



Retina
International

Report:
Retina International
**Global Genetic Testing
Patient Taskforce**

Phase 3 of the Retina International Genetic
Testing and Diagnosis Initiative

Report: Retina International Global Genetic Testing Patient Taskforce

Phase 3 of the Retina International Genetic Testing and Diagnosis Initiative

Contents

Background	3
Phase 1 and 2 – Data generation (2020-2021)	3
Phase 3: Global Genetic Testing Patient Taskforce (2022)	4
Objectives of Taskforce:	4
Scope	4
Meeting 1: Plenary Session on Barriers to Accessing Genetic Services	4
Meeting Objectives:	4
Output: Key Takeaways from Meeting 1	4
Meeting 2: Identifying and Prioritising the Solutions to Accessing Genetic Services	5
Meeting Objectives:	5
About OPERA	5
Output: OPERA Results	5
Internal Process: Developing the Indicators	6
What is an indicator?	6
Phase One – Preparation and Establishing a Framework	6
Phase Two – Development of Indicators within Framework	6
Output of Internal Process:	6
Meeting 3: Reviewing the Proposed Universal Indicators for access and delivery of Genetic Diagnostic Services	8
Meeting Objectives:	8
Output: Final Version - Retina International Universal Indicators for Access to and Delivery of Genetic Diagnostic Services	8
Output: Desired Further Outcome Statements	8

Retina International Universal Indicators for Access to and Delivery of Genetic Diagnostic Services.....	9
Using the Indicators	11
Scoring	11
Template Scoring Card:	12
Rationale.....	13
International Perspective	13
Dr. Petia Stratieva MD. PhD., Policy Manager, Retina International	13
Mr. Franz Badura, Chairperson, Retina International	13
Regional Perspectives.....	14
Claudette Medefindt, Retina South Africa	14
Dominique Sturz, Vice-Chair Pro Rare Austria, Chair ePAG ERN-Eye	14
Jane Cherry - Retina Australia, Retina International Youth Council, Graduate of RI Education Hub Programme.....	15
Eric Hartman – Director of Advocacy, CureCHM	15
Next Steps – Preparing Stakeholders for Policy Action	16
Conclusion	16
Acknowledgements.....	16
References	17

Background

IRDs are actionable conditions, and for patients, clinicians, and researchers alike, accurately diagnosing these conditions is critical. The Retina International community understands that to receive a comprehensive diagnosis, one must receive both a clinical diagnosis (phenotype) as well as genetic diagnosis (genotype), where possible. Clinical diagnostics are generally carried out by specialised Ophthalmologists, however, to receive a genetic diagnosis, one must engage with genetic services, which consists of a beginning to end process of genetic testing and genetic counselling combined. The process of accessing genetic services varies greatly globally and even regionally.

A genetic diagnosis is a prerequisite for IRD patients to be considered for inclusion in research studies and clinical trials. Through accessing genetic services and receiving a genetic diagnosis, patients can gain greater understanding of the inheritance patterns and disease progression associated with their condition, enabling them to make informed life planning decisions. Data from genetic testing is also essential to advancing research in retinal disease through developing registries that support natural history studies and clinical trial recruitment.

Retina International (RI) has observed a number of barriers to accessing genetic testing and counselling services for IRDs, which can vary from region to region. RI has undertaken a multi-phase initiative to investigate and take action on access to genetic testing and diagnosis for IRDs. To date, three phases of this initiative have been completed. The first two Phases revolved around generating real-world data that would support an evidence-based approach to advocacy.

Following these studies, RI formed a special interest taskforce representing 16 countries with a view to reviewing the data, consulting on future policy actions for the community, and developing a set of universal policy indicators. These policy indicators are designed to provide a framework for advocacy work on genetic testing for IRDs at global and national levels, as well as enable cross-sector collaboration with clinical and research stakeholders, as well as other disease groups with similar needs.

This report details the processes and outputs of this taskforce, as well as the next steps in this multi-phase initiative.

Phase 1 and 2 – Data generation (2020-2021)

To support its actions, RI conducted two global studies to investigate and generate data on the current genetic testing and counselling landscape by way of processes and patient experience. Phase 1 (2020) examined processes of accessing genetic testing and counselling, and Phase 2 (2021) collected over 400 global responses on the patient experience of genetic testing and counselling.

