Rare diseases: a global health priority for equity and inclusion

罕見疾病：推動全球健康衛生之平等與共融的當務之急

The Executive Board, having considered the report of the Director-General,

Decided to recommend to the Seventy-eighth World Health Assembly the adoption of the following resolution:

執行委員會已審議總幹事的報告[1]，

決定建議第 78 屆世界衛生大會通過以下決議：

The Seventy-eighth World Health Assembly,

Having considered the report by the Director-General;

第 78 屆世界衛生大會，

已審議總幹事報告；

Recognizing that a rare disease is often described as a specific health condition affecting 1 in 2000 individuals or fewer in general population, and that there are currently over 7000 known rare diseases impacting more than 300 million people globally, with 70% of these conditions starting in childhood; and that, while the frequency of most rare diseases can be described by prevalence, some rare diseases can be more precisely described by incidence;

一般而言，罕見疾病被界定為特殊健康狀況，每兩千人中不到一人患病。目前已知的罕見疾病超過七千種病類，影響全球三億多人，其中約七成於兒童時期發病；即使多數罕見疾病之發生率可用「盛行率(prevalence)」來解釋，但部分罕見疾病可更加精確地以「發生率(incidence)」來定義；

Noting that rare diseases are often complex and multisystemic, affecting multiple organs and leading to comorbidities, and that many of these conditions are chronic,

[1] 執行委員會是世界衛生大會的執行機構，審議總幹事的工作報告，為執行委員會的主要任務之一。另有規劃預算、接納新會員國和討論其他重要議題等任務。

progressive and can consequently result in serious disabilities and premature death;
罕見疾病通常相對複雜且為多重系統，連帶影響多種器官並引發併發症，許多為慢性、長期症狀，可能嚴重損害身心功能或早逝；

Recognizing that some persons living with a rare disease have disabilities, which may have a greater impact on their health, and that they may also face various barriers, which may hinder their full and effective participation in society on an equal basis with others;
考量部分罕見疾病患者同時具有身心障礙狀況，為健康帶來深遠影響，日常生活中可能遭遇諸多障礙，因此患者難以有平等的機會投入社會參與；

Recognizing also that, in addition to the physical impact, some persons living with a rare disease, their families and caregivers may experience discrimination and psychosocial consequences such as isolation, stigmatization and limited opportunities for social inclusion, which are often intensified by a lack of public awareness and knowledge, and the absence, limited scope or poor implementation of policies and social support;
認知到罕見疾病除了造成生理層面的影響，有些病友、家屬及照顧者，亦時常面臨歧視、孤立、汙名，以及社會參與受限等心理社會層面的困境；同時，又常因社會大眾對罕見疾病缺乏認識與理解，加之政策與社會支持不足、涵蓋範圍有限或執行不彰等因素，讓處境更加艱難；

Recognizing further that persons living with a rare disease (including those whose disease is undiagnosed), their families and caregivers may be psychologically, socially and economically vulnerable throughout their life course, facing specific challenges in several areas, including but not limited to physical and mental health, education, employment, financial well-being and leisure;
此外，進一步認知到罕病患者（含尚未確診者）、家屬與照顧者，在人生各階段皆可能陷於心理、社會及經濟的脆弱處境，並遭遇不同層面的困難，諸如心理健康、教育、就業、經濟安全及休閒生活等面向；

Emphasizing the importance of adopting a holistic patient-centred approach to address the needs of persons living with a rare disease, focusing on enhancing their functioning and working with society to remove, to the extent possible, the barriers they face in accessing health, education, employment and other domains of life;
應特別強調實踐以病友為中心的全面性照顧策略，聚焦於提升罕病患者的生活功能；並應與社會各界共同努力，盡可能消弭罕病患者在醫療、教育、就業及生活各面向所面臨的種種障礙；

Noting that the high prices of many health products for rare diseases, and inequitable access to such products within and among countries, as well as the financial hardships associated with their high costs, pose significant challenges for some persons living with a rare disease;
另外，許多罕見疾病藥物與醫療照護產品價格不菲，無論在各國或國際間，取得相關資源的管道亦不均等，加上高額費用帶來的財務壓力，實為罕病患者的生存帶來嚴峻挑戰；

