regional evidence underscores the gravity of this challenge: up to 90% of PWA in Malawi develop actinic damage by age 20 (Tomás-Velázquez *et al*., 2024), while in Tanzania, the median life expectancy for individuals with albinism is less than 40 years largely due to untreated skin malignancies (Kassang *et al*., 2025). In Ghana, dermatology units report a rising incidence of precancerous lesions and skin cancers among PWA presenting late to hospitals, reflecting persistent inequities

in sunscreen access, dermatological outreach, and health education (Africa Albinism Network, 2024).

Beyond health vulnerabilities, PWA also face systemic educational and social exclusion. Ghanaian studies highlight that children with albinism are often bullied, isolated, or retained in lower grades due to limited access to vision aids and untrained teachers (Affram, Teye-Kwadjo & Gyasi-Gyamerah, 2019; Daklo & Obadire, 2024). These educational gaps restrict employment opportunities. At the community level, stigma remains pervasive, over 60% of respondents in a 2019 Ghanaian survey associated albinism with "curses" or "misfortune," perpetuating discrimination in marriage, housing, and employment (Affram *et al*., 2019). Such disadvantages limit social participation and undermine human dignity.

In response, non-governmental organisations such as Engage Now Africa (ENA) have initiated interventions aimed at improving the welfare of PWA through sunscreen distribution, dermatological screening, educational support, and public sensitisation. While these efforts are commendable, their effectiveness, impact, and sustainability have not been systematically evaluated. Existing literature in Ghana largely documents the lived experiences of PWA without assessing whether implemented programmes are relevant to beneficiary priorities, produce measurable improvements in health and education, or effectively reduce stigma (Dzah & Gyaase, 2021). The absence of rigorous evaluation creates critical gaps in accountability and evidence-based planning. Applying the OECD-DAC evaluation framework offered a structured approach to address this gap. Evaluating ENA's interventions within this framework helped generate empirical evidence on their outcomes, reveal alignment or divergence from the actual needs of PWA, and inform future programme design and policy integration.

1.3 Rationale of study

This study is urgently needed for four main reasons. First, it addresses a clear academic gap. While research in Ghana and across Africa has documented the social stigma, educational exclusion, and health vulnerabilities of PWA (Affram, Teye-Kwadjo and Gyasi-Gyamerah, 2019; Franklin *et al.,* 2018; Daklo and Obadire, 2024), very few studies have gone beyond description to systematically evaluate interventions. By applying the OECD-DAC evaluation framework, this study moves the discourse from highlighting problems to assessing solutions, filling a critical gap on disability and inclusion.

Second, the study carries significant practical importance. For NGOs such as Engage Now Africa, systematic evaluation offers evidence on what works and what does not, ensuring that interventions are relevant to beneficiaries and efficient in resource use. By centering the perspectives of PWA, the study provides feedback loops that can help NGOs refine programme design, scale up effective components, and avoid activities with limited impact. This contributes directly to improving accountability and maximising the return on donor and community investment.

Third, the study holds strong educational relevance**.** By examining how limited access to appropriate learning aids, teacher preparedness, and inclusive environments affect educational outcomes for PWA, the study extends its implications beyond public health to the broader educational domain. Evaluating ENA's support mechanisms will provide insights into how educational barriers can be mitigated through targeted interventions. The findings will therefore be valuable to the Ministry of Education.

Finally, evidence from this evaluation can guide policymakers in integrating albinism-specific needs into health, education, and social protection policies. By aligning with Sustainable Development Goals (SDGs), particularly SDG 3 (health), SDG 4 (education), and SDG 10 (reduced inequalities), the study ensures that national and international commitments are operationalised in practice.

By systematically evaluating ENA's interventions through the OECD framework, it ensures that the voices and priorities of PWA are central to programme and policy design. The findings will provide actionable recommendations to advance dignity, inclusion, and well-being for one of Ghana's most marginalised groups.

1.4 Conceptual Framework

This study adopted the OECD Development Assistance Committee (OECD-DAC) evaluation framework as its guiding theoretical lens. Revised in 2019, the OECD-DAC criteria remain the most widely recognized international standard for evaluating development programmes, designed to enhance accountability, transparency, and learning (OECD, 2019). Out of the six criteria, this study focuses on four, relevance, effectiveness, impact, and sustainability, as they best capture the dimensions necessary for assessing interventions targeted at persons with albinism (PWA) in Ghana.

Relevance considers the extent to which interventions align with the priorities, needs, and rights of beneficiaries. For PWA in Ghana, relevance entails assessing whether the initiatives of Engage Now Africa (ENA) such as sunscreen distribution, health screenings, educational support, and sensitisation campaigns, address the pressing healt0h risks, social stigma, and educational barriers

documented in the literature. Interventions that fail to reflect the lived experiences of PWA risk being misaligned with actual needs, even if well-intentioned (UNDP, 2020).

Effectiveness relates to the achievement of stated objectives. In the case of ENA's interventions, this means examining whether sensitisation campaigns have reduced stigma, whether scholarships and school support have improved retention and educational outcomes, and whether dermatological screenings have enhanced access to timely care. Effectiveness requires measuring outcomes against intended goals, highlighting whether resources and strategies are producing tangible improvements in the wellbeing and inclusion of PWA (Dzah and Gyaase, 2021).

Impact goes further by assessing the broader, long-term effects of interventions — both intended and unintended. For ENA's programmes, this includes investigating whether initiatives have produced lasting changes in community perceptions, policy integration, or economic opportunities for PWA. It also requires considering whether the interventions have influenced systems beyond immediate beneficiaries, such as shifting institutional practices within schools or health facilities (Shawa, 2019).

Sustainability assesses the likelihood that benefits will continue once external support is withdrawn. For PWA in Ghana, sustainability involves determining whether sunscreen remains available and affordable after distribution programmes end, whether sensitization campaigns foster long-term attitudinal change, and whether educational and health support become institutionalised within government systems (UNICEF, 2021).

Together, these four criteria provide a comprehensive and structured framework for evaluating ENA's interventions. By situating the study within the OECD-DAC model, the research ensures

that analysis moves beyond anecdotal or descriptive accounts to systematically evaluate programme performance.

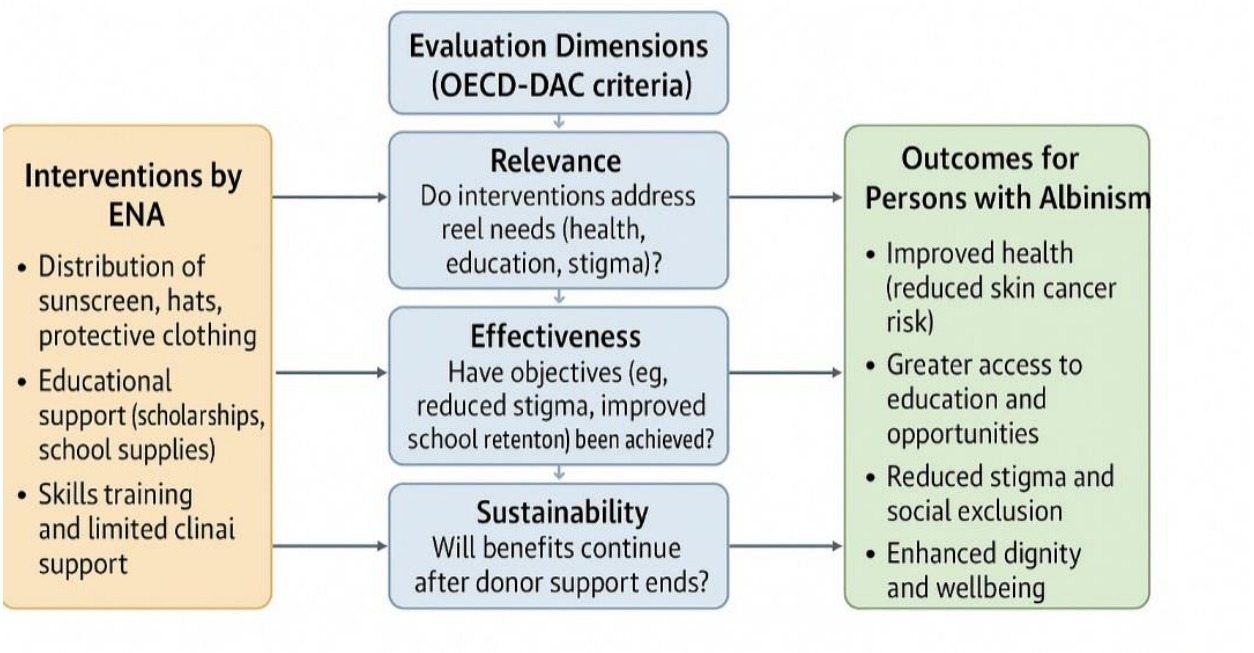

Figure 1.1 Conceptual Framework
Source: Author's own construct

1.5 Research Questions

1. What range of interventions has Engage Now Africa implemented for persons living with albinism in Ghana?
2. How relevant are these interventions in addressing the expressed needs and priorities of beneficiaries?
3. How effective are the interventions in improving the wellbeing and life outcomes of persons with albinism?
4. What is the broader impact of the interventions on empowerment, community attitudes, social inclusion, and their sustainability beyond project support?

1.6 General Objective:

To explore the interventions implemented by Engage Now Africa (ENA) and their role in improving the wellbeing, empowerment, and social inclusion of persons living with albinism in Ghana.

1.7 Specific Objectives:

1. To describe the range of interventions implemented by Engage Now Africa for persons living with albinism in Ghana.
2. To examine the relevance of these interventions in addressing the expressed needs and priorities of beneficiaries.
3. To explore the effectiveness of the interventions in improving the well-being and life outcomes of persons with albinism.
4. To assess the broader impact and sustainability of the interventions on empowerment, community attitudes, and social inclusion.
5. To investigate the sustainability of the interventions and their potential for long-term continuation beyond project support.