Preliminary findings:

- Receiving a genetic diagnosis and counselling is a long and difficult process

- Greater **awareness and training** is needed for HCPs, patients, and their families on the benefits of genetic testing and counselling for IRDs
- Patients do not have equitable access to best practice genetic testing services for IRDs.

The data from these studies enables RI to develop effective advocacy campaigns for equitable, affordable, accessible and timely genetic testing services for IRDs.

Phase 3: Global Genetic Testing Patient Taskforce (2022)

RI undertook a 3-month Patient Taskforce initiative to develop global patient consensus, and co-create universal policy indicators for access to a genetic diagnosis. 21 representatives of members of Retina International from 16 countries took part. Countries represented included: Australia, Austria, Bulgaria, Brazil, Canada, Germany, Greece, Ireland, Italy, New Zealand, Russia, South Africa, Sweden, Switzerland, Turkey and the United States of America.

Objectives of Taskforce:

1. Compare and contrast regional and universal challenges regarding process and access to genetic diagnosis
2. Evaluate and prioritise best practices for process and access to genetic diagnosis
3. Design a set of universal policy indicators for process and access to genetic diagnosis
4. Consult on RI advocacy strategy for further genetic services policy actions.

Scope

- Identify challenges and best practices with regard to genetic services from a global perspective.
- Scope of discussion included accessibility, equitability, affordability, and timelines of genetic testing and counselling services.

Meeting 1: Plenary Session on Barriers to Accessing Genetic Services

January 2022

Meeting Objectives:

- Introduce Taskforce Members
- Outline Purpose, Scope and Objectives of Taskforce
- Plenary Discussion on Findings from Phase 1 and 2 Studies

Output: Key Takeaways from Meeting 1

- The experience of receiving a genetic test and genetic counselling should to be referred to as genetic diagnosis.
- There is a lack of referral to centres of expertise in genetic diagnosis by health care providers.
- There is a cohort of patients that have not engaged with health care providers, nor received a new genetic test in many years.
- There is a lack of clarity around what genetic counselling is from within the clinical and policy-making communities.
- Genetic counselling is often not recognised as a medical discipline.

- There is a lack of capacity for accessing genetic counselling.
- The sustainability of foundational support, and the public-private funding model for genetic testing and counselling is a limiting factor and threat to the continued, expanded provision of these services

Meeting 2: Identifying and Prioritising the Solutions to Accessing Genetic Services

February 2022

Meeting Objectives:

1. Develop ideas and suggestions for global indicators - Facilitation Technique: OPERA
2. Co-create first draft of global indicators

About OPERA

OPERA is an acronym that stands for OWN, PAIR, EXPLAIN, RANK, and ARRANGE. It is a meeting facilitation technique that enables consensus driven and engaged problem solving. This methodology was used during Meeting 2 of the RI Genetic Testing and Diagnosis Taskforce, with the goal of identifying and prioritising solutions to the barriers to accessing genetic testing and genetic counselling. Below is a step by step outline of the methodology. REFERENCE

1. The Task

The process starts with the presentation of the task, usually as an open question.

2. Own Suggestions

The participants ponder the leading question individually and note their own suggestions to addressing the question or task at hand.

3. Pair Suggestions

The participants discuss their thoughts and suggestions in pairs/small groups (this will be done via breakout rooms on Zoom), and decide together which suggestions will be presented to the entire group in step 4.

4. Explanations

Each pair/small group briefly explains to the rest of the audience the suggestions they have created together. The facilitator will record these suggestions on a digital work board.

5. Ranking

Each pair/small group selects, in accordance with agreed selection criteria, which suggestions that have been put forward they believe are the most important ones.

6. Arranging

When each pair has presented their ranked suggestions, the facilitator will arrange the suggestions according to themes, following the instructions of the participants. Following discussion, a consensus driven, ranked list of final suggestions will be assembled.

Output: OPERA Results

Proposed solutions developed using OPERA technique characterised by themes:

- Education and Awareness of all stakeholders
- Secure, expanded funding for genetic services
- Provision of universal tools, guidelines, and resources to be used at a local level
- Innovative solutions for addressing testing deserts, and pooling resources
- Collection of interoperable real world data at international scale

Internal Process: Developing the Indicators

Between Meeting 2 and 3, the RI executive team supporting this taskforce followed an internal process to analyse, organise, and structure the taskforce findings in a format conducive to their presentation as Universal Policy Indicators. This process was done in two phases, with the method of both outlined below. The first phase was to research and prepare, the second was the development of the indicators themselves.

What is an indicator?

