Towards A Disability Inclusive Health Reform In Malaysia

Recommendations To The Malaysian Health White Paper

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31 July 2023

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MINDAKAMI

DAWN
PERTUBUHAN ADVOKASI DAN KESEJAHTERAAN PEKAK MALAYSIA

Umi

MyBIM
Persatuan Bahasa Isyarat Malaysia dan Pengajian Pekak
Malaysian Sign Language and Deaf Studies Association

NowBIM
Pertubuhan Kebangsaan Pengajar Bahasa Isyarat Malaysia
National Organisation of Malaysian Sign Language Instructors

Towards A Disability Inclusive Health Reform In Malaysia

Table of Acronyms and Abbreviations

CRPD	Convention on the Rights of Persons with Disabilities
CSOs	Civil Society Organisations
GDP	Gross Domestic Product
HCPs	Healthcare Providers
JKM	Department of Social Welfare
JPOKU	Department of Development of Persons with Disabilities
KPWKM	Ministry of Women, Family and Community Development
MCMC	Malaysian Communications and Multimedia Commission
MINDEF	Ministry of Defence
MOH	Ministry of Health
MOHE	Ministry of Higher Education
NCDs	Non-Communicable Diseases
NHMS	National Health and Morbidity Survey
OPDs	Organisations of Persons with Disabilities
PWLE	Persons with Lived Experiences
PWDs	Persons with Disabilities
SDH	Social Determinants of Health
SDGs	Sustainable Development Goals
SRH	Sexual and Reproductive Health
TWG	Technical Working Group
WCAG	Web Content Accessibility Guideline
WHO	World Health Organisation

EXECUTIVE SUMMARY

We, the community of Malaysians with disabilities, alongside our family members, care partners[1], our organisations and allies, wholeheartedly support the Malaysian Government's commitment to reform the Malaysian healthcare system. We, as the users of local healthcare services and facilities, face various barriers to accessing healthcare in Malaysia, in the form of structural environmental barriers, process barriers, and socio-demographic barriers.

The COVID-19 pandemic widened and amplified the inequalities in the healthcare sector. Until today, the consequences remain hindering persons with disabilities, senior citizens, care partners and other marginalised groups. The current systemic inequities are also compounded by the rise of mental health issues among the Malaysian community and the increasingly terrifying effects of climate change.

However, the reform of the Malaysian healthcare system should be guided by appropriate fundamentals so the reform will be substantial, transformative and meaningful to Malaysian citizens, especially persons with disabilities, senior citizens, care partners and other marginalised communities. We strongly urge that the health reform agenda must adopt:

- The social model of disability, which shifts from individuals' impairment to barriers that exist in society (e.g., attitudinal, physical, technological, structural, socio-cultural) as the causes of disability;
- Social determinants of health; and,
- Health as a fundamental human right.

To fully embrace and strategically translate the social model of disability and the recognition of the rights of persons with disabilities, senior citizens and other marginalised communities in the implementation of the reform goals as outlined in the Health White Paper, we strongly urge the Ministry of Health (MOH) to take the following Principal Actions:

1. Establish continuous platforms for rights-based consultation with persons with disabilities, organisations of persons with disabilities and other relevant stakeholders.
2. Appointing at least three (3) representatives of persons with disabilities and care partners into the MOH Health White Paper Council.
3. Appointing at least three (3) representatives of persons with disabilities and care partners in each Technical Working Group (TWG) which will be established soon.

[1] A care partnership is a two-way process that involves mutual giving and receiving. We use the term 'care partner' because it emphasizes the relationship and equal partnership between the person giving care and the person receiving it, and focuses on the dignity of both parties.

It is very crucial to understand that every pillar and sub-pillar outlined in the Health White Paper is relevant to the well-being of persons with disabilities, senior citizens, their family members, care partners and other marginalised communities. This recommendation paper put forward poignant measures according to the predetermined pillars, sub-pillars, and the phases of reform as outlined in the Health White Paper.

We implore MOH to seriously consider and integrate the Principal Actions and recommendations presented in this paper. We look forward to more engagement and the inclusion of persons with disabilities, senior citizens, care partners and other marginalised communities, as well as their representative organisations in the health reform agenda.

CONTEXT SETTING

The WHO Global Report on Health Equity for Persons with Disabilities estimated that 1.3 billion people, accounting for 16% of the global population, live with significant disabilities[2]. In Malaysia, the National Health and Morbidity Survey (NHMS) in 2019 found the prevalence of adults with disabilities is at 11.1% with one in every four adults living with functional difficulties[3].