1.8 Profile of Study

This study was conducted in Ghana, with a population of about 30,832,019 as of 2021. In order to address issues related to population size, share, and growth, sex composition, population density, number of households, and household size by region, district, and type of locale, the nation has been divided into 16 regions, 261 metropolitan, municipal, and district assemblies, and 275 constituencies. More than half of the population of the country are from the Greater Accra Region (17.7%), Ashanti Region (17.6%), Eastern Region (9.5%), and Central Region (9.3%) and other

citizens from the Northern Region (7.5%), Western Region (6.7%), Volta (6.7%), Upper East (4.2%), Bono Region (3.9%) Upper west (2.9%), Western North (2.9%), Oti Region (2.4%), Northeast(2.2%), Savannah Region(2.1%) and Ahafo Region(1.8%)(Ghana Statistical Service, 2022). Overall, there are more females (8,961,329), representing 51.3%, in urban areas than males (8,511,201), representing 48.7%. Nevertheless, in rural areas, there are slightly more males (50.1%) than females (49.9%) (Ghana Statistical Service, 2022).

Figure 1.2 Map of Ghana

Source: The Permanent Mission of Ghana of the United Nations

1.9 Scope of the Study

This study focuses on interventions implemented by Engage Now Africa (ENA) for persons living with albinism in Ghana. The scope is limited to the range, relevance, effectiveness, and broader

impact of these interventions on health, education, livelihood empowerment, and social inclusion. The study also considers sustainability issues, particularly the extent to which the interventions can continue beyond direct project support. The research is geographically restricted to selected communities where ENA operates, and participants include persons living with albinism, caregivers, and key stakeholders. The findings are therefore not intended to represent the experiences of all persons with albinism in Ghana, but rather provide insights into the impact of ENA's programmes within the studied contexts.

1.10 Organization of the Report

The report is structured into six chapters. Chapter One presents the background to the study, statement of the problem, research objectives, research questions, significance, justification, scope, and organization of the study. Chapter Two reviews relevant theoretical and empirical literature on albinism, social inclusion, and intervention programmes. Chapter Three outlines the research methodology, including the study design, population, sampling procedures, data collection methods, and data analysis techniques. Chapter Four presents the findings of the study, while Chapter Five discusses the results in relation to existing literature. Finally, Chapter Six provides the conclusions and recommendations based on the study's findings.

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Literature Review Introduction

Research work on albinism has broadened over the past decade from biomedical descriptions to social, cultural, and rights-based perspectives. Persons with albinism (PWA) face both medical vulnerabilities, including heightened risk of skin cancer and visual impairment, and social challenges such as stigma, discrimination, and exclusion from education and employment (Kromberg, Flynn and Kerr, 2023). These realities underscore the need for interventions that address not only health but also the wider determinants of wellbeing. Yet, much scholarship has focused on describing challenges rather than assessing the outcomes of interventions, leaving gaps in evidence on what works for PWA and in which contexts (Franklin *et al.,* 2018).

Globally, responses vary. High-income countries often integrate low-vision services and subsidised skin protection into health systems, while low-resource settings rely on NGO-led support. Evidence shows that prevention of non-melanoma skin cancers is possible through consistent sun protection, but sustainability is difficult without systemic government backing (Kromberg, Flynn and Kerr, 2023; Tomás-Velázquez *et al.,* 2024). These findings highlight that integration into mainstream systems enhances effectiveness, whereas donor-driven programmes risk fragility.

In sub-Saharan Africa, literature emphasises the intersection of medical and social exclusion. Children with albinism face barriers safety and dignity, education and participation (Franklin *et al.,* 2018). While Tanzania has advanced sunscreen distribution through NGO-state partnerships, Malawi and Nigeria continue to struggle with inconsistent supply chains and funding (Tomás-

Velázquez *et al.,* 2024). Interventions lacking cultural fit, affordability, and local ownership often suffer poor uptake.

In Ghana, interventions exist but remain fragmented. Studies report persistent stigma despite sensitisation campaigns (Affram, Teye-Kwadjo and Gyasi-Gyamerah, 2019), and ongoing exclusion in schools, employment, and housing (Daklo and Obadire, 2024). Civil society highlights unreliable prevalence data and harmful practices, revealing weak integration into national disability frameworks (Africa Albinism Network, 2024). These gaps justify the present study's focus on systematically evaluating Engage Now Africa's interventions from the perspective of beneficiaries.

2.2 Interventions Implemented for Persons with Albinism

Efforts to support persons with albinism (PWA) have taken multiple forms across the world, often reflecting the intersection of biomedical, educational and social needs that define their lived experiences. The rationale for these interventions is grounded in evidence that PWA are not only at higher risk of preventable medical conditions such as skin cancers and low vision, but also disproportionately exposed to discrimination and exclusion in schools, workplaces and communities (Kromberg, Flynn and Kerr, 2023). Over the past decade, interventions have increasingly moved from charity-based provision of sunscreen and spectacles to broader rights-based approaches that integrate empowerment, awareness and policy advocacy (Reimer-Kirkham *et al.,* 2024). Yet the scope, quality and sustainability of such interventions remain uneven, with many programmes heavily donor-driven and lacking rigorous evaluation of outcomes.

Globally, interventions have largely clustered around three domains: health, education, and social sensitisation. In high-income settings such as the United States and Europe, dermatology services

and sunscreen are integrated into routine health coverage, while visual aids are provided through mainstream disability programmes (Lund and Gaigher, 2019). This has enabled early detection and management of skin cancers, and improved retention of children with albinism in schools through the provision of low-vision devices and teacher training (Kromberg, Flynn and Kerr, 2023). In low- and middle-income countries, however, interventions are predominantly led by NGOs, with varying results. For example, non-profit programmes in Latin America have distributed sunscreen and sunglasses to marginalised groups with albinism, but critiques highlight that these short-term donations rarely guarantee continuity of protection once funding ends (Reimer-Kirkham *et al.,* 2024). This underscores a recurring global challenge: interventions are often designed with strong intentions but without mechanisms for sustainability.

In Africa, interventions for PWA have been shaped both by health imperatives and by urgent protection needs, particularly in countries with a documented history of attacks. Tanzania has been at the forefront of NGO-led and government-backed responses. Programmes there have included the distribution of sunscreen through hospitals, establishment of dermatology outreach clinics, and community sensitisation campaigns to challenge myths and prevent ritual killings (Hong, Zeeb and Repacholi, 2019). While these initiatives have reduced the number of reported killings in recent years, critiques argue that they remain concentrated in urban centres and have not addressed structural issues such as poverty and systemic exclusion from employment (Franklin *et al.,* 2018). In Malawi, dermatology clinics supported by international partners have demonstrated success in reducing the incidence of late-stage skin cancers among PWA, but sustainability has been difficult to achieve in the absence of national-level funding for sunscreen (Tomás-Velázquez *et al.,* 2024).

South Africa represents another important case. Here, the rights-based approach to disability has helped incorporate albinism into national education and disability policy frameworks. This has led

to targeted teacher training, inclusive curriculum adjustments, and advocacy on access to sunscreen as an essential health commodity (Shawa, 2019). Yet despite this relatively enabling policy environment, stigma in local communities persists, highlighting that legal frameworks alone cannot fully dismantle discriminatory attitudes. In Nigeria, civil society organisations have implemented awareness campaigns and provided basic support packages such as hats and sunscreen. However, the impact of these interventions is limited by weak monitoring and evaluation, making it difficult to assess whether community perceptions or health outcomes have significantly changed (Ifeanyi and Iheanacho, 2020). Taken together, African evidence shows that interventions can improve wellbeing in measurable ways but are often undermined by poor reach, weak government ownership, and lack of rigorous outcome evaluation.

In Ghana, interventions for PWA remain relatively under-documented in academic literature, but evidence suggests that civil society groups have been instrumental in filling critical gaps. Affram, Teye-Kwadjo and Gyasi-Gyamerah (2019) show that despite sensitisation activities, stigma remains pervasive, suggesting that existing campaigns may not have sufficiently resonated with community attitudes. Civil Society reports to the UN have also indicated that harmful practices, including social exclusion and lack of institutional recognition, continue to limit opportunities for PWA (Africa Albinism Network, 2024). Within this context, Engage Now Africa (ENA) has emerged as one of the most visible NGOs addressing the needs of PWA. ENA's interventions include distribution of sunscreen, wide-brimmed hats, and protective clothing; scholarships and school supplies to support educational participation; and community sensitisation programmes aimed at challenging myths and stereotypes (Engage Now Africa, 2022). ENA has also piloted locally made sunscreen products to reduce dependency on imports and enhance sustainability.

While these interventions represent important steps, they have not been systematically evaluated. Daklo and Obadire (2024) report that many PWA in Ghana continue to face barriers in education, healthcare and employment, raising questions about whether interventions fully address their lived realities. Moreover, sunscreen distribution, while valuable, often depends on external funding cycles, leaving gaps in consistent protection. Similarly, sensitisation campaigns may create temporary awareness but do not always result in long-term attitudinal change or reduction in stigma. These critiques underscore the importance of evaluating interventions not only in terms of what is provided but also in relation to their relevance, effectiveness and sustainability.

In summary, the literature shows that interventions for PWA globally, regionally and in Ghana have centred on health, education and awareness, but with mixed outcomes. Global evidence suggests that integration into health and education systems ensures continuity, while African experiences highlight both innovation and fragility in NGO-led responses. In Ghana, ENA's interventions stand out as critical efforts to address gaps, but their impact and alignment with the needs of PWA remain underexplored. This underscores the necessity of systematic evaluation through frameworks like the OECD-DAC to ensure that interventions are not only implemented but also meaningful and transformative for those they seek to support.