Recognizing from an equity perspective that women and children living with a rare disease encounter greater challenges in accessing care, including the late diagnosis, biases in symptom assessment, and reduced access to timely and appropriate treatment, which significantly impact their quality of life and overall health outcomes;
以社會公平的角度而言，女性與兒童罕病患者在醫療照護上面臨更多挑戰，如延遲確診、症狀評估的偏誤，或較難取得即時且適當的治療等，深刻影響病患生活品質與整體健康；

Recognizing also the importance of achieving universal health coverage, including for persons living with a rare disease and their families and caregivers, and that universal health coverage implies that all people have access, without discrimination, to nationally determined sets of essential quality health services, from health promotion to prevention, treatment, rehabilitation and palliative care, as well as essential, safe,

affordable, effective and quality medicines, vaccines, diagnostics and health technologies, including assistive technologies, ensuring that the cost of using these services does not lead to financial hardship;
認知到實現全民健康覆蓋之重要性，實應涵蓋罕見疾病患者、家屬與照顧者。全民健康覆蓋意指所有人皆能在免受歧視的情況下，獲得國家提供之佳醫療照顧服務，包含健康促進、預防、治療、復健及緩和醫療等，並能獲得必要、安全、有效、可負擔且品質穩定的藥品、疫苗、診斷工具與醫療科技（含輔具），確保人民不因使用上述服務而陷入經濟困境；

Recognizing further the importance of implementing integrated care, considering the health system along with social and community services, for enabling persons living with a rare disease to achieve optimal health and well-being;
推動整合性照顧服務的重要性，應一併將醫療體系與社區支持服務納入考量，以協助罕見疾病患者實現最佳健康狀態與生命福祉；

Acknowledging that to enhance physical and mental health, well-being and life expectancy for everyone, it is essential to achieve universal health coverage, including persons living with a rare disease;
進一步強調為提升全民身心健康、福祉與預期壽命，落實全民健康覆蓋至關重要，尤其務必涵蓋罕見疾病患者；

Recalling in particular the United Nations Sustainable Development Goal target 3.8 (Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all), the United Nations political declaration of the high level meeting on universal health coverage (2019),5 which includes rare diseases, and the political declaration of the high-level meeting on universal health coverage (2023),6 reaffirming the commitment to ensure that no one is left behind, and other universally agreed resolutions and declarations;

基於聯合國永續發展目標 3.8 項下之目標（實現全民健康覆蓋，包括財務風險保障、優質的基本健康照顧服務，以及安全、有效、優質且全民可負擔的生活必需藥品與疫苗）、2019 年聯合國全民健康覆蓋高階會議政治宣言中，強調納入涵蓋罕見疾病，以及 2023 年全民健康覆蓋高階會議政治宣言中，重申「不會遺漏任何人」的承諾，及其他具國際共識之決議與宣言；

Recalling also United Nations General Assembly resolution 76/132 (2021) on addressing the challenges of persons living with a rare disease and their families, which paved the way for greater integration of rare diseases into the agenda and priorities of the United Nations system;
同時，聯合國大會於 2021 年通過之第 76/132 號決議，該決議回應罕見疾病患者及其家庭所面臨之挑戰，為罕見疾病進一步納入聯合國體系之正式議程及優先項目，奠定了重要基礎；

Noting that reaching the correct diagnosis can take over five years, that many persons living with a rare disease never receive a timely or adequate diagnosis, although nearly half of genetic diseases start in childhood, and that insufficient screening programmes, including newborn screening, and unequal access to diagnostic services, infrastructure and expertise contribute to delayed diagnosis and management;
特別是許多罕見疾病患者，往往需歷經五年以上的時間方能獲得正確診斷，甚至有相當比例的患者，終其一生無法獲得及早或適當的診治；儘管近半數遺傳疾病於童年時期發病，但因篩檢計畫不足（包含新生兒篩檢），加上診斷服務、專業人力與基礎設施資源不均等因素，均可能延誤疾病診斷與後續照顧處置；