Only 637,537 persons with disabilities are registered officially with the Department of Social Welfare as of January 31, 2023[4], which is about 1.9% of the Malaysian population, far smaller compared to WHO estimation. It is important to understand that registration of persons with disabilities with the Department of Social Welfare is not mandatory in Malaysia. Furthermore, there are select groups of individuals living with impairments and health conditions that are not recognised as disabled by the Department of Social Welfare. Societal stigma and discrimination against persons with disabilities within our society, particularly in education and employment, also plays a big part in the low registration numbers.

According to WHO's estimates, there were 1 billion people aged 60 years and older in 2019[5]. Approximately 11.1% of the Malaysian population or 3.6 million people aged 60 years and older in 2022[6]. The Department of Statistics projected that Malaysia will be an ageing nation

[2] Global report on health equity for persons with disabilities - https://www.who.int/publications/i/item/9789240063624
[3] Institute for Public Health (IPH), National Institutes of Health, Ministry of Health Malaysia. 2020. National Health and Morbidity Survey (NHMS) 2019: Vol. I: NCDs – Non-Communicable Diseases: Risk Factors and other Health Problems, p. 237
[4] Jabatan Kebajikan Masyarakat - Statistik Pendaftaran OKU, 31 Januari 2023 - https://www.jkm.gov.my/jkm/index.php?r=portal/full&id=ZUFHVTB1NnJWM0EreGtwNC9Vb1hvdz09
[5] WHO: Ageing - https://www.who.int/health-topics/ageing#tab=tab_1
[6] Population Quick Info - 2022, Department of Statistics - https://pqi.stats.gov.my/search.php?tahun=2022&kodData=2&kodJadual=1&kodCiri=1&kodNegeri=Semua

by 2030 with individuals aged 60 years and above expected to reach 15.3% of the population[7].

By this estimation, approximately 31.3% of the population will have disabilities or enter the cohort aged 60 years and above by 2030. When we consider their family members and care partners, this demographic will make up nearly half of the Malaysian population.

The purpose of presenting this context is to underscore to the Government of Malaysia, specifically the Ministry of Health (MOH), the utmost importance of the necessity of our recommendations, the basis of which are our combined lived experiences, referenced data and publications.

We firmly believe that, in order to achieve the goal of reforming the health system into one that is equitable, supportive, and compassionate, the MOH must fully comprehend and integrate several key frameworks put forward by disability rights movements, both within the country and globally.

Persons with disabilities are often unseen, unheard, and excluded from policymaking at all levels. Figure 1 below illustrates the cycle of inaccessibility that continuously affects persons with disabilities. This inaccessibility can emerge and reproduce in a subtle way or at a very basic level, such as stereotypes towards persons with disabilities among healthcare professionals and lack of accessible facilities in healthcare institutions, to the structural level, such as ableist provisions in health-related policies, laws and regulations or lack of funding on specific or inclusive health initiatives for the disabled community.

[7] The Star: M'sia may become an ageing nation earlier than expected, statistics show - https://www.dosm.gov.my/uploads/content-downloads/file_20221003121211.pdf

Figure 1: The Inaccessibility Cycle.

Source: @KamiSIUMAN twitter page

To better understand how inaccessibility affects persons with disabilities across different levels, we shall explain several key ideas as the fundamentals of this paper.

The Social Model of Disability

The idea that we must understand and embrace is the social model of disability. The social model of disability shifts the focus from individuals' impairment to hindrances, restrictions and expectations that exist in society and the environment. The Convention on the Rights of Persons with Disabilities (CRPD) recognises that "… disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".[8]

As an example: A person who uses a wheelchair becomes disabled where there is no support system that makes a wheelchair available and affordable, where buildings provide stairs instead of elevators or where there are no universally-designed washrooms.

[8] Convention on the Rights of Persons with Disabilities, Preamble, Para (e) - https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities

There are three main barriers in the healthcare system:

- Structural environmental barriers[9], such as inaccessible facilities, out-of-reach locations[10], unaffordable service costs and lack of accessible technologies;
- Process barriers[11], such as long waiting times, lack of knowledge and discriminatory practices among healthcare professionals and lack of sign language interpretation services; and,
- Socio-demographic barriers[12], such as individuals' level of education, culture and economic status.

These barriers are prevalent in Malaysia and significantly impact persons with disabilities, especially women.[13][14]

Social Determinants of Health

The second key idea is the Social Determinants of Health and its impact on the health and wellbeing of persons living with disabilities. The Social Determinants of Health (SDH)[15] refers to non-medical elements that surround and affect one's life since birth such as socio-economic status, social safety net, infrastructure and political system. Figure 2 below illustrates the breakdown of SDH components that affect one's health outcome.