A policy indicator is a quantitative or categorical measure that provides information on conditions and developments that are relevant for the policy making process. Given the heterogeneity of health systems globally, and to ensure the relevance and functionality and adaptability of these indicators for regional use, it was elected to use categorical measures, i.e., the measure listed is either in place fully, partially, or not at all, or is otherwise irrelevant.

Phase One – Preparation and Establishing a Framework

1. Align

- Identify Assumptions
- Define Terms
- Define requirements

2. Research

- Reference papers compiled and reviewed (see References)
- framework established

Phase Two – Development of Indicators within Framework

3. Review and Organise

- Proposed Solutions from Meeting 2 were characterised by Desired Outcomes
- Desired outcomes categorised by OECD policy “building block”

4. Draft

- Categorised outcomes developed and framed as Policy Indicators

5. Test and Refine

- Assess whether all talking points from Taskforce learnings can be argued for/defended adequately under existing Indicators

Output of Internal Process:

Following careful review of reference papers, an adapted version of the OECD (Organisation for Economic Co-operation and Development) building blocks was selected as a suitable framework for the RI Universal Policy Indicators to be developed. This building block framework was originally designed for implementation of the UN 2030 Sustainable

Development Goals, and as such fit criteria of being appropriate for categorical indicators that were transferrable to a diverse range of national and regional contexts, as well as being readily integrated into existing international commitments such as the SDGs.

The adapted building blocks, and a description of each building block's objective and purpose is as follows:

Political Commitment;

Ensuring that governments have a plan to provide equitable access to a genetic diagnosis for those living with IRDs, and that they intend to carry out

Policy Integration and Coordination;

Creation of efficient, intelligent policy solutions that allow and encourage different departments and tiers of government to collaborate and work synergistically. This building block also ensures that equitable access to genetic testing for IRDs is considered and protected during the development of all relevant new health policies.

Long-Term Perspective;

Futureproofing policies to ensure equitable access to genetic testing for those living with IRDs through sustainable funding, and fostering the multi-stakeholder networks required to support sustained policy implementation.

Stakeholder Engagement and Education;

Increasing awareness amongst all stakeholders about IRDs, the importance of genetic testing, and ways for patients to access it. This indicator also describes the need for structures and fora that enable stakeholders to advise and collaborate on policy development.

Monitoring and Reporting;

Generating data that supports research, policy implementation, and also ensures accountability of governments in fulfilling political commitments.

These building blocks and their descriptors were used as the basis from which the Universal Indicators were created.

Meeting 3: Reviewing the Proposed Universal Indicators for access and delivery of Genetic Diagnostic Services

March 24 2022

Meeting Objectives:

1. Review and Agreement on Final Indicators
2. Consult RI on Phase 4 of Initiative and establish Desired Further Outcome Statements

Output: Final Version - Retina International Universal Indicators for Access to and Delivery of Genetic Diagnostic Services

The full and final version of the Retina International Universal Indicators for Access to and Delivery of Genetic Diagnostic Services as developed by this Taskforce are available on page nine overleaf.

Output: Desired Further Outcome Statements

The desired outcomes as established by this taskforce from further advocacy work by RI and its membership on access to genetic testing and diagnoses are as follows:

Education and Awareness

- Consensus driven approach to advocacy
- Informed multi-stakeholder engagement
- Building partnerships for the future that strengthen the community
- Fostering innovative collaboration
- Reducing inequality

Funding

- Dedicated state funding for genetic services, including genetic testing services

Universal Guidelines for access and delivery of Genetic Diagnostics

- A standard operation procedure that ensures high quality of care and access to a genetic diagnosis, regardless of geography or circumstance.

Collection, curation, and utilisation of real world data at international scale

- Creation of universal international data hub
- Improved quality of care
- Generation of real world evidence that drives innovation

Retina International Universal Indicators for Access to and Delivery of Genetic Diagnostic Services