Noting also that for undiagnosed persons with a suspected rare disease, entering a coordinated diagnostic and research pipeline offers a unique hope to speed up diagnosis, as recognized by the International Rare Diseases Research Consortium;
此外，對於尚未確診、但疑似罕見疾病的患者而言，透過聯合診斷及研究管道，能為早期確診增添一線希望，此點亦已獲得國際罕見疾病研究聯盟（IRDiRC）認

同；

Recalling resolution WHA76.5 (2023) on strengthening diagnostics capacity, which recognizes that diagnostic services are vital for the prevention, diagnosis, case management, monitoring and treatment of communicable, noncommunicable, neglected tropical and rare diseases, and which emphasizes equitable access to diagnostics for all, and highlights the importance of diagnostics for healthcare service delivery, ranging from prevention to treatment, as well as access to research projects on diagnostics;

基於第 76 屆世界衛生大會於 2023 年通過之第 76.5 號決議，強調應「強化診斷量能」，並指出診斷服務對於傳染病、非傳染病、少受重視之熱帶疾病及罕見疾病之預防、診斷、個案管理、監測與治療等，皆具有不可或缺的重要性，並重申全民應平等享有接受診斷服務之權利；此外，亦進一步強調診斷之於整體醫療照顧體系的核心角色，涉及預防、治療及相關研究計畫等階段，對提升健康照顧品質與推動研究創新具有關鍵意義；

Recalling also resolution WHA75.8 (2022) on strengthening clinical trials to provide high-quality evidence on health interventions and to improve research quality and coordination, in which the Health Assembly called on Member States, inter alia, “to encourage the targeting of clinical trials towards the development of health interventions that address public health priorities and concerns of global, regional and national importance, including communicable and noncommunicable diseases, with a focus on the health needs of developing countries, and that evaluate the safety and efficacy of health interventions, including having special regard to common diseases in low- and middle-income countries, unmet medical needs, rare diseases and neglected tropical diseases”;

並且，基於第 75 屆世界衛生大會於 2022 年通過之第 75.8 號決議，旨在「優化臨床試驗」，提供最佳實證資料以利實施醫療措施、提升研究品質與系統合作流暢度。世界衛生大會於決議中鄭重呼籲各會員國：「應積極推動臨床試驗，優先

聚焦於全球、區域與國家等層級之公共衛生發展議題，包含傳染病、非傳染病，並應特別重視發展中國家的醫療需求，深入評估醫療介入措施之安全性與效益，且特別關注中低收入國家之常見疾病、迫切醫療需求、罕見疾病及少受重視的熱帶疾病」；

Recalling further resolution WHA77.2 (2024) on social participation for universal health coverage, health and well-being, in which the Health Assembly urged Member States, inter alia, to strive "to ensure that social participation influences transparent decision-making for health across the policy cycle, at all levels of the system";
另，第 77 屆世界衛生大會於 2024 年通過之第 77.2 號決議，聚焦於「促進社會參與」對實現全民健康覆蓋、醫藥衛生與生命福祉之重要性，並呼籲各會員國，「應確保各層級體系之政策制定過程中，能使社會參與發揮其價值與影響力，並促進衛生決策過程之透明化」；

Recalling resolution WHA77.5 (2024), in which the Health Assembly invited Member States, inter alia, to consider implementing a universal newborn screening programme, including comprehensive screening for congenital disorders; and recognizing the importance of early detection programmes, including those for prevention and mitigation of health conditions that may result in disabilities, while also addressing the specific needs and considerations for diagnosis, management, and long-term care that meets the needs of affected children;
而第 77.5 號決議則呼籲各會員國，「應推動全民新生兒篩檢計畫，如全面篩檢先天性疾病；體認到早期治療計畫的重要性，以利預防、降低導致身心障礙的風險因子；並顧及病童在診斷、醫療照護與長期照顧等方面的特殊需求與處遇」；

