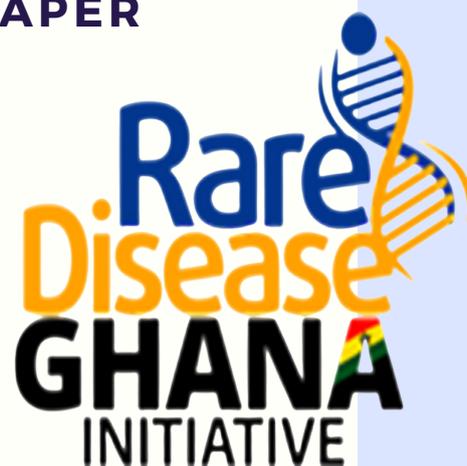




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NATIONAL HEALTH POLICY
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HEALTH COVERAGE FOR
RARE DISEASES AND THE
UNDIAGNOSED?

A POSITION PAPER





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INTRODUCTION

The Constitution of the World Health Organisation (1946) states that ‘the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition’. This powerful and transformative statement is reiterated in the Constitution of the Republic of Ghana which recognizes health as a right of all citizens¹, and it comes to life in the country’s new National Health Plan.

To address the health challenges faced by the largest proportion of the population, Ghana’s public health policies have historically prioritized infectious diseases, perinatal and maternal mortality, and treatment of malnutrition. While the expansion of public health services has resulted in significant positive change in the health of the average citizen in the 21st century, considerable gaps remain, and are particularly felt by persons living with rare diseases and their families.

On 2 November 2020, President Nana Akuffo-Addo launched the new National Health Policy (NHP). The policy is expected to provide clear strategic direction to the Ministry of Health over

¹ According to Article 34 Clause 2 of the 1992 Constitution, ‘The President shall report to Parliament at least once a year all the steps taken to ensure the realization of the policy objectives contained in this Chapter; and, in particular, the realization of basic human rights, a healthy economy, the right to work, the right to good health care and the right to education’



the next 10 years, and strengthen universal health coverage, ensuring all Ghanaians can access quality healthcare and services without financial hardship.

For those living with rare conditions often neglected by national health strategies, the new National Health Policy brings the promise of better integration and cover from the public health system. In this article, the [Rare Disease Ghana Initiative \(RDGI\)](#)², a national NGO for rare diseases, examines the potential impact of the new National Plan and its promise of Universal Health Coverage. It also offers recommendations to ensure the new policy meets its commitment to all people, including persons living with undiagnosed, genetic and rare diseases.

THE REALITY OF RARE DISEASES IN GHANA

The challenges faced by persons living with rare diseases in Ghana are pervasive and reflect the urgent need for investment in health infrastructure, financing/payment for healthcare services, information management and research.

Rare diseases are often chronic, complex and heavily disabling. The impact of rare disease is exacerbated by delayed and inconsistent access care and therapies. Due to the genetic nature and chronic course of a majority of rare diseases, disability may occur in childhood, progress in severity, and reduce life expectancy.

The journey to diagnosis is interminable and financially crippling for many families confronting life with a rare disease. Pathways to diagnosis and treatment are unclear and often require patients and families to see numerous medical professionals and be referred from one facility to the other, before ultimately accessing limited tertiary institutions and specialized care.

² The Rare Disease Ghana Initiative is the national NGO leading advocacy, and coordinating care for persons living with undiagnosed, genetic and rare disorders in Ghana. RDGI brings together patients, caregivers, health professions and rare disease organisations to advocate for national frameworks to better support individuals and families affected by rare disease.



Furthermore, equipment and expertise needed to diagnose rare diseases are frequently unavailable in the public healthcare system, and patients and families routinely face considerable out-of-pocket costs for diagnosis and treatment.

This burden of financial risk is especially worrying considering that only 35% of Ghanaians are enrolled in the National Health Insurance Scheme³. Moreover, for patients with rare diseases covered by the scheme, the financial protection offered by the national plan is relatively low, covering mainly consultation fees and essential services. Outpatient care, long-term physical therapy, imaging procedures, and other expenses are paid directly by patients or covered by donor agencies.⁴

THE REVISED NATIONAL HEALTH POLICY

The new National Health Policy is developed within the context of Ghana's medium-term policy development framework, as well as the Coordinated Programme of Economic and Social Development Policies (2017-2024)

While the previous National Health Policy (2007) sought to expand the focus of health which had been largely curative to include health promotion and prevention of ill-health, the scope of the revised edition recognizes the wider operational definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity".⁵ It adopts a comprehensive description that encompasses preventive, promotive, curative, rehabilitative and palliative services which is particularly important for persons living with rare diseases who often have unique and specific needs.