[9] Van Rooy, G., Amadhila, E.M., Mufune, P., Swartz, L., Mannan, H., & MacLachlan, M., (2012). Perceived barriers to accessing health services among people with disabilities in rural northern Namibia. Disability & Society, 27(6), 761-775.
[10] Aizan Sofia Amin & Jamiah Manap. (2015). Geografi, kemiskinan dan wanita kurang upaya di Malaysia. Geografia: Malaysian Journal Society & Space, 11(7), 82-91.
[11] Scheer, J., Kroll, T., Neri, M. T., & Beatty, P. (2003). Access barriers for persons with disabilities. Journal for Disability Policy Studies, 13(4), 221-230.
[12] Ramjan, L., Cotton, A., Algoso, M., & Peters, K. (2015). Barriers to breast and cervical cancer screening for women with physical disability: A review. Women & Health.
[13] Alfa Nur Aini Erman Efendi. (2019). Akses, Partisipasi dan Pemerkasaan Penjagaan Kesihatan Wanita Kurang Upaya di Lembah Klang. Disertasi tidak diterbitkan.
[14] Alfa Nur Aini Erman Efendi, Kamal Solhaimi Fadzil, Khoo Ying Hooi. (2018). "Better die at home than here in this hospital": Exploring challenges of women with disabilities in accessing healthcare in Malaysia. *SARJANA*, 33(1), pp. 1-10.
[15] WHO: Social determinants of health - https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1

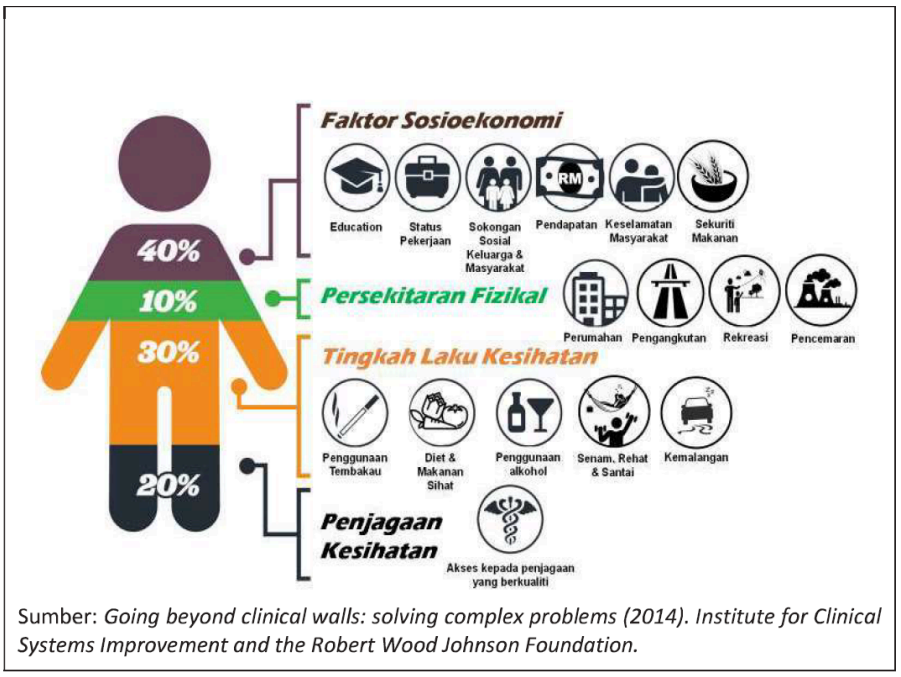

Figure 2: SDH from the Health White Paper

The social model of disability is inherently linked to the Social Determinants of Health. The SDH has to be closely examined to understand the factors that contribute to the exclusion and barriers faced by persons with disabilities. The SDH are also crucial for identifying, interrogating and providing a practical basis for developing solutions that advance the Malaysian health reform agenda.

Health as a Fundamental Human Right

The third key idea is that health is a fundamental human right. The right of persons with disabilities to health is guaranteed in the CRPD through Article 25 which states the following:

> States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:
>
> (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
>
> (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as

appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

(c) Provide these health services as close as possible to people's own communities, including in rural areas;

(d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

(e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

(f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Malaysia, as a signatory to both CRPD and the Sustainable Development Goals (SDGs), should proactively support the mainstreaming of disability issues[16] and they should be part of the decision-making process of all policies and programs[17].