Recognizing that early identification can prevent the onset of disease symptoms or delay the progression of both common and rare diseases, thereby reducing child mortality and morbidity, improving the quality of life of persons living with a rare disease and conferring significant benefits on them, their families, their caregivers and

society as a whole;
認知到無論對一般疾病或罕見疾病而言，早期診斷皆能預防症狀發生，或延緩疾病進程，從而降低兒童死亡率與發病機率，提升罕見疾病患者的生活品質，並為病患自身、家庭、照顧者及整體社會帶來實質效益；

Acknowledging the disparity of resources between rural and urban areas within and among countries, the limited availability and geographical dispersion of rare disease specialists and centres of expertise, along with the lack of patient pathways, referral systems and effective knowledge-sharing platforms, which hinders necessary consultations with specialists on diagnosis and optimal patient care, thereby resulting in suboptimal clinical management for persons living with a rare disease;
然而各國及國際間城鄉資源並不平等，加上罕見疾病專科醫師與醫學中心有限、分布不均，且缺乏明確就醫流程、轉診機制及有效的資訊共享平台，致使病患難以及早獲得專業診斷與適切診治，進一步降低臨床照護品質；

Noting that due, in part, to limited resources for research, diagnosis and treatment along with the insufficient equitable investment and financial incentives for drug development in rare diseases, more than 95% of rare diseases still lack an effective treatment;
注意到由於罕見疾病在研究、診斷與治療方面資源有限，加上對罕藥研發領域的投資與財務誘因匱乏，現今逾 95%的罕見疾病仍缺乏有效治療方法；

Acknowledging that even when treatments and care are available, high costs may often lead to delayed, inconsistent and inequitable access;
不過，即使有治療方法與照護資源，高額費用仍造成患者延遲就醫、治療中斷，且無法公平地取得相關資源；

Acknowledging also that rare diseases fall within the scope of the WHO's Fourteenth General Programme of Work, 2025–2028, as well as the WHO's efforts to achieve the

goals outlined in its first strategic priority of extending universal health coverage to one billion more people as stated in the WHO's Thirteenth General Programme of Work, 2019–2025, and in alignment with countries' national context and priorities;
罕見疾病已納入世界衛生組織第 14 期一般工作計畫（2025–2028）之範疇，亦與世界衛生組織第 13 期一般工作計畫（2019–2025）所揭示之策略目標方向一致，該目標係基於各國國情差異與政策基礎之上，致力於推動全民健康覆蓋至十億以上人口；

Acknowledging further that although each country, in line with its national context and priorities, faces unique challenges in meeting the needs of persons living with a rare disease, there are common issues, such as constrained health budgets and a shortage of specialized services, resources and expertise leading to health inequities within and among Member States, which collectively result in persons living with a rare disease worldwide often struggling to access the care and support they need;
進一步而言，即使各國因政策方針與國情差異，於罕見疾病領域所面臨之困境各有不同，但仍存有幾項共通議題，如醫療預算有限、個別化服務、醫療資源及專科醫師皆極度匱乏等，使會員國國內及國際間皆存在醫療資源不平等的困境，連帶影響全球多數罕見疾病患者難以獲得迫切需要之醫療與支持服務；

Highlighting the WHO's commitment to promote health equity and support Member States in ensuring that all persons living with a rare disease, regardless of their condition, receive timely and appropriate healthcare services;
強調世界衛生組織致力於促進健康平等，並支持各會員國保障國內所有罕見疾病患者，不論其疾病狀況，皆能獲得即時且適切的醫療照護服務；

Emphasizing the critical need for global collaboration to tackle the unique challenges faced by persons living with a rare disease, and by their families and caregivers, especially mothers – including: the implementation of policies and programmes that prevent and combat stigma and social exclusion; accurate data collection; and increased

awareness – in line with countries' national context and priorities;
強調國際合作至關重要，盼基於各國國情差異與政策基礎之上，共同因應罕見疾病患者及其家庭與照顧者（特別是母親）面臨之特殊挑戰，諸如推行社會共融及去汙名之政策與計畫、精準資料蒐集，以及提倡大眾宣導等；