Building Block	Indicator
1. Political commitment	1.1 Existence of explicit commitment to ensure access to a genetic diagnosis as a standard of care for patients living with IRDs, that has been formally included into national legislation and/or national strategy and/or action plan.
	1.2 Regional governments publish a time-bound action plan for making progress to ensure access to a genetic diagnosis for patients living with IRDs as a standard of care.
2. Policy Integration and Coordination	2.1 Access to genetic diagnosis as a standard of care is systematically included in government’s proposals for health regulations or policies, and assessed against existing universal best practice guidelines as well as declarations such as the SDGs and UN Declaration for PLWRD
	2.2 Existence of a mechanism for cross-departmental, regional, and international coordination that allow ministries and public sector agencies to share data that optimise the quality of care for those living with IRDs
3. Long-term perspective	3.1 Provisions to ensure sustained efforts beyond electoral cycles, and that future government programmes and budget preparations include dedicated state funding for genetic diagnostic services
	3.2 There is a plan to build and strengthen cross-sectoral partnerships and dialogue with all stakeholders
4. Stakeholder engagement and education	4.1 There exists a framework that facilitates an informed, consensus driven approach to policy development that includes all stakeholders
	4.2 The government has a bespoke mandate to promote awareness on benefits, access, and delivery of genetic services for those living with IRDs to all relevant stakeholders
5. Monitoring and Reporting	5.1 Existence of formal provisions or mandates to regularly monitor and report progress on policy coherence, that are publicly accessible and used to adjust policy as appropriate
	5.2 Collection, curation, and utilisation of real world data derived from genetic testing, for the purposes of developing care pathways and driving research and innovation at an international scale.

Table 1. Retina International Universal Indicators for Access to and Delivery of Genetic Diagnostic Services

Using the Indicators

Using the indicators allows designing of advocacy strategies and implementation at a national and global level:

- The proposed indicators can be used as a self-assessment tool, to aid and support local advocacy efforts.
- Assessment can be carried out using the scoring rubric below to measure and track status and progression
- These assessments can be submitted to RI to be displayed on the Know Your Code website www.kyc.retinaint.org to promote and encourage international collaboration and information sharing.

Scoring

These categorical indicators are transferrable and can be used at a global, national, and regional advocacy level.

The scoring rubric below is adapted from the OECD Building Blocks Framework.

Colour	Score	Title	Description
White	0	Not applicable	The Indicator is not applicable to the context where the assessment takes place
Red	1	Not in place	The Indicator under assessment does not exist and there are no plans or actions for putting it in place
Orange	2	Building Block under development	The Indicator does not exist yet, but it is under development
Yellow	3	In place, not implemented	The Indicator is in place, but it is not implemented (e.g. statements of commitment, but no action)
Light green	4	In place, partly implemented	The Indicator is in place but the level of implementation is not complete.
Dark Green	5	In place, functioning	The Indicator under assessment is complete and relevant.

Table. 2 – Scoring Rubric for Universal Indicators

Template Scoring Card:

Building Block	Indicator	Colour	Score
1. Political commitment	1.1 Existence of explicit commitment		
	1.2 time-bound action plan		
2. Policy Integration and Coordination	2.1 Included in health policy as standard of care, and meets best practice guidelines		
	2.2 Cross-departmental and cross-tier coordination amongst governing bodies		
3. Long-term perspective	3.1 Sustainable and secure resourcing		
	3.2 A plan to develop reliable cross-sectoral and multi-stakeholder networks		
4. Stakeholder engagement and education	4.1 framework for consensus driven policy development		
	4.2 promote awareness on genetic services		
5. Monitoring and Reporting	5.1 regularly monitor and report progress		
	5.2 Collection, curation, and utilisation of real world data		
		TOTAL	

Table 3. Template Scoring Card for Indicators Assessment

Rationale

International Perspective

Dr. Petia Stratieva MD. PhD., Policy Manager, Retina International

There are over 300 genes responsible for IRDs. Most of these conditions are ultra-rare. The heterogeneity of these conditions makes the needs of the IRD community very specific. The indicators as described in this report have been created by patients, and are essential to empowering the IRD community to act on a global and a national level and ensure IRD-specific needs are considered by all governments.

These indicators provide an essential tool for effective networking of our IRD community with experts beyond the IRD space, centers of expertise, and patient organizations with similar needs in order to foster health care systems strengthening.

Strengthening health systems to adequately and equitably support those living with rare diseases is a global priority. These indicators allow, at the national level, to track progress on policy coherence, and fulfillment of international commitments such as:

- UN 2030 Agenda for Sustainable Development Goals (SDGs);
- UN Political Declaration on Universal Health Coverage (UHC), and most recently;
- UN Resolution on “Addressing the challenges of persons living with a rare disease and their families” (UN RES 76/132), adopted by consensus in December 2021 by the UN General Assembly. This UN Resolution calls upon Member States to strengthen health systems in order to provide universal access to a wide range of healthcare services and to increase support for research, by strengthening international collaboration and coordination of research efforts and the sharing of data.
- The World Health Organization’s 13th General Programme of Work 2019-2023 (GPW13) which includes strengthening healthcare systems by fostering collaboration, aggregating expertise, and delivering a patient-centered approach to multidisciplinary areas concrete steps toward UHC.