2.3 Perceptions of the Relevance of Interventions

Relevance, as defined in evaluation literature, reflects the extent to which interventions address the actual priorities and lived realities of beneficiaries (OECD, 2019). For persons with albinism (PWA), relevance extends beyond immediate health needs such as access to sunscreen and dermatological services to encompass education, livelihood opportunities, and the reduction of stigma and discrimination. Literature consistently shows that interventions which are designed in consultation with affected populations are more likely to be accepted, culturally appropriate, and

sustainable. Conversely, programmes developed from external agendas without adequate engagement often fail to resonate with those they aim to serve, diminishing their long-term value (Bamberger, Vaessen and Raimondo, 2016). Understanding beneficiary perceptions of relevance is therefore essential, since interventions that appear well-aligned from a provider's perspective may still be regarded as marginal or insufficient by recipients.

Globally, research on rare disease interventions highlights the importance of participatory approaches in ensuring relevance. A comparative analysis of community health initiatives across Latin America and Asia found that programmes designed with active beneficiary input were more likely to be perceived as relevant, especially when they combined medical and social interventions (Lungu *et al.,* 2020). In the context of albinism, Reimer-Kirkham *et al*. (2024) emphasise that interventions focused exclusively on clinical risks may overlook the pressing social realities of exclusion, poverty, and marginalisation. This resonates with findings from public health campaigns more broadly, which suggest that interventions perceived as externally imposed are often rejected or under-utilised, regardless of their technical merits (UNDP, 2020). These insights highlight a recurring theme: relevance is as much about cultural and social fit as it is about technical soundness.

Across sub-Saharan Africa, the gap between intervention design and beneficiary priorities is well documented. In Tanzania, where sunscreen distribution campaigns have been scaled up, studies show that beneficiaries welcomed access to protective products but often criticised their inconsistency, limited rural coverage, and lack of complementary services such as regular skin checks and education on sun safety (Hong, Zeeb and Repacholi, 2019). While the interventions were medically sound, their perceived relevance was weakened by distribution challenges and by failing to address wider socioeconomic concerns. In Malawi, Tomás-Velázquez *et al*. (2024) found

that while dermatological clinics reduced skin cancer prevalence among PWA, community members reported that broader priorities, such as access to schooling and employment, were insufficiently addressed, limiting the perceived overall relevance of the programmes.

Perceptions of relevance are also closely tied to the degree of stigma reduction achieved by interventions. In Nigeria, Ifeanyi and Iheanacho (2020) found that while awareness campaigns provided factual information about albinism, many PWA felt that these interventions had limited effect on entrenched community attitudes, thus undermining their relevance. Similarly, Franklin *et al*. (2018) argued that programmes in multiple African countries remained heavily donor-driven, often prioritising visibility or advocacy at international forums rather than targeting the daily challenges of beneficiaries. These critiques demonstrate that interventions judged relevant by providers may not be perceived as such by recipients when they do not respond to the realities of exclusion in education, housing, and livelihoods.

In South Africa, however, more integrated approaches have achieved relatively higher perceived relevance. Shawa (2019) documents how disability rights frameworks have helped incorporate albinism into broader national disability policies, making PWA feel recognised and included. Here, the relevance of interventions was strengthened by embedding them into systemic reforms rather than treating albinism as an isolated issue. This comparative example suggests that embedding interventions into existing health and education systems increases beneficiary perceptions of their legitimacy and relevance.

In Ghana, available evidence suggests mixed perceptions of the relevance of interventions for PWA. Affram, Teye-Kwadjo and Gyasi-Gyamerah (2019) found that despite sensitisation campaigns, stigma remained a major barrier, suggesting that community awareness programmes may not fully align with the needs of PWA, who often prioritise tangible support in education and

employment. Daklo and Obadire (2024) further reported that many PWA questioned the adequacy of NGO interventions, noting that while sunscreen and school materials were useful, the lack of structural support for jobs, vocational training, and government integration limited the relevance of these programmes to their long-term wellbeing. Civil society submissions to the UN echo this concern, stating that interventions often fail to address systemic issues such as access to healthcare infrastructure and policy inclusion, leading to gaps between provision and perceived needs (Africa Albinism Network, 2024).

Within this context, Engage Now Africa (ENA) has implemented a range of programmes, including sunscreen distribution, scholarships, and sensitisation campaigns. Yet questions remain about how beneficiaries perceive their relevance. For example, while ENA's scholarship programme addresses an acknowledged barrier to education, PWA interviewed in local studies reported that lack of visual aids and discriminatory classroom environments continued to undermine their school experiences (Daklo and Obadire, 2024). Similarly, sensitisation campaigns may raise public awareness but often fail to dismantle entrenched stereotypes, limiting their perceived relevance for everyday life. Moreover, while sunscreen provision is medically essential, inconsistent supply chains mean that beneficiaries may regard such interventions as partial rather than comprehensive responses to their needs.

Overall, the literature demonstrates that perceptions of relevance hinge on whether interventions align with the everyday realities of PWA. Global and African experiences underscore that technical validity does not guarantee perceived relevance if programmes are externally driven, limited in scope, or unsustainable. Ghanaian evidence suggests that while ENA's interventions address some immediate needs, beneficiaries often perceive them as insufficient in tackling the systemic barriers of exclusion, poverty, and stigma. This highlights the need for systematic evaluation to better

understand and respond to beneficiary perspectives, ensuring that interventions are truly relevant to those they aim to serve.

2.4 Perceptions of Effectiveness of Interventions

Effectiveness in evaluation refers to the extent to which stated objectives of an intervention are achieved, taking into account both intended outcomes and unintended consequences (OECD, 2019). In the case of persons with albinism (PWA), effectiveness entails assessing whether programmes reduce health risks, improve educational participation, alleviate stigma, and enhance wellbeing. Importantly, effectiveness is not only determined by measurable outputs such as the number of sunscreen bottles distributed or sensitisation sessions held, but also by beneficiary perceptions of whether these activities have brought about real, positive changes in their lives. Literature on disability and minority health interventions consistently underscores that programmes deemed effective by donors or implementers may be perceived as less so by recipients if they do not translate into meaningful improvements in daily living (Bamberger, Vaessen and Raimondo, 2016).

Globally, evidence on the effectiveness of interventions for rare genetic conditions highlights both successes and limitations. In high-income contexts, the integration of sunscreen into essential health benefits and the availability of visual aids in schools have demonstrably reduced morbidity and improved quality of life for PWA (Kromberg, Flynn and Kerr, 2023). Yet in low-resource settings, even where interventions exist, their effectiveness is often constrained by lack of follow-up, weak monitoring, and gaps in systemic support. Tomás-Velázquez *et al*. (2024), for instance, demonstrated that dermatological outreach in Malawi successfully reduced the incidence of advanced skin cancers among PWA, but long-term effectiveness was undermined when clinics could not guarantee continuous sunscreen provision. This case illustrates that technical

interventions can show short-term success while failing to sustain outcomes in the absence of systemic integration.

Effectiveness also depends heavily on social and cultural context. A cross-country review of stigma-reduction campaigns for minority groups found that interventions using participatory and culturally sensitive methods were more likely to achieve sustained changes in attitudes than those relying on one-off information sessions (Reimer-Kirkham *et al.,* 2024). This resonates with albinism-focused campaigns: awareness programmes often succeed in raising temporary visibility but fall short of shifting entrenched beliefs, leading beneficiaries to perceive them as less effective in addressing everyday discrimination (Hong, Zeeb and Repacholi, 2019).

Within Africa, interventions have generated mixed perceptions of effectiveness. In Tanzania, the distribution of sunscreen through hospitals and clinics was widely welcomed, yet studies noted that beneficiaries continued to report preventable sunburn and skin damage because supply chains were inconsistent and products were not always affordable (Franklin *et al.,* 2018). As a result, while coverage targets were met, the lived effectiveness for beneficiaries was limited. Similarly, in Nigeria, Ifeanyi and Iheanacho (2020) observed that while awareness campaigns improved public knowledge about the genetic basis of albinism, PWA reported limited improvement in actual experiences of discrimination, highlighting a gap between outputs and outcomes. In Malawi, despite notable success of dermatology interventions in preventing advanced cancers, beneficiaries often noted that education and employment opportunities remained unaddressed, constraining the overall effectiveness of programmes (Tomás-Velázquez *et al.,* 2024).

South Africa presents a contrasting picture, where rights-based frameworks embedded albinism support into broader disability policies. Shawa (2019) reports that training of teachers and provision of low-vision aids increased school retention and improved perceptions of programme

effectiveness among PWA. However, even in this more enabling environment, stigma in local communities persisted, suggesting that interventions were only partially effective in addressing holistic needs. These findings across Africa converge on a common critique: interventions may achieve measurable biomedical or educational gains but are often perceived as less effective by beneficiaries because they leave structural barriers—such as employment discrimination, poverty, and community stigma—largely intact.

In Ghana, perceptions of the effectiveness of interventions remain under-explored, but existing studies point to gaps. Affram, Teye-Kwadjo and Gyasi-Gyamerah (2019) showed that stigma continues to significantly depress wellbeing, suggesting that sensitisation campaigns, though widespread, have not effectively dismantled deep-rooted social attitudes. Similarly, Daklo and Obadire (2024) reported that many PWA perceived NGO interventions as piecemeal and inadequate, noting that while sunscreen distribution was useful, its irregular availability meant protection was inconsistent. Beneficiaries also highlighted that scholarships and school supplies were positive but did not resolve underlying barriers such as lack of classroom accommodations or teacher training, reducing the perceived effectiveness of education-related support.

Engage Now Africa (ENA), one of the most prominent NGOs in this space, has reported achievements in sunscreen provision, awareness-raising, and educational support (Engage Now Africa, 2022). Yet from the perspective of PWA, effectiveness is mixed. While beneficiaries often acknowledge the immediate utility of receiving sunscreen or school materials, many question whether these interventions translate into lasting improvements in dignity, health, or inclusion. This critique is consistent with broader literature on NGO programmes in low-resource contexts, where beneficiaries may value specific outputs but remain unconvinced of long-term outcomes if

interventions fail to address structural issues such as poverty, systemic discrimination, or government inaction (Dzah and Gyaase, 2021).