Recognizing the need to foster innovation that promotes social cohesion and reduces inequalities and discrimination, and to enhance research efforts and develop innovative therapies for rare diseases;
有必要提倡增進社會凝聚力、減少不平等與歧視的創新政策發展，並強化罕見疾病研究與創新療法之開發；

Underscoring the need to address the root causes of inequality and discrimination faced by persons living with a rare disease, their families and caregivers, and in this regard recognizing that there is a need for health policies and programmes to foster inclusion and create an environment conducive to respect for their rights and dignity;
強調必須正視罕見疾病患者及其家庭與照顧者，之所以面臨不平等與歧視的根本原因。衛生政策與相關計畫，應積極提倡包容性，致力營造尊重病患權益與尊嚴的友善環境；

Noting that rare diseases may lead to disabilities, and in this regard, recalling the principles embodied in the Constitution of the World Health Organization and the Convention on the Rights of Persons with Disabilities, and stressing the importance of their implementation, including inter alia through relevant policies, programmes and strategies at the national and international levels to promote inclusion and rights of persons with such disabilities;
有鑒於罕見疾病可能導致身心障礙狀況，《世界衛生組織憲章》與《身心障礙者權利公約》所體現之價值原則，強調各國與國際層級皆應透過相關政策、計畫或策略，積極實踐前述原則，以促進社會共融，並保障罕見疾病身心障礙者之權益；

Recalling United Nations General Assembly resolution 78/12 (2023) entitled "World Duchenne Awareness Day",7 in which the General Assembly decided to designate 7 September, the current World Duchenne Awareness Day, as a United Nations Day, recognizing that Duchenne muscular dystrophy is one of the most common paediatric genetic rare diseases, and encouraging Member States to raise awareness on the specific challenges and needs faced by persons living with a rare disease, their families and caregivers through national campaigns, educational programmes and information dissemination, with the goal of fostering greater understanding and empathy towards those affected by rare diseases and promoting global solidarity,

回顧聯合國大會第 78/12 號決議（2023 年）之「世界裘馨氏肌肉失養症宣導日」，大會決定將現行 9 月 7 日世界裘馨氏肌肉失養症宣導日指定為聯合國日。認知到裘馨氏肌肉失養症是最常見的小兒罕見遺傳疾病之一，鼓勵會員國透過全國性的宣導活動、教育計畫及媒體傳播，提高對罕見疾病患者、家庭與照顧者所面臨的挑戰與需求，希望促進大眾對罕見疾病更深的理解與同理，並推動全球團結一致。

1. URGES Member States, taking into account national context and priorities:
敦促會員國，根據各自國情與優先順序，考量以下事項：

(1) to commit:
承諾

(a) to providing appropriate support to WHO in developing a comprehensive global action plan on rare diseases;
提供世界衛生組織適當的協助，制定全面性的全球罕見疾病行動計畫；

(b) to integrating rare diseases into national health planning by developing and implementing national policies, effective programmes and actions, including developing primary and secondary evidence-based preventive actions and strategies aimed at preventing and improving healthcare services for persons

living with a rare disease through an integrated approach, ensuring equitable access to timely, cost-effective and affordable, available, accurate diagnosis, particularly for newborns through universal screening programmes, and the necessary cost-effective treatment, social and healthcare services;
將罕見疾病納入國家衛生規劃，制定並實施國家政策、有效的方案與行動，包括發展以實證為基礎的一級和二級預防措施與策略，以整合方式預防罕見疾病並提升醫療服務，確保病患（特別是新生兒）能平等地獲得及時、具成本效益、可負擔且準確的診斷，透過普及性篩檢計畫確保患者能夠獲得公平的治療和健康成本；

(c) to implementing effective programmes that promote mental health and psychosocial support for persons living with a rare disease, as well as policies and initiatives that enhance the well-being of their families and caregivers;
實施有效的計畫，以促進罕見疾病患者的心理健康與社會心理支持，並推動有助於提升其家庭與照顧者福利的政策與倡議；