Mr. Franz Badura, Chairperson, Retina International

Retina International is proud to present this report on behalf of its global membership, marking a critical step in the journey to securing equitable access to a genetic diagnosis for those living with Inherited Retinal Degenerative conditions worldwide.

Retina International and its members have an established and long standing relationship with the wider research and HCP community who strive to bring therapies to those living with IRDs. With concerted effort over the past 50 years and more, there have been major advances in the field.

IRDs are now actionable conditions, and receiving a genetic diagnosis is a crucial element of enabling that action. Despite the clear benefits of genetic testing to the patient and research community, access to genetic services remains elusive to many living with IRDs. This can be due to pervasive challenges with resourcing, reimbursement, and awareness, that either funnel patients into an already overloaded system, provide financial barriers to accessing

these services, or result in patients not being referred to genetic services at all. These are challenges that coherent and integrated policy can address. These universal indicators allow the community to advocate for effective policies that enable equitable access to genetic services with a unified voice.

It is essential now that the entire community of patients, researchers, clinicians, and decision makers, unite as a single voice and use these indicators to advocate for equitable access to a genetic diagnosis for those living with IRDs.

Regional Perspectives

Members of the Retina International Global Genetic Testing Patient Taskforce share their views.

Claudette Medefindt, Retina South Africa

Retina South Africa welcomes the report on Genetic testing by the taskforce of Retina international.

South Africa is a unique mix of both 1st world and 3rd world societies and this is most apparent in our health care system. The affluent citizens have access to private medical funding, superb health care and Genetic counselling. Genetic testing is not covered and expensive private genetic diagnosis is funded by the patients.

More than 80 % of the population relies on the State health care system which is completely swamped by the HIV pandemic still raging in South Africa. The Covid pandemic only added to this dire state of inadequacy. Genetic counselling only is offered by a few State hospitals. A comprehensive Genetic Services guideline was drawn up in 2020 with contributions from all the genetic stake holders but has been totally ignored.

We know that the excellent genetic indicators in the report will add fuel to our Equity Plan for Vision that we are presenting to the State and Provincial Departments of Health. This report, coupled with the RI Cost of Blindness studies gives us the statistics to support our case for action. Retina International has determined the path, given us the ammunition and now it is up to the international retinal groups to use these tools to effect immediate change.

Dominique Sturz, Vice-Chair Pro Rare Austria, Chair ePAG ERN-Eye

Genetic Diagnosis Universal Indicators - Their relevance and their impact as seen by a European patient advocate for Usher Syndrome, Rare Eye Diseases and Rare Diseases

International and national RD-, RED- or IRD-action plans, fitted into national health strategies and implemented together with national vision related organisations and RD Alliances, with retinal experts and all vision related institutions and professionals and with political stakeholders should help to:

- Get funding for genetic diagnosis to be recognized as a standard of care diagnostic tool including genetic counselling as part of patients' rights to equal access to accurate diagnosis, treatment and (standard of) care - best practice early genetic diagnosis of

Usher Syndrome at age 3 to 6 months after detection of a hearing disorder at Newborn Hearing Screening in many EU countries

- Enhance referral to expert centres for genetic diagnosis by health care providers
- Implement minimum standard testing panel and guideline how to proceed with inconclusive results
- Recognize genetic counselling as a medical discipline attractive to junior MDs and recognize genetic testing always to be accompanied by genetic counselling
- Include patients not seeing eye experts on a regular basis and cover white spots (geographically) and build wider and reliable patient cohorts
- Build IRD patient registry, national and international FAIR* data hubs (Rare Disease Registries e.g. REDgistry at ERN-Eye, EU Health Data Space) to be connected to scientific research consortiums in order to
- Enhance therapeutic innovation and identify patients to give them timely access to clinical trials and upcoming innovative treatments and to adequate integrated care (e.g. automatic access to social services and benefits)

Genetic Diagnosis Universal Indicators proposed by Retina International Genetic Diagnosis Taskforce - A guide for a consistent strategy and for policy actions for patient advocates in the Rare Disease field in the EU context and at national levels.