Taken together, global, regional, and Ghanaian evidence highlight that effectiveness cannot be judged solely by the scale of activities but must be understood through the lens of beneficiary perceptions. Technical interventions such as sunscreen distribution or school scholarships may be necessary, but they are not sufficient if they do not translate into holistic improvements in quality of life. The literature shows that in Ghana, interventions for PWA—including those by ENA—have yet to fully achieve effectiveness as perceived by beneficiaries, underscoring the need for systematic evaluation using frameworks such as OECD-DAC that prioritise both outcomes and lived experiences.

2.5 Gaps in the Literature

Although the body of research on albinism has expanded over the last decade, several critical gaps remain that justify the need for this study. First, most existing literature is descriptive, focusing on the social stigma, health vulnerabilities, and discrimination faced by persons with albinism (PWA), with limited empirical attention to the evaluation of interventions. Franklin *et al*. (2018) emphasise the rights deficits of children with albinism but stop short of examining whether interventions designed to address these challenges are achieving their intended outcomes. Similarly, global prevalence studies (Kromberg, Flynn and Kerr, 2023) provide important epidemiological insights but offer little evidence on programme performance or beneficiary experiences. This lack of evaluation leaves policymakers and NGOs with insufficient guidance on how to design effective, contextually grounded interventions.

Second, there is a scarcity of research that foregrounds the perspectives of PWA themselves. Studies in Tanzania, Malawi and Nigeria highlight the availability of sunscreen or awareness campaigns but rarely examine how beneficiaries perceive the relevance or effectiveness of these initiatives (Hong, Zeeb and Repacholi, 2019; Tomás-Velázquez *et al.,* 2024). In Ghana, Daklo and Obadire (2024) note that while NGOs such as Engage Now Africa (ENA) provide support in education and healthcare, few studies have systematically captured how recipients evaluate these programmes. This absence of participatory evaluation risks perpetuating interventions that look effective on paper but fail to resonate with lived experiences.

Finally, a significant methodological gap exists. Few studies employ established evaluation frameworks such as the OECD-DAC criteria to assess interventions for PWA. The absence of such systematic approaches results in fragmented evidence, limiting opportunities for cross-country learning and comparative analysis. Addressing these gaps is therefore crucial.

2.6 Conclusion

The literature reviewed demonstrates that while interventions for PWA globally and regionally have made some progress in addressing biomedical and social needs, they remain uneven, fragmented and inadequately evaluated. Globally, success has been most evident where interventions are integrated into mainstream health and education systems, but in low-resource settings, NGO-driven responses dominate and are often short-lived. Across Africa, interventions such as sunscreen provision, awareness campaigns, and educational support are widespread but face persistent challenges of sustainability and cultural resonance. In Ghana, ENA has spearheaded critical initiatives, yet evidence shows that beneficiaries often perceive them as partial, insufficient, or disconnected from deeper structural barriers.

The gaps in evaluation, particularly the lack of beneficiary-centred perspectives and weak attention to sustainability, underscore the need for systematic analysis using robust frameworks. By applying the OECD-DAC criteria and focusing on the perceptions of PWA themselves, this study responds directly to the deficiencies identified in the literature. It contributes not only by documenting what interventions exist but also by critically assessing their relevance, effectiveness and perceived value. Ultimately, the review reinforces the necessity of moving beyond descriptive accounts of stigma toward rigorous evaluations that can guide policy, strengthen NGO programming, and promote the rights and wellbeing of persons with albinism in Ghana.

CHAPTER THREE

3.0 METHODOLOGY

3.1 Introduction

This chapter presents the methodology employed in the study, which explored the perceptions and effectiveness of interventions implemented by Engage Now Africa (ENA) for persons living with albinism (PLWA) in Ghana. The chapter outlines the study design, data source, study population, inclusion and exclusion criteria, sampling strategy, data handling procedures, analytical methods, ethical considerations, and dissemination plan. The study was based entirely on secondary qualitative data obtained from a project evaluation previously conducted by ENA. The use of this dataset enabled the researcher to critically examine the lived experiences and perspectives of PLWA in relation to ENA's intervention strategies.

3.2 Study Design

The study adopted a qualitative exploratory design, specifically employing a phenomenological and descriptive approach using secondary data. This design was appropriate for gaining in-depth understanding of participants' lived experiences, perceptions, and evaluations of Engage Now Africa's (ENA) interventions. The phenomenological approach allowed the study to interpret how persons with albinism made meaning of ENA's support in relation to their health, education, and social inclusion, while the descriptive component provided a detailed account of the outcomes and perceived effectiveness of these interventions. The original dataset comprised in-depth interviews conducted as part of an internal programme evaluation by ENA, designed to assess the relevance, accessibility, and impact of its interventions targeting persons with albinism.

3.3 Study Site

Although no new data were collected by the researcher, the secondary dataset was drawn from interviews conducted in communities across the Northern, Upper East, and Volta Regions of Ghana, where ENA has implemented interventions. These interventions include public sensitization campaigns, distribution of sun protection materials, educational support, and health screenings.

3.4 Study Population

The study population consisted of persons living with albinism who participated in ENA's project. These individuals had received one or more interventions from ENA and were selected by the organization's project team to participate in qualitative interviews for the purpose of assessing program performance and impact. The datas*et al*so included a small number of caregivers speaking on behalf of minors with albinism.

3.5 Inclusion and Exclusion Criteria

3.5.1 Inclusion Criteria

The study included individuals who self-identified as persons living with albinism at the time of the original data collection. All participants had directly engaged with or benefited from one or more interventions implemented by Engage Now Africa, such as dermatological screenings, educational support, or community sensitization campaigns. Additionally, the dataset included a small number of caregivers who provided information on behalf of minors with albinism.

Participants were selected for the original evaluation based on their availability, willingness to share their experiences, and informed consent to participate in the interviews. Only interviews that

were complete, clearly transcribed, and ethically cleared for academic use were included in this study.

3.5.2 Exclusion Criteria

The study excluded any individuals who did not receive or participate in any of ENA's interventions. It also excluded interviews with incomplete transcripts, unclear responses, or missing consent documentation.

3.6 Sample Size and Sampling Procedure

The original dataset included 40 in-depth interview transcripts, collected using purposive sampling by ENA's evaluation team. Participants were selected to reflect diverse demographic characteristics including gender, age, and geographic location. The sampling strategy ensured representation from various districts within the regions of intervention. For this academic study, the entire dataset was re-analyzed. No additional sampling or data collection was undertaken.

3.7 Data Collection Methods and Instruments

The data were collected using an interview guide (see Appendix I) developed by Engage Now Africa's programme evaluation team. The guide was structured to explore five broad thematic areas that aligned with the objectives of this study. The first section focused on the socio-demographic profiles of participants, seeking background information such as age, education, occupation, and marital status

The second area explored perceptions and beliefs about albinism, inviting participants to share their understanding of albinism, cultural myths, and community beliefs that shape public attitudes.

These questions provided insights into the persistence of stigma and misconceptions surrounding albinism in different communities.

The third area addressed health and educational challenges, focusing on participants' experiences with skin and eye conditions, access to healthcare, and use of protective resources such as sunscreen, eyewear, and clothing. It also explored barriers to schooling and employment. These questions enabled a deeper understanding of the intersection between health vulnerabilities and limited access to educational opportunities.

The fourth thematic area examined socioeconomic and psychosocial experiences, including livelihood barriers, community attitudes, family relations, coping strategies, and sources of emotional or practical support.

Finally, the fifth section centred on engagement with Engage Now Africa (ENA) and programme evaluation. This portion of the interview explored participants' awareness of ENA's initiatives, the nature of their involvement, and the perceived outcomes of these interventions. These questions directly addressed the core aim of the study, to evaluate ENA's interventions through the perspectives of beneficiaries and assess their relevance, effectiveness, and sustainability.

3.8 Data Handling

The secondary data was accessed with formal approval from Engage Now Africa. Transcripts will be stored in encrypted, password-protected files accessible only to the researcher and academic supervisors. Ethical standards regarding privacy, confidentiality, and responsible use of secondary data was rigorously maintained.

3.9 Data Analysis

Data was analyzed thematically using ATLAS.ti, a qualitative data analysis software. Thematic analysis followed Braun and Clarke's six-phase framework: (1) familiarization with data, (2) generation of initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report. Both deductive codes (derived from the research objectives) and inductive codes (emerging from the participants' narratives) were applied to capture insights related to the nature, relevance, and perceived effectiveness of ENA's interventions. Themes were refined through continuous comparison and peer debriefing with the supervisory team to enhance analytical accuracy.

3.10 Ethical Issues

This study used secondary data that had been collected with informed consent by Engage Now Africa as part of an ethically approved evaluation process. Permission to use the data for academic research was formally obtained from ENA prior to analysis. The researcher ensured compliance with ethical principles including respect for persons, beneficence, and confidentiality. No personal identifiers were included in the analysis, and all data was securely stored. The study was submitted for ethical review and clearance by Ensign Global University's Institutional Review Board.

3.11 Limitations of the Study

Like any research, this study was subject to certain limitations. First, the findings are based on data collected from selected communities where Engage Now Africa (ENA) operates; therefore, the results may not be generalizable to all persons living with albinism in Ghana. Second, the study relied heavily on self-reported data from participants, which may have introduced recall bias or socially desirable responses, especially on sensitive issues such as stigma and discrimination.