Besides that, the rights of Malaysians living with disabilities to health is also protected through Section 35(1) of the Persons with Disabilities Act 2008 (Act 685) which states the following:

(1) Persons with disabilities shall have the right to the enjoyment of health on an equal basis with persons without disabilities.

Despite this, Malaysians with disabilities continue to face barriers that hinder their access to healthcare and the quality of healthcare that they receive. It is important that the MOH keeps these rights and the government's obligations in mind as it works on the health reform agenda.

[16] Convention on the Rights of Persons with Disabilities, Preamble, Para (g).
[17] Convention on the Rights of Persons with Disabilities, Preamble, Para (o).

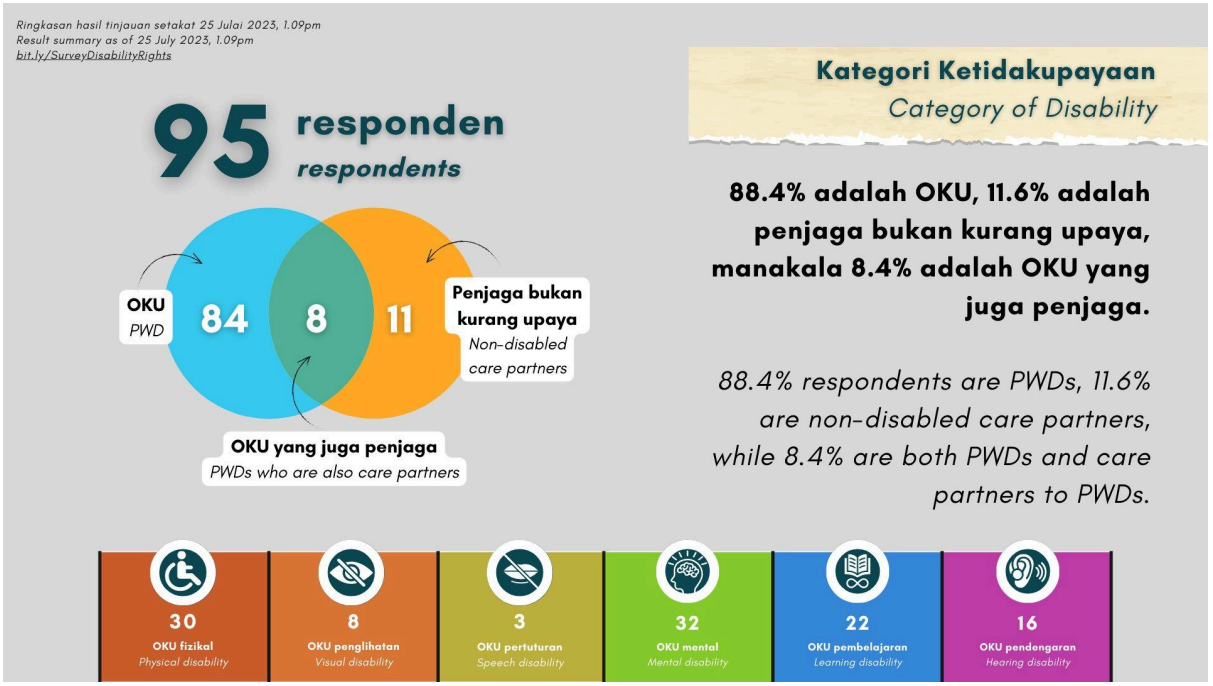

Figure 3: Demographics of survey respondents from SIUMAN's survey on Disability Rights in Malaysia