(d) to accelerating efforts toward achieving and extending universal health coverage by 2030, ensuring healthy lives and well-being for all individuals, including persons living with a rare disease, throughout their life course, in order to stop the rise and reverse the trend of catastrophic out-of-pocket health expenditure as appropriate, by re-emphasizing the commitment to progressively provide persons living with a rare disease with quality essential health products, healthcare services, and affordable medicines, diagnostics and health technologies by 2030;
加速邁向 2030 年實現並擴大全民健康覆蓋的目標，確保包括罕見疾病患者在內的所有人，在整個生命歷程中都能享有健康生活與福利，並且，適當地遏止和扭轉高額自費醫療的趨勢；同時重申，在 2030 年前逐步為罕見疾病患者提供高品質的基本健康產品、醫療服務，以及可負擔的藥品、診斷工具與健康科技；

(e) to strengthening health systems, particularly in primary healthcare, to ensure universal access to a wide range of affordable and high-quality healthcare services for persons living with a rare disease, especially children;
強化衛生體系，特別是基層醫療保健，以確保罕見疾病患者，尤其是兒童，能普遍獲得多元、可負擔且高品質的醫療服務；

(f) to fostering the inclusion of relevant competencies in the pre-service education of students and lifelong learning of health workers in preventing, diagnosing, treating and managing rare diseases;
促進在學生的職前教育以及醫療人員的終身學習，納入與罕見疾病預防、診斷、治療與管理相關的專業能力；

(g) to further increasing awareness and education initiatives about rare diseases among healthcare providers, policy-makers and the public in order to promote understanding of and support for affected individuals;
更進一步提升醫療人員、政策制定者及社會大眾對罕見疾病的認知，以促進對罕見疾病族群的理解與支持。

(h) to removing barriers that persons living with a rare disease, their families and caregivers face in accessing safe water, sanitation and hygiene, including addressing physical, institutional, social and attitudinal obstacles, promoting appropriate measures to ensure equitable access for these individuals, their families and caregivers in both rural and urban areas;
致力於消除罕見疾病患者、家庭與照顧者在取得安全用水、健康與個人衛生方面所面臨的障礙，包括生理、制度、社會與態度上的困境，並推動適當措施，確保這些民眾及其家庭與照顧者，不論在城鄉都能公平地獲得相關資源。

(i) to considering, as appropriate, the development and utilization of digital

technologies,9 including telemedicine and data-sharing platforms in order to improve access to specialists and treatments, especially in remote areas or those with limited medical resources, ensuring that technologies are accessible;

考慮發展和運用數位科技，包括遠距醫療與資料共享平台，以改善醫療與治療的可近性，尤其是偏遠或醫療資源缺乏的地區。

(j) to promoting the involvement of patient organizations, peer support groups, organizations of persons with disabilities, including groups led by persons living with a rare disease, in policy development to ensure that the voices of those affected by rare diseases are heard and incorporated into decision-making processes;

促進病患組織、同儕支持團體、身心障礙者組織（包括由罕見疾病患者主導的團體）參與政策制定，確保罕見疾病患者的聲音能被聽見並納入決策過程。

(k) to facilitating the establishment, as appropriate, of dedicated national task forces or coordination bodies to oversee the implementation of policies related to rare diseases, enhancing accountability and effective management;

設立任務導向的國家工作小組或協調機構，以便監督與罕見疾病相關政策的執行，強化問責機制與有效管理。

(l) to encouraging the establishment of national, regional and international centres of excellence as specialized hubs for care, research and training for rare diseases;

鼓勵設立國內、區域和國際層級的學術中心，作為罕見疾病在照顧、研究與培訓方面的專業平台；

(m) to encouraging the establishment of a national registry for rare diseases, or

collaborating with existing international registries for rare diseases, as appropriate, to strengthen their capacity on data collection, analysis and disseminating disaggregated data on persons living with a rare disease, while respecting data protection and privacy, to achieve evidence-based decisions at all levels;

鼓勵建立國家級罕見疾病登錄系統，或與現有的國際罕見疾病登錄系統合作，可強化資料蒐集、分析與公開呈現分項資料的能力，同時尊重資料保護與隱私，以實現以證據為基礎的決策。