3.12 Assumptions

The study was conducted with the following assumptions:

1. Participants provided honest, accurate, and reliable information regarding their experiences with ENA interventions.
2. Engage Now Africa implemented the interventions as planned and reported in project documents.
3. The perspectives of the sampled participants were assumed to be reflective of broader experiences within the communities studied.
4. The socio-cultural contexts within which the interventions were implemented were assumed to have remained relatively stable during the study period, allowing findings to be interpreted without major disruptions.

CHAPTER FOUR

4.0 RESULTS

4.1 Demographic characteristics

As shown in Table 4.1, participants ranged in age from 10 to 50 years, with the largest proportion (23.1%) being in the 36–40 year group. The majority (56.4%) of the participants were single, while 43.6% were married. In terms of education, nearly half (43.6%) had completed secondary education, while 30.8% had tertiary education. A smaller share (5.1%) had no formal schooling. Students formed the largest occupational group (38.5%), followed by teachers (12.8%) and self-employed participants (7.7%). Other occupations included health workers, artisans, traders, and programme coordinators. This distribution reflects a diverse set of experiences across age, education, and livelihood contexts.

Table 1 Demographic characteristics

Variable	Category	Frequency (n = 40)	Percentage (%)
Age (years)	10–15	3	7.5
	16–20	3	7.5
	21–25	7	17.5
	26–30	5	12.5
	31–35	3	7.5
	36–40	9	22.5
	41–45	6	15.0
	46–50	4	10.0
Marital Status	Married	17	42.5
	Single	23	57.5
Level of Education	Primary	3	7.7

	Secondary	17	43.6
	Tertiary	12	30.8
	Masters	5	12.8
	No formal education	3	5.1
Occupation	Student	15	37.5
	Teacher	5	12.5
	Private company	2	5.0
	Nurse	2	5.0
	Head teacher	3	7.5
	Self-employed	3	7.5
	Unemployed	2	5.0
	National service	1	2.5
	Trader	1	2.5
	Motor rider	1	2.5
	Albinism programme coordinator	1	2.5
	Driver	1	2.5
	Retired	1	2.5

4.2 Interventions implemented by Engage Now Africa for persons living with albinism in Ghana

Participants described a broad set of interventions implemented by Engage Now Africa (ENA), spanning health, education, advocacy, and livelihood empowerment. These were recognised as crucial support that addressed the everyday challenges of persons with albinism (PWAs).

Health Interventions

Several respondents associated ENA's support with improved health outcomes, particularly in managing skin conditions. Interventions such as the provision of sunscreen, creams, and occasional health assistance were emphasised.

- *"Even when there's an ongoing problem like breaking of the skin, Engage Now Africa can come in with support."* (*Female Respondent*, D4)

- *"Yes they have helped us, and I think Engage Now Africa can extend their help more, especially when it comes to health, because most of us suffer from skin problems and eye issues."* (*Female Respondent*, D5)

These reflections highlight how ENA's interventions in the area of health addressed the most visible vulnerabilities of PWAs, particularly skin and eye care. However, participants also called for more consistent and extended support.

Educational Support

Educational assistance was the most frequently cited intervention. ENA provided scholarships, paid fees, and supplied materials, which respondents described as decisive in their ability to continue schooling despite challenges of poor vision and financial strain.

- *"Engage Now Africa, they financially support me. If not for that, I would have stopped schooling long ago."* (*Female Respondent*, D2)

- *"And also, Engage Now Africa, they also paid my fees. The second year they paid half of my fees and loans, a whole lot. Even the phone I'm using now is from Engage Now Africa."* (*Female Respondent*, D5)

- *"Yes. Last year I received support from Engage Now Africa, and it helped me to continue my schooling."* (*Female Respondent*, D8)

These testimonies demonstrate that ENA's educational interventions directly prevented school dropouts, gave material relief, and provided institutional advocacy in schools.

Advocacy and Awareness Creation

Community sensitisation was another major intervention valued by participants. ENA carried out community meetings, radio discussions, and awareness campaigns aimed at tackling myths and stigma around albinism.

- *"Then when I also associated myself with Engage Now Africa, they were very helpful to us, especially with advocacy."* (*Female Respondent*, D7)

- *"Oh, I think yes, Engage Now Africa is, yes, ENA is helping us a lot in terms of community sensitisation."* (*Female Respondent*, D10)

- *"The Sweden Ghana, the program that we went. It was just about we, the persons living with albinism, how we will engage ourselves with the community people, all those who are around us and our family members. And we learned so many things from the program, which will help us if like we take it into place."* (*Female Respondent*, D1)

Such reflections indicate that ENA's advocacy work was seen as relevant and empowering, helping PWAs to be more accepted within their communities.

Livelihood and Empowerment Initiatives

Although less frequently mentioned, ENA also supported livelihood and empowerment through training and skills development. These interventions were highlighted as important for building independence and self-reliance.

- *"And the Engage Now Africa in the form of training, they trained us and empowered us with useful skills."* (*Male Respondent*, D11)
- *"Sometimes they are still training for people with albinism in certain skills."* (*Female Respondent*, D10)

These accounts illustrate how livelihood support, though not as widely distributed as health or education support, created opportunities for participants to become more economically independent.

From participants' accounts, ENA's interventions can be grouped under four key areas: health protection, educational support, advocacy and awareness creation, and livelihood empowerment. These supports directly responded to the intersecting needs of PWAs — from managing skin and eye health, to staying in school, to reducing stigma, and pursuing self-reliance. While respondents valued these efforts, they also pointed to concerns of adequacy and continuity, noting that interventions were sometimes irregular or limited in scope.

4.3 Relevance of these interventions in addressing the expressed needs and priorities of beneficiaries.

Relevance of ENA's Interventions

Analysis of participants' accounts showed that Engage Now Africa's (ENA) interventions were widely viewed as relevant to the lived realities of persons with albinism (PWAs) in Ghana. The interventions directly addressed pressing needs in education and health, which participants consistently described as their most significant challenges. While the interventions were meaningful, concerns about adequacy and reach were mentioned. Two main sub-themes emerged: educational support and health and sunscreen provision.

Educational Needs

Education was consistently emphasised as a priority area where ENA's support proved highly relevant. Visual impairment, systemic neglect, and financial challenges made schooling particularly difficult for PWAs. ENA's scholarships, awareness creation in schools, and provision of materials were described as critical in reducing the risk of school dropout.

- *"I went to JHS at 2015 and I graduated at 2019. So when I was in school, I was always having problem looking on the board. So, because of that, some of my classmates, like, they were using that to tease me. And some of the masters… they would print the notes. Or after that, they would give me their book to go and copy the notes. Or some of my friends, I would go and collect it from them and copy."* (*Female Respondent*, D1)

- *"Engage Now Africa, they financially support me. If not for that, I would have stopped schooling long ago."* (*Female Respondent*, D2)

- *"…when we went, we were lucky that we met the social welfare director and he gave me the form to fill. When I finished, it was not even up to two weeks, they called me to come for the school fees. So I went and took their money from them, went and paid the school fees… if I didn't get that money, I wouldn't have been able to further up my education."* (*Female Respondent*, D1)

At the same time, some participants expressed that support was not always sufficient or equally distributed:

- *"Our challenges is the education. So the education, because of the eyes errh the sight, some of us are not being able to finish our education or being part of the school… So we are facing challenges about the education. And again, our health."* (*Female Respondent*, D1)

- *"Okay… the education… maybe they can help. They can help people to acquire more knowledge by supporting them or giving them a scholarship."* (*Female Respondent*, D9)

These accounts highlight the needs that ENA's scholarships and school sensitisation programmes aimed to address, making their interventions directly relevant to the educational struggles of PWAs.

Health and Sunscreen Provision

Participants also strongly linked ENA's relevance to their health needs, especially concerning skin protection and eye care. Sunscreen and other protective items were consistently mentioned as critical for daily functioning, since exposure to the sun leads to painful burns and long-term risks of skin cancer. One participant stated that;

- *"If like, if like we could get eyeglasses and the sunscreen it will help us on our health side and on the education side too it will help us." (Female Respondent, D5)*

- *"I didn't know how to take care of the skin, how to take care of myself, how to like, use the cream, sunscreen."* (*Female Respondent*, D1)

She also noted improvement in skin condition was described as a direct outcome of using the sunscreen provided by ENA, underscoring the relevance of the intervention to participants' health priorities.

- *"So as of now, even if you see my skin, people will ask me how come your skin is like this?"* (*Female Respondent*, D1)

Other respondents also highlighted relevance but concerns were raised about coverage.

- *"Even when there's an ongoing problem like breaking of the skin, Engage Now Africa can come in with support."* (*Female Respondent*, D4)

- *"Yes, I think Engage Now Africa can extend their help more, especially when it comes to health, because most of us suffer from skin problems and eye issues."* (*Female Respondent*, D5)

Despite the high relevance of sunscreen provision, concerns were raised about inconsistency and coverage. Beneficiaries stressed that without regular supply, they reverted to painful conditions, highlighting the need for continuity and reliability.

Overall, the relevance of ENA's interventions lies in their direct alignment with the expressed needs of PWAs: access to education and protection from sun-related health risks. The interventions

were experienced as meaningful because they responded to vulnerabilities that participants themselves identified as priorities. Nevertheless, gaps were evident. Educational support did not always cover assistive devices; sunscreen provision was sometimes irregular. This suggests that while ENA's interventions were highly relevant, their continued value depends on expansion, consistency, and integration with broader systemic reforms.

4.4 Effectiveness of the interventions in improving the well-being and life outcomes of people with albinism.

Participants' accounts revealed mixed but generally positive perceptions of the effectiveness of Engage Now Africa's (ENA) interventions. While many highlighted tangible improvements in their lives, others pointed out gaps in consistency and reach. Three main sub-themes emerged: educational outcomes, health improvements, and stigma reduction.

Educational Outcomes

Educational support from ENA was widely described as effective in keeping children and young adults with albinism in school, helping them complete courses, and creating more supportive learning environments. Respondents gave direct accounts of how financial and institutional assistance enabled their progression through different levels of education.