³ National Health Policy (p 18, 2020)

⁴ Such donor agencies include Rare Disease Ghana Initiative, One in 5000 Foundation, Hemophilia Society of Ghana, OI Ghana Foundation, ShareCare etc.

⁵ Constitution of the World Health Organisation (pp1, 1948)



The implementation of a holistic and extensive approach to health expressed in the NHP is essential to achieving Universal Health Coverage. In September 2019, Ghana, together with the other 192 Member States of the United Nations, endorsed the UN Political Declaration on Universal Health Coverage, committing to giving special attention to vulnerable and marginalized segments of the population, including strengthening efforts to address rare diseases.

UHC will not be truly universal unless the needs of people living with rare diseases are addressed, and the new plan is a concerted effort to expand the scope of healthcare to better address the challenges of groups historically neglected by national programs. However implementation of the plan and allocation of resources will determine whether Ghana meets the goal of UHC and strengthens the country's health systems to adequately address persons living with complex and rare conditions.

ADDRESSING THE CHALLENGES FACED BY PERSONS LIVING WITH A RARE DISEASE

- **Equity not equality**

Though the policy document does not mention 'rare diseases' by name, the healthcare system has to address the challenges faced by this group and recognize that the complexity of rare diseases requires equally complex strategies and approaches to health and social care. The needs of persons living with rare diseases can only be addressed on the basis of equity as their challenges and needs often differ from what is appropriate for the majority of the population.

- **Access to holistic care**

The country's new health policy aims to address inequities and gaps in the health system through support and promotion of rehabilitation and palliative care services as well as 'ensuring that challenges of access to care by persons with any form of disability, including discrimination and



stigmatization, are removed'. Furthermore, the NHP promotes the availability and use of high-quality assistive devices and technologies without significant out-of-pocket costs.

However, policy implementation will be critical and should include:

- Increase in the number of centres with rehabilitation services, especially in rural communities.
- Greater subsidization of costs of healthcare services. Outpatient palliative and rehabilitation services are currently billed per consultation and are not totally covered under the National Health Insurance Scheme (NHIS) with patients paying a percentage. Considering that rare diseases are chronic and may require multiple sessions, which can put a strain on family's finances in the long run. In addition, costs associated with rare disease diagnosis and laboratory investigations are inadequately covered by under the national scheme.
- Improving physical access to facilities for persons with limited mobility and other disabilities i.e. wheelchairs, ramps and disability-friendly furniture and fixtures

THE WAY FORWARD

The revised National Health Policy highlights equity within the broad approach to UHC and states clearly that the healthcare system will be supported to provide quality and affordable healthcare services. The forward-thinking and inclusive nature of the NHP is commendable, especially with regards to strengthening health systems to better cater for vulnerable persons and the development of socially supportive and integrated societies. However implementation of the policy will require increased investment and resource allocation to ensure that all people can access expert care without suffering financial hardship and will need meaningful inclusion of all relevant stakeholders including civil society.



With the challenges of persons living with rare diseases in Ghana being multifactorial, strategic partnership between government, civil society organisations and patient advocacy groups is crucial for proper implementation of the new national health policy, ensuring no one is left behind.

Due to their low prevalence and lack of awareness within the healthcare system and society at large, addressing the challenges posed by rare diseases such as delayed diagnosis, lack of proper care coordination and stigma, will require dialogue and partnerships with CSOs already working with families living with rare diseases and supporting Ghana's rare disease community.

THE RARE DISEASE GHANA INITIATIVE

The Rare Disease Ghana Initiative is the national NGO leading advocacy, and coordinating care for persons living with undiagnosed, genetic and rare disorders in Ghana. We bring together patients, caregivers, health professions and specific rare disease organisations to advocate for national frameworks to better support individuals and families affected by rare diseases.

We are active members of global rare diseases initiatives including Rare Diseases International (RDI), the International Rare Diseases Research Consortium (IRDiC), and Undiagnosed Diseases Network International (UDNI). Collaboration with the international rare diseases community provides opportunity for resource and knowledge sharing, policy formulation and technical supports for national projects.

Over the years RDGI has partnered with different organizations to develop a number of projects to help promote awareness of rare diseases; develop, seek wide endorsement and advocate for the implementation of a plan to support education, research, service development and increase support for affected individuals and their families.



Rare Disease Ghana Initiative also manages a therapeutics program with the aim of providing resources and assistance for effective management and treatment of rare diseases in Ghana. This program hopes to introduce new and existing therapies which are promising to the Ghanaian community. The organization also provides resources and support to rare disease families to enable them to access these therapies.

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