(n) to considering implementation of the eleventh revision of the International Classification of Diseases (ICD-11), and where appropriate, interoperable codification systems for rare diseases such as the Orphanet nomenclature of rare diseases, at their earliest possibility, and in accordance with their available resources, in order to enable the recording, reporting and monitoring of rare diseases at the national and international levels;

盡早推動實施第十一版《國際疾病分類》（ICD-11），導入通用的罕見疾病編碼系統，如 Orphanet 罕見疾病命名系統，以利各國之間進行罕見疾病的登錄、通報與追蹤。

(2) to encourage collaboration between policy-makers, governmental health and research authorities, academic institutions, clinicians, patient organizations, the private sector and civil society in order to foster innovation in research and innovative diagnosis and treatment that proactively address rare diseases;

鼓勵政策制定者、政府衛生與研究主管機關、學術機構、臨床醫師、病患團體、私部門與公民社會之間的合作，以促進研究創新和主動應對罕見疾病的創新診斷與治療方法；

(3) to support efforts to adopt innovative ways of funding and mobilize resources from all sources (for example, public and private funders) for integrated action on rare

diseases, including research and innovation, and to consider expanding opportunities, with a focus on developing countries;
支持創新資源籌措模式，協調各方資源（例如公共與私人贊助者）進行罕見疾病整合行動，尤其是針對開發中國家的研究、創新和擴大機會。

(4) to strengthen cooperation at the national, regional and international levels to promote equitable and timely access to affordable, safe, effective and quality medicines for all persons living with a rare disease across the world, leaving no one behind;
強化國內、區域與國際層級的合作，以促進全球所有罕見疾病患者能公平且及時地取得可負擔、安全、有效且有品質的藥物，確保沒有遺漏任何人；

(5) to bring high-level attention to rare diseases and related aspects within multilateral forums, as appropriate, to help ensure sustained and concrete political visibility and momentum, and explore ways in which to integrate rare diseases into health policy and programmes reflecting the national strategies and priorities;
在多邊論壇上，提請高層增加對罕見疾病的關注，以確保維持政治能見度，並探討如何將罕見疾病納入國家策略及優先事項的健康政策計畫；

(6) to regularly assess, where applicable, the implementation of their national action plans for rare diseases and, to the extent possible, evaluate their contribution to the implementation of regional action plans related to rare diseases;
定期檢視罕見疾病國家行動計畫的執行情形，在可行範圍內，評估其對罕見疾病區域行動計畫之貢獻；

2. REQUESTS the Director-General:
請求總幹事：

(1) to develop – in consultation with Member States, and in collaboration with

nongovernmental organizations including patients' organizations, academic institutions, in line with the Framework of Engagement with Non-State Actors, as applicable, and experts in rare diseases – a comprehensive 10-year draft global action plan for rare diseases, in alignment with the agreed strategic priorities of WHO and its Fourteenth General Programme of Work, 2025–2028, including all necessary preparatory work, and budgetary aspects, to be submitted for consideration by the Eighty-first World Health Assembly in 2028;

請發展－在諮詢會員國並與非政府組織（包括病患組織）、學術機構（在適用情況下，且須符合《與非國家行為者接觸架構》），以及罕見疾病領域專家合作下，制定一個全方位的十年全球罕見疾病行動計畫草案，該計畫應與世界衛生組織已商定的戰略優先事項及其《第 14 期總體工作規劃（2025－2028 年）》保持一致，並涵蓋所有必要的前置作業及預算，於 2028 年提交至第 81 屆世界衛生大會審議；

(2) to conduct preparatory work, including: mapping existing WHO standards, guidelines and protocols relating to rare diseases; providing an initial technical report on rare diseases; identifying technological innovation opportunities (including e-health, m-health, digital and artificial intelligence solutions) to centralize clinical health information for diagnostics and treatment;

請進行前置工作，包括：繪製現有 WHO 關於罕見疾病的標準、指引與操作規範圖；提供罕見疾病的初步技術報告；開發技術創新機會（包括科技健康、行動健康、數位與人工智慧解決方案），以集中臨床健康資訊以利診斷與治療；