- *"…they called me to come for the school fees. So I went and took their money from them, went and paid the school fees. And now send the receipt to them. So I was very happy. I would say like, if I didn't get that money, I wouldn't have been able to further up my education. Because they wouldn't have allowed me to write the exams."* (*Female Respondent*)

- *"I then have opportunity to talk to Engage Now Africa. They even support me to complete the course…"* (*Female Respondent, D2*)

- *"When I completed, they also supported me to do an internship program."* (*Female Respondent*, D2)

These testimonies show that ENA's financial and institutional interventions had a direct effect on school retention, course completion, and exam participation.

Respondents also highlighted improvements in the classroom environment as evidence of effectiveness. Some described how teachers and peers adjusted to their needs, making participation in class more possible:

- *"…some of the master, they would print the notes. And they would give me their book to go and copy the notes. Or some of my friends, I would go and collect it from them and copy."* (*Female Respondent*, D1)

- *"for my classmates, when I was not able to see from afar, I sit on a desk then they read to me to write."* (*Female Respondent*, D9)

These reflections demonstrate that ENA's interventions were effective not only in providing material support but also in promoting changes in the learning environment that reduced exclusion and enabled PWAs to remain engaged in education.

Health Improvements

Participants consistently described greater capacity to manage their skin and health conditions as a result of Engage Now Africa's (ENA) health-focused interventions. The distribution of

sunscreen, educational outreach, and periodic clinical screenings enabled them to adopt preventive practices and reduce the discomfort associated with prolonged sun exposure.

- "*As I said earlier, it's about covering the skin … giving us sunscreens and then I apply them whenever I'm going out."* (*Female Respondent*, D5)
- *"So I've been also able to teach them and then now they are also applying the treatments"* (*Female Respondent*, D5)
- *"they bring doctors from different hospitals to educate us about our skin and how to go about it"* (*Female Respondent*, D5)

Overall, participants' accounts indicate that ENA's health interventions were effective in improving day-to-day management (regular sunscreen use, applying protection before going out, access to doctors and screenings).

Stigma Reduction and Social Relations

Many participants emphasised Engage Now Africa's (ENA) advocacy campaigns as effective in reducing stigma and improving their social relationships. Respondents described how sensitization in schools and communities helped reduce teasing, improved how they were addressed, and created more respectful environments.

- *"When they came to talk to my schoolmates, they stopped teasing me like before."* (*Female Respondent, D4*).
- *"In my community, after the programme, people started greeting me and treating me better."* (*Male Respondent, D6*)

- *"The radio discussions helped. People in my town called me by my name, not insults."* (*Female Respondent, D3*)
- *"The durbar they organised made my chief speak on our behalf, and now the community respects me."* (*Male Respondent, D7*)

These accounts reflect how advocacy made immediate differences in social interactions. Several participants noted feeling a stronger sense of dignity and belonging after ENA programs.

At the same time, not all participants experienced the same level of change. Some explained that stigma persisted despite the campaigns:

- *"Some people still insult, even after the programme. It doesn't stop completely."* (*Female Respondent, D6*)
- *"It helps for a short time, but later some go back to the old ways."* (*Male Respondent, D6*)

A few others also pointed out that while sensitisation worked in public spaces or schools, it did not always translate to deeper attitude change at family or community level:

- *"The teasing reduced in class, but when we go home, some neighbours still laugh at us."* (*Female Respondent, D10*)
- *"It made a difference for some people, but others, they don't change their mind."* (*Female Respondent, D9*)

Overall, ENA's interventions were effective in improving educational participation, protecting health, and reducing stigma among PWAs. Respondents described clear benefits, such as staying in school, experiencing healthier skin, and enjoying better community relations. However,

effectiveness was often limited by irregular supply, incomplete coverage, and lack of long-term reinforcement. This indicates that ENA's interventions achieved significant change for many individuals, but greater consistency and wider reach would be required to maximise effectiveness across the community.

4.5 Impact of interventions on empowerment, community attitudes, and social inclusion.

Participants' narratives highlighted the wider changes brought about by ENA's interventions, beyond immediate outcomes. These impacts were observed at both the individual and community level, including empowerment, shifts in social attitudes, and expanded opportunities.

Empowerment and Self-Confidence

Several respondents described feeling more empowered and confident because of ENA's interventions. Educational support, counselling, and training opportunities made them believe in their ability to achieve and participate fully in society.

- *"They made me feel I can work hard and achieve something, not just be pitied."* (*Female Respondent, D10*)
- *"Because of ENA, I now feel I can stand in front of people and talk about my condition."* (*Male Respondent, D6*)
- *"The counselling they gave us encouraged me. I don't hide myself anymore."* (*Female Respondent, D3*)
- *"Learning skills through their programme has given me confidence to support myself."* (*Female Respondent, D6*)

At the same time, a few participants expressed that empowerment was partial:

- *"It helps my confidence, but society still doesn't fully accept us, so it is not complete."* (*Male Respondent, D7*)

These reflections suggest that ENA's interventions had a strong empowering impact, though broader societal barriers sometimes limited its full expression.

Community Attitudes and Stigma Reduction

A recurring theme was the positive shift in community perceptions and behaviours towards persons with albinism, attributed to ENA's awareness campaigns and advocacy work.

- *"When they came to my community to talk about albinism, people stopped insulting me the way they used to."* (*Female Respondent, D4*)
- *"In my community, after the programme, people started greeting me and treating me better."* (*Male Respondent, D6*)
- *"The radio discussions helped. People in my town called me by my name, not insults."* (*Female Respondent, D3*)
- *"The durbar they organised made my chief speak on our behalf, and now the community respects me."* (*Male Respondent, D7*)

Yet some participants felt the change was not always long-lasting:

- *"It helps for a short time, but later some go back to the old ways."* (*Male Respondent, D6*)

These accounts demonstrate that ENA's interventions had a visible community-level impact, though sustaining the change remained a challenge.

Broader Social Inclusion and Opportunities

Finally, participants noted broader impacts on social inclusion, such as being accepted in schools, workplaces, and leadership spaces. Interventions created opportunities that would have been closed to them without ENA's support.

- *"Because of ENA, my teachers now understand better and they don't punish me when I can't see the board."* (*Female Respondent, D10*)
- *"They involved us in community meetings, and I felt like I was part of decisions for the first time."* (*Male Respondent, D6*)
- *"I learnt soap-making through their programme. It has helped me get some money on my own."* (*Female Respondent, D6*)
- *"My family is now proud of me because I contribute small money from the training ENA gave."* (*Male Respondent, D7*)
- Still, limitations were noted:
- *"The opportunities are good, but they reach only a few people. Many of us are still left out."* (*Female Respondent, D9*)

This indicates that while ENA's interventions expanded inclusion and opportunity for some PWAs, scaling up remains essential.

The analysis shows that ENA's interventions had a meaningful impact on empowerment, community attitudes, and social inclusion. Beneficiaries reported greater confidence, reduced stigma, and expanded opportunities. However, the impacts were uneven and sometimes short-

lived, pointing to the need for more sustained and scaled-up programming. Overall, the interventions did not only meet immediate needs but also influenced longer-term social dynamics in ways that aligned with the aspirations of PWAs.

4.6 sustainability of the interventions and their potential for long-term continuation beyond project support.

Sustainability was a less frequently discussed theme, but participants did reflect on whether Engage Now Africa's (ENA) interventions could last beyond the organisation's direct involvement. Their accounts revealed two contrasting perspectives: optimism about lasting change through knowledge and empowerment, and concern about dependency and discontinuity.

Perceived Continuity through Empowerment and Knowledge

Some participants expressed confidence that the skills, knowledge, and social changes introduced by ENA would endure even if material support ended.

- *"The awareness they created in schools will not go away. Teachers and students now understand us better."* (*Female Respondent, D3*)
- *"The things I learnt, like soap-making, I can continue even if ENA is not here."* (*Female Respondent, D6*)
- *"Because of the education and advocacy, my community will not go back to the old ways completely."* (*Male Respondent, D7*)

These reflections suggest that interventions promoting skills, knowledge, and attitude change were perceived as having longer-term benefits that could persist without direct external input.

Concerns about Dependency and Discontinuity

Other respondents, however, were less optimistic, pointing to concerns that many interventions—particularly health-related ones—would not continue without ENA's regular support.

- *"If they don't bring the sunscreen, we cannot get it anywhere else. That means we will suffer again."* (*Male Respondent, D6*)
- *"Sometimes they stop the support for some months, and then things become difficult for us."* (*Female Respondent, D9*)
- *"The help is good, but it depends on ENA. When they are not around, everything stops."* (*Male Respondent, D7*)

These accounts highlight fears that without consistent institutional or government backing, interventions may not be sustainable in the long run. Overall, participants' reflections indicate that sustainability remains the weakest link in ENA's interventions. While educational advocacy, community sensitisation, and skills training were perceived as having lasting impacts, health-related support—particularly sunscreen provision—was seen as dependent on continued external input. This suggests that for long-term sustainability, stronger partnerships with government agencies, local institutions, and supply chains are needed to ensure continuity and reduce dependency on a single NGO.

CHAPTER FIVE

DISCUSSION

5.1 Interventions by Engage Now Africa for Persons with Albinism

The study shows that Engage Now Africa (ENA) implements a well-rounded package of interventions for persons with albinism (PWAs) in Ghana. These include health support (sunscreen, creams, eye care), educational assistance (scholarships, fees, materials), advocacy and awareness (community sensitisation, radio, programmes), and livelihood/empowerment through skills training. This mix aligns with what PWAs report as their immediate and pressing challenges in skin protection, vision, stigma, schooling, and economic independence.