* FAIR: Findable, Accessible, Interoperable, Reusable

Jane Cherry - Retina Australia, Retina International Youth Council, Graduate of RI Education Hub Programme

These indicators provide us a clear path towards a unified standard of care for those living with Inherited Retinal Diseases.

These building blocks open a number of possibilities for improving access to genetic diagnoses, formation of a standardised treatment plan, creation of global databases and enhanced knowledge sharing, all things that can completely alter the trajectory of younger generations living with IRDs.

The ability to have a global vision to advocate locally is a powerful thing.

Eric Hartman – Director of Advocacy, CureCHM

Access to genetic diagnosis as a standard of care is so very crucial both in the pursuit of research and in meaningful patient community support. Over 70% of our patient community were initially diagnosed with a different IRD before getting a Genetic diagnosis of CHM. The power of our global patient voice and our patient support must be based on definitive genetic diagnosis!

Next Steps – Preparing Stakeholders for Policy Action

In consultation with taskforce members, RIs next steps for this initiative include:

1. Engagement with medical stakeholders: Targeted and facilitated engagement with clinicians and other relevant health care providers, learned societies, and industry partners to drive multi-stakeholder consensus building.
2. Grassroots activation amongst patient advocacy network: Grassroots activation and collaboration with RI membership and International Rare Disease community members with same need to develop consistent approach, as well as development of centralised bespoke website portal [Know Your Code](#).
3. Project Management: Dedicated and concerted effort from the RI executive to ensure forward momentum of the project by continuing to coordinate, plan, manage, and report progress.

These actions will shape Phase 4 of the RI Genetic Testing and Diagnosis Initiative: Preparing Stakeholders for Policy Action, an ambitious multi-stakeholder project that will run from July 2022 to July 2023.

Conclusion

Retina International have undertaken a multi-phase initiative to address barriers and inequitable access to genetic testing for those living with IRDs. Following two global studies on the genetic testing landscape, RI called on its membership to assemble a taskforce that would review these data and developed a set of Universal Policy Indicators.

The indicators described in this report follow an established framework that support their use in a diverse range of national and regional contexts. For Retina International, these Indicators mark a pivotal point that will launch this multi-phase Genetic Testing and Diagnosis Initiative towards Policy Action, where RI will endeavour to build cross-sector collaboration with clinical and research stakeholders, as well as other disease groups with similar needs.

The outputs of this taskforce will shape future advocacy work in access to genetic services for those living with IRDs, and ensure a consistent and measurable approach for RI and its members.

Acknowledgements

Retina International would like to sincerely thank the RI Members and their representatives who dedicated their time, insight, and expertise to this taskforce.

References

Lam, B.L., Leroy, B.P., Black, G. et al. Genetic testing and diagnosis of inherited retinal diseases. *Orphanet J Rare Dis* 16, 514 (2021). <https://doi.org/10.1186/s13023-021-02145-0>

Black, G.C., Sergouniotis, P., Sodi, A. et al. The need for widely available genomic testing in rare eye diseases: an ERN-EYE position statement. *Orphanet J Rare Dis* 16, 142 (2021). <https://doi.org/10.1186/s13023-021-01756-x>

We Cultivate Blog. 2022. How to identify a collective way forward in simple steps (using OPERA process). [online] Available at: <https://wecultivate.wordpress.com/2016/02/25/how-to-identify-a-collective-way-forward-in-simple-steps-using-opera-process/> [Accessed 31 May 2022].

OECD (2018), "Eight building blocks for coherent implementation of the SDGs", in *Policy Coherence for Sustainable Development 2018: Towards Sustainable and Resilient Societies*, OECD Publishing, Paris, <https://doi.org/10.1787/9789264301061-5-en>

United Nations, 2015. *Transforming Our World: The 2030 Agenda for Sustainable Development*. New York: UN Publishing

Wright S, Mabejane R. The 2019 UN high-level meeting on universal health coverage. *The Lancet*. 2019;393(10184):1931. doi:10.1016/s0140-6736(19)30349-6

Addressing the challenges of persons living with a rare disease and their families:. United Nations Digital Library System. <https://digitalibrary.un.org/record/3953832?ln=en>. Published 2022. Accessed May 31, 2022.

World Health Organization. (2019). *Thirteenth general programme of work, 2019–2023: promote health, keep the world safe, serve the vulnerable*. World Health Organization. <https://apps.who.int/iris/handle/10665/324775>. License: CC BY-NC-SA 3.0 IGO