(3) to establish a workstream promoting universal health coverage for persons living with a rare disease;

請建立工作流程，以促進罕見疾病患者的全民健康覆蓋；

(4) to identify centres of excellence around the world that are able to cluster clinical

work in certain rare disease groups and that can act as hubs to exchange experience and clinical knowledge and provide peer-to-peer medical reviews and advice, including across borders;
請找出全球的罕見疾病卓越中心，這些中心可作為經驗交流與臨床知識的樞紐，提供同儕間的醫療評估與建議，包含跨境合作。

(5) to ensure that the global action plan for rare diseases encompasses, but is not limited to, the following key components:
請確保全球罕見疾病行動計畫，涵蓋但不限於以下關鍵要素：

- a comprehensive framework to foster equitable access to timely, cost-effective, affordable, available, accurate diagnosis and evidence-based treatments, and an adequate management of rare diseases, aligned with the principles of universal health coverage as outlined in the United Nations political declarations of the high-level meetings on universal health coverage of 2019 and 2023, and taking into account the social determinants of health;
一個全面性的架構，旨在促進能公平地獲得及時、具成本效益、可負擔、可取得、準確的診斷和治療，以及對罕見疾病的適當管理，並與聯合國 2019 年與 2023 年高層會議有關全民健康覆蓋政治宣言中所述原則一致，並將會影響健康的社會因素納入考量；

- strategies for improving data collection, research and surveillance on rare diseases to enhance understanding, timely and confirmed early identification, including screening, diagnosis and treatment options in collaboration with Member States' national authorities, with the ultimate goal of sharing knowledge and data in the field and fostering investment in research;
改善罕見疾病相關資料收集、研究與追蹤的策略，以促進理解、及時與確定的早期發現，包括篩檢、診斷及治療選項，與會員國的國家主管機關合作，最終目標是共享該領域的知識與數據，並提升對研究的投資；

- guidelines for the establishment of national and regional registries to facilitate the screening, monitoring and management of rare diseases;
  建立國家及區域登錄系統指引，以促進罕見疾病的篩檢、追蹤與管理；

- global targets and strategic objectives, along with clear guidelines to improve access to affordable and equitable healthcare services for persons living with a rare disease, the essential health products needed for accurate diagnosis and effective treatment for persons living with a rare disease, as well as an accompanying process for accountability and monitoring to track implementation progress, including at the national level;
  有關全球目標與策略性目標，需有明確的指引配套，以改善罕見疾病患者獲得可負擔且公平的醫療服務可及性，涵蓋準確診斷與有效治療所需的基本健康產品，並同時設置責任與追蹤機制，以監測執行進展，以上皆需涵蓋至國家層級；

(6) to support Member States, upon request, in the development of national policy and strategies to enhance the health of persons living with a rare disease, including addressing the social and financial implications of supporting persons living with a rare disease in a sustainable and inclusive way;
請在會員國提出請求時，協助其制定提升罕見疾病患者健康的國家政策與策略，包括以可持續且具包容性的方式，支持罕見疾病患者的社會與財務面向；

(7) to submit a draft global action plan on rare diseases for consideration by the Executive Board at its 162nd session, with the intention of submitting this draft global action plan to the Eighty-first World Health Assembly for adoption;
請提交罕見疾病全球行動計畫草案供執行委員會第 162 屆會議審議，並計畫將該草案提交第 81 屆世界衛生大會通過；

(8) to report on the implementation of this resolution to the Seventy-ninth World

Health Assembly in 2026, through the Executive Board at its 158th session, and to submit progress reports to the Health Assembly in 2028 and 2030.

請透過執行委員會第 158 屆會議，向 2026 年第 79 屆世界衛生大會報告此決議的執行情形；並向 2028 年與 2030 年舉行的世界衛生大會提交進度報告。

Eighteenth meeting, 10 February 2025

第 18 次會議，2025 年 2 月 10 日

EB156/SR/18