Comparatively, global literature shows similar intervention patterns. In many contexts, programmes for PWAs often begin with skin and vision health interventions and educational support. Franklin *et al*. (2018) found that children with albinism in sub-Saharan Africa face significant skin and eye health issues, and interventions commonly prioritize dermatological care and educational inclusion before broader livelihood programming. Reimer-Kirkham *et al*. (2024) also emphasize that advocacy and policy must go hand in hand with tangible supports like health and education if interventions are to have sustainable impact.

In African studies, evidence similarly highlights that support for PWAs tends to centre on health, education, and stigma reduction. Franklin *et al*. (2018) document that across several African countries, children with albinism receive skin protection, vision aids, and school support but still face gaps in assistive devices and livelihood training. Regional assessments also note that while awareness campaigns are common, livelihood support is less frequent and often limited in scale

(GPE KIX, 2024). This mirrors the pattern observed in ENA's programming, where advocacy and education feature strongly but livelihoods are less consistently delivered.

Within Ghana, studies affirm the importance of these interventions. Daklo (2021) highlights that health needs, financial burdens, and knowledge deficits are among the strongest challenges facing PWAs, which ENA's interventions attempt to address. Similarly, the Alternative Report on Persons with Albinism in Ghana to the CRPD notes that inclusive education, scholarships, and sensitisation remain priority areas, but also stresses persistent gaps in assistive devices and consistent resourcing (Africa Albinism Network, 2024). These findings converge with participants' accounts in this study, showing that while ENA fills important service gaps, sustainability and comprehensiveness remain limited.

The implications are clear: ENA is broadly aligned with global and African best practices for supporting PWAs in terms of intervention domains. However, there is a need to strengthen livelihood components, expand access to assistive devices, and institutionalise consistent educational accommodations such as large-print materials and teacher training. For policy, Ghana's ministries of health and education should collaborate to integrate these interventions into state provision, reducing dependence on NGO initiatives. Comparative experiences suggest that where governments invest in inclusive teacher training, regular provision of assistive devices, and integrated health–education programming, outcomes for PWAs are more sustainable and equitable.

5.2 Relevance of ENA's Interventions

The findings indicate that Engage Now Africa's (ENA) interventions are highly relevant to the lived realities of persons with albinism (PWAs) in Ghana. Participants consistently emphasised two main areas where ENA's support was most aligned with their expressed needs: educational

support and health protection, particularly sunscreen provision. Education emerged as a critical domain because of challenges such as poor vision, stigma in school environments, and financial barriers, while sunscreen was identified as indispensable for managing daily exposure to the sun and preventing severe burns. The direct testimonies of participants confirm that these interventions not only matched their priorities but also filled service gaps not adequately met by state systems. However, concerns were expressed about inconsistency, partial coverage, and uneven distribution of benefits, suggesting that while relevance is high, adequacy remains a challenge.

Global research strongly supports the centrality of education and health interventions for PWAs. The United Nations Independent Expert on the enjoyment of human rights by persons with albinism has repeatedly stressed that education and healthcare are the two most urgent areas requiring intervention for PWAs worldwide (United Nations Human Rights Council, 2019). Studies further show that poor vision and photosensitivity create barriers to educational attainment unless targeted supports, such as large-print materials and visual aids, are provided (Hong *et al*., 2020). Health-related needs, especially sunscreen provision, are globally recognised as a life-preserving intervention, given the high risk of skin cancer among PWAs in tropical regions (Wright *et al*., 2017). This aligns with the priorities expressed by ENA's beneficiaries in Ghana, who stressed that without sunscreen, their daily functioning was compromised.

In the African context, the relevance of education and sunscreen interventions is equally well documented. Franklin *et al*. (2018) highlight that across East and Southern Africa, PWAs frequently drop out of school due to poor vision, stigma, and financial burdens, and interventions providing fee support and school sensitisation directly improve retention. Similar studies in Tanzania and Malawi have shown that consistent provision of sunscreen and protective clothing not only reduces medical costs but also improves quality of life (Brocco, 2016). These findings

converge with the Ghanaian case, where ENA's sunscreen distribution and scholarships directly targeted beneficiaries' most pressing vulnerabilities. However, the African evidence also suggests that many programmes struggle with sustainability and coverage, echoing participants' concerns in this study.

At the national level, Ghanaian studies corroborate the high relevance of ENA's interventions. Daklo (2021) emphasises that access to healthcare and financial support for education are among the most urgent needs for PWAs, and NGO interventions such as scholarships and sunscreen provision are therefore well-targeted. The Africa Albinism Network's (2024) report to the CRPD similarly highlights that educational assistance and health protection remain the two areas of greatest need, although coverage is often patchy and assistive devices (such as eyeglasses) are underprovided. This corresponds with participants' calls for continuity and for extending interventions beyond sunscreen to include other health-related supports like regular eye care.

The implications for practice and policy are significant. ENA's interventions demonstrate that aligning support with the sta

ted priorities of PWAs enhances programme relevance and beneficiary trust. However, the unevenness in coverage highlights the need for stronger institutional partnerships to ensure consistency. At the policy level, integrating sunscreen provision into Ghana's National Health Insurance Scheme (NHIS) and ensuring inclusive education policies that provide learning aids could strengthen the long-term relevance of interventions. Global evidence suggests that when governments integrate sunscreen and inclusive education into formal policy frameworks, programmes are not only more relevant but also more sustainable (Hong *et al*., 2020).

5.3 Effectiveness of ENA's Interventions

The findings from this study showed that ENA's interventions were generally effective in improving the well-being of persons with albinism (PWAs), though the extent of effectiveness varied across domains. Educational outcomes were the most consistently highlighted, with scholarships, fee support, and advocacy ensuring school retention and completion for many beneficiaries. Health outcomes also improved through the provision of sunscreen, medical support, and health education, which allowed participants to better manage skin conditions and reduce sun-related risks. Advocacy campaigns were described as effective in reducing stigma, with participants reporting changes in peer and community behaviour. However, effectiveness was not uniform; respondents noted that interventions were sometimes inconsistent, not reaching all in need, and that the reduction in stigma was often temporary.

Globally, research affirms that the effectiveness of interventions for PWAs depends on their ability to address systemic barriers while being consistent and long-term. Lund and Gaigher (2016) established that educational interventions are effective when they incorporate both financial and institutional support, allowing children with albinism to complete schooling despite vision challenges. More recent evidence suggests that health-focused interventions such as sunscreen distribution and clinical outreach directly reduce the risk of skin cancers and improve daily quality of life for PWAs in sun-intense regions (Hong *et al*., 2020). However, international studies also caution that stigma reduction is most effective when advocacy is continuous and embedded in community structures rather than one-off campaigns (Wan, 2021). This resonates with the Ghanaian findings, where participants valued sensitisation programmes but noted that their impact often faded with time.

African evidence further supports the mixed but positive picture of effectiveness. Franklin *et al*. (2018) found that scholarships and targeted financial aid effectively kept children with albinism in school across Malawi and Tanzania, but gaps remained in providing learning aids and vision devices. Brocco (2016) observed that sunscreen distribution programmes in Tanzania reduced health risks but their effectiveness was undermined by irregular supply. Similarly, community sensitisation initiatives in Malawi were effective in reducing stigma in schools, but had limited reach in rural areas where myths and harmful practices remained deeply entrenched (Lund and Njoka, 2016). These findings mirror the Ghanaian case, where ENA's health and education interventions were effective at the point of delivery but constrained by coverage and continuity.

In Ghana, recent research underscores both the successes and challenges of such interventions. Daklo (2021) highlights that sunscreen provision by NGOs improved skin health outcomes for PWAs but could not be sustained without consistent supply. The Africa Albinism Network's (2024) report confirms that scholarships and fee support are highly effective in preventing school dropout but stresses that effectiveness is compromised by the absence of complementary supports like magnifying glasses, protective hats, and braille or large-print materials. On stigma reduction, Ahadzi (2020) found that sensitization campaigns reduced ridicule in schools and improved teacher attitudes but did not eliminate discrimination in broader community life. This aligns closely with participants' accounts in the present study, who reported reduced teasing in schools but lingering insults within neighborhoods.

The findings have the following implications. First, effectiveness is clearly enhanced when interventions directly target the barriers identified by PWAs, such as education costs and health needs. However, limited coverage and irregularity undermine impact, suggesting the need for integration of NGO efforts with state provision. Second, stigma reduction requires not only

awareness campaigns but also structural measures, such as embedding disability and albinism sensitisation into school curricula and community development programmes. Ultimately, the Ghanaian evidence demonstrates that ENA's interventions are effective in transforming lives, but scaling and embedding these initiatives in broader systems would ensure more consistent and lasting impact.

5.4 Impact and Sustainability of ENA's Interventions

The findings showed that ENA's interventions generated meaningful impacts at both the individual and community level. Beneficiaries described improvements in empowerment and self-confidence, positive shifts in community attitudes, and broader opportunities for social inclusion. Participants noted that scholarships, counselling, advocacy, and skills training enabled them to see themselves as capable of contributing to society. In communities, sensitisation campaigns helped reduce stigma, with chiefs, teachers, and peers beginning to treat PWAs with greater respect. At the same time, participants highlighted limitations: empowerment was sometimes partial, stigma reduction was not always sustained, and opportunities reached only a few. These impacts, though significant, were uneven and often constrained by the scale of interventions. Sustainability emerged as a weaker dimension. While knowledge-based interventions such as advocacy and skills training were perceived as continuing beyond ENA's direct support, beneficiaries worried that essential health provisions, especially sunscreen, were entirely dependent on external supply. This contrast between perceived continuity of empowerment and fragility of health-related support reflects a wider structural challenge.

Globally, empowerment and social inclusion are recognised as central impacts of well-designed interventions for PWAs. The United Nations Independent Expert on albinism has noted that advocacy and awareness programmes often transform perceptions and enable PWAs to participate

more fully in education and civic life (United Nations Human Rights Council, 2019). Studies in Latin America and Europe have shown that skills training and peer support programmes enhance self-confidence and reduce isolation (Kiprono *et al*., 2019). However, global evidence also confirms that stigma reduction requires continuous reinforcement; without sustained programming, discriminatory behaviours often return (Wan, 2021). The sustainability challenge identified in Ghana is similarly echoed worldwide. Research in countries such as Tanzania, Kenya, and South Africa shows that sunscreen provision is rarely institutionalised within public health systems, leaving PWAs dependent on NGO or donor supply (Hong *et al*., 2020). This parallels the Ghanaian accounts of reliance on ENA for sunscreen, which beneficiaries feared would collapse if the NGO withdrew.

African studies reinforce these findings. Franklin *et al*. (2018) document how advocacy campaigns in Malawi and Tanzania helped reduce ridicule in schools and communities, but effects were uneven, with rural areas experiencing slower change. Brocco (2016) observed that stigma reduction in Tanzania was strongest when community leaders publicly endorsed inclusion, echoing Ghanaian testimonies about the role of chiefs in durbars. Empowerment through vocational skills training has also been reported in Nigeria and Kenya, where NGOs offered soap-making, tailoring, and ICT skills to PWAs, enabling some to gain livelihoods (Mwanri *et al*., 2017). Yet, like Ghana, African studies consistently show that sustainability is undermined by over-reliance on NGOs. Sunscreen provision, in particular, remains a major gap: Wright *et al*. (2017) found that inconsistent supply left many PWAs unprotected despite initial improvements.

At the Ghanaian level, research corroborates the mixed picture of impact and sustainability. Daklo (2021) found that NGO-led sensitisation reduced open ridicule and improved teacher attitudes, but stigma persisted in family and neighbourhood contexts, echoing the partial impact noted by

participants here. The Africa Albinism Network (2024) similarly highlights empowerment through scholarships and training, but stresses that these benefits remain limited in reach. Sustainability concerns are equally documented. Ahadzi (2020) reported that while school sensitisation programmes changed peer attitudes, the absence of systemic follow-up meant these impacts faded over time. Sunscreen provision in Ghana is almost entirely NGO-dependent, and its exclusion from the National Health Insurance Scheme (NHIS) represents a structural gap that undermines sustainability.

The implications are clear. ENA's interventions generate real and valued impacts, empowering individuals, shifting community attitudes, and opening opportunities for inclusion. Yet these gains are fragile when not embedded in larger systems. For sustainability, there is a pressing need to institutionalise key supports. Integrating sunscreen into NHIS benefits, embedding albinism sensitisation in school curricula, and linking vocational training to state and private-sector job schemes would help extend the longevity of interventions. At the same time, advocacy must move from episodic campaigns to continuous engagement with community leaders, schools, and families. Without such systemic anchoring, the impacts observed will remain significant but uneven, and sustainability will continue to depend on the limited resources of NGOs.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

This study examined the interventions implemented by Engage Now Africa (ENA) for persons with albinism (PWAs) in Ghana, analysing their relevance, effectiveness, impact, and sustainability through the OECD-DAC framework. The findings show that ENA's interventions addressed the most urgent needs of PWAs, particularly in health, education, and stigma reduction. Scholarships and fee support prevented school dropouts and created opportunities for progression, while sunscreen provision and health education mitigated the severe risks of sun exposure. Advocacy and sensitisation reduced ridicule in schools and communities, and skills training promoted empowerment and livelihood opportunities.

Overall, the interventions were found to be highly relevant and effective in improving life outcomes for PWAs. They generated significant impacts by enhancing self-confidence, reducing stigma, and enabling greater participation in social and community life. However, sustainability emerged as the weakest dimension. While knowledge, advocacy, and skills-based initiatives have potential for continuity, essential health interventions remain heavily dependent on ENA and are not integrated into state systems.

The study concludes that ENA's interventions are critical, but their long-term value depends on systemic integration, stronger partnerships, and sustained government ownership. Ensuring continuity requires aligning NGO contributions with national health, education, and social protection policies.

6.2 Recommendations

1. ENA should ensure continuous and equitable distribution of sunscreen, hats, and eye-care materials to avoid interruptions that expose beneficiaries to health risks. Forming partnerships with dermatology clinics, pharmacies, and local producers can improve long-term availability.
2. Regular community sensitisation should be expanded to include practical demonstrations on skin protection, early detection of lesions, and eye-care management. This will build local capacity and reduce over-reliance on periodic NGO visits.
3. Beyond scholarships, ENA should advocate teacher training, and school policy adjustments to make classrooms more inclusive for PWA. Collaboration with the Ghana Education Service can institutionalise these supports.
4. Vocational programmes should be scaled up and linked to micro-finance or cooperative groups to ensure participants can convert training into sustainable income.
5. ENA's sensitisation campaigns should adopt long-term, behaviour-change communication strategies to reinforce acceptance of PWA and prevent relapse of stigma after campaigns.
6. To reduce donor dependency, ENA should pursue strategic partnerships with the Ministry of Health (MoH), National Council on Persons with Disability (NCPD), and corporate sponsors to mainstream albinism support within national disability and health programmes.

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APPENDICES

Appendix I: Interview Guide: Lived Experiences of Persons with Albinism in Ghana

1. Can you please tell us about yourself, your name, age, level of education, what you do for a living, and your marital status?
2. How would you personally describe albinism?
3. When and how did you first become aware that you had albinism?
4. Are there any myths or superstitions about albinism in your community that you're aware of?
5. Have any of these beliefs or superstitions ever affected you personally? If yes, in what ways?
6. Can you share with us some of the challenges you've faced as someone living with albinism?
7. Have you had any difficulties when it comes to your education, work, or relationships?
8. What kinds of health challenges do you face—particularly with your eyes or skin?
9. Can you describe any economic challenges you've faced, such as finding work or being employed?
10. What do you think are the reasons why it may be difficult for people with albinism to get employed in your area?
11. Have you ever experienced stigma or discrimination because of your condition? Can you share specific experiences?
12. How do people in your community treat persons with albinism today? Has this changed over time?
13. How do your peers or family members relate to you as someone living with albinism?
14. What has helped you cope with the challenges you face? What keeps you going?
15. Have you received any support—financial, emotional, or practical—from your family or friends?
16. Have you ever received support from any organizations?
17. Have you heard of Engage Now Africa (ENA)? If yes, how did you first come into contact with them?

18. Can you describe the nature of your engagement with ENA?
19. What kind of conversation did you have with ENA representatives, and how did it make you feel?
20. Have you participated in any of ENA's programs or events, like International Albinism Day?
21. Has your interaction with ENA had any lasting impact on your life? If so, in what way?
22. What do you think ENA could do to improve its work with persons living with albinism?
23. Do you use any protective resources like sunscreen, special clothing, or eye lenses? How do you manage your skin and eye care?
24. How often do you visit the hospital for health concerns related to your albinism?
25. Are there any helpful services, organizations, or networks in your community that support people with disabilities?
26. Have you ever received special treatment or favors because of your condition?
27. What aspirations do you have for yourself in the future?
28. What hopes do you have for the albinism community more broadly?
29. How do you think ENA or other NGOs can help you achieve your personal goals?
30. What message would you like to share with the general public about albinism?
31. What advice would you give to someone newly diagnosed with albinism who may be going through challenges similar to yours?
32. Is there anything else you would like to share with us that we haven't discussed?

Appendix II: Interview Guide for Students with Albinism Benefiting from Interventions-Focus Group)

Background

1. How old are you, and what class are you in?

Talk briefly about ENA interventions (educational support, sensitization, livelihood support)

2. Have you noticed any changes in how your classmates or teachers treat you since the interventions began?

Probes

- How many friends do you have at school?
- Tell me about how you play with them?
- Do you always have fun with them?

3. Do you feel more included in school activities after the interventions? Can you give examples?
    - Which school activities are you involved in?
    - How did you get involved in this activity?
4. How has the intervention helped you take better care of your health, especially related to albinism?

    -(eye care, skin care)

ENA interventions

5. Can you describe the support or interventions you received through the albinism campaign? ***Probe: (e.g., educational support, medical care, etc.)?***
6. How did these interventions help you? ***Probe: In your daily life at school? Outside school?***
7. Did the educational support (e.g., financial assistance, learning materials, skin or eye care services) make a difference in your studies? ***Probe: How? And how did it help you?***
8. How has the intervention affected your performance or confidence in the classroom? ***Probe: Can you see any changes in your performance since the intervention? Are you able to understand what is taught and pass your exams after the intervention?***

9. How did the interventions affect how you feel about being a student with albinism at this school?
10. Did you face any challenges or difficulties in accessing the support provided by the intervention?
11. What do you think could be done better to support students with albinism in the future?
12. Is there anything else you'd like to share about how the interventions have impacted your life, both at school and outside of it?

Thank you for your time.

Appendix III: Ethical Clearance

ENSIGN GLOBAL
UNIVERSITY

OUR REF: ENSIGN/IRB/EL/SN-300/03
YOUR REF:

August 4, 2025

INSTITUTIONAL REVIEW BOARD SECRETARIAT

Edmund Enam Amoabeng
Ensign Global University
Kpong.

Dear Edmund,

ETHICAL CLEARANCE TO UNDERTAKE POSTGRADUATE RESEARCH

At the General Research Proposals Review Meeting of the *INSTITUTIONAL REVIEW BOARD (IRB)* of Ensign Global University held on Friday, August 1, 2025, your research proposal entitled **"Exploring the Perceptions and Effectiveness of Engage Now Africa's Interventions for Persons Living with Albinism in Ghana"** was considered.

You have been granted Ethical Clearance to collect data for the said research under academic supervision within the IRB's specified frameworks and guidelines.

We wish you all the best.

Sincerely,

Dr. (Mrs.) Rebecca Acquaah-Arhin
IRB Chairperson

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