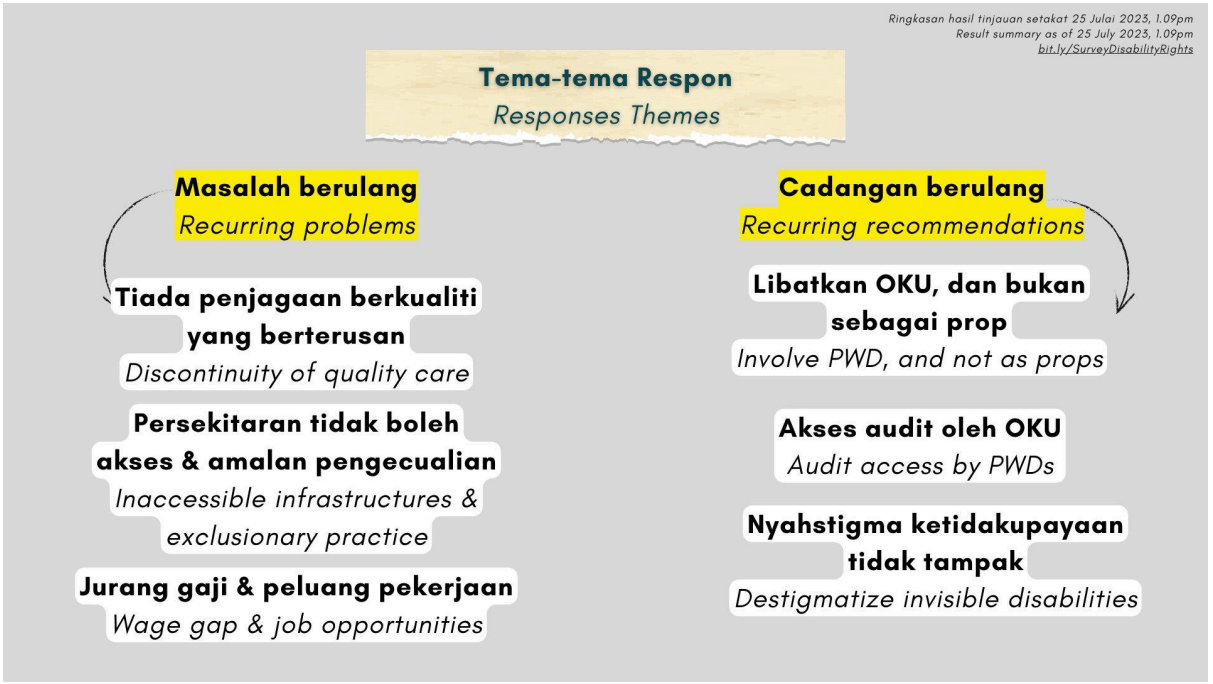

Figure 4: Responses Themes derived from SIUMAN's survey on Disability Rights in Malaysia

Findings from a recent survey by SIUMAN on Disability Rights in Malaysia as shown in Figures 3 and 4 also supports these key ideas and our recommendations for the Health White Paper.

Why These Key Ideas Are Important?

- To provide a firm stance and emancipatory framework in identifying, interrogating and addressing broader social, structural and environmental causes of barriers to health among persons with disabilities and other marginalised communities in Malaysia;
- To ensure a human rights-based transformative equality approach as an integral part of the Health White Paper conceptualisation, operationalisation, implementation and evaluation;
- To ensure that MOH recognises the roles and values of persons with disabilities as co-decision makers and facilitators for an inclusive implementation of the health reform in Malaysia, particularly regarding healthcare issues among persons with disabilities; and,
- To urge MOH to organise active, continuous and meaningful consultations and engagements with persons with disabilities, their representative organisations and other relevant stakeholders in all decision-making processes relating to Malaysia's health reform agenda, including its implementation and monitoring.

PRINCIPAL ACTIONS

To fully adopt an equitable, inclusive approach to health reform that embraces the social model of disability, the socioeconomic determinants of health, the recognition of the human right to health for all, and to ensure that the voices of people with disabilities are heard clearly[18], we call upon the MOH to implement the following Principal Actions.

Principal Action 1

Establish continuous platforms for rights-based consultation with persons with disabilities (PWDs), organisations of persons with disabilities (OPDs), the disabled community, their family members and care partners as well as other relevant stakeholders.[19]

These population groups must be at the centre of health reform because they face greater health disparities and barriers to access healthcare resources. Placing them with their combined lived experiences at the centre of health reform will help reduce these disparities. A population-centred approach can help identify and address the underlying social determinants of health that contribute to poor health outcomes among vulnerable populations. Ultimately, placing vulnerable populations at the centre of health reform can improve health outcomes for both the individuals within these populations and society as a whole. [20]

Principal Action 2:

Appoint at least three (3) representatives of persons with disabilities and care partners into the MOH Health White Paper Council.

These appointments are important for the following reasons:

1. To ensure the structural and strategic mainstreaming of the perspectives and interests of persons with disabilities and other relevant stakeholders in the overall health reform agenda;
2. To facilitate and coordinate the appointment of representatives of persons with disabilities and other relevant stakeholders to the Technical Working Groups (TWGs) and during all engagements which will be conducted by these TWGs;

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[18] Advocacy for Disability Inclusion in Malaysia: Report - https://www.okurightsmatter.com/advocacy-for-disability-inclusion-in-malaysia-report

[19] Convention on the Rights of Persons with Disabilities Articles 4.3 and 33.3, General comment No. 7 (Article 4.3 and 33.3) and General comment No. 6 (Article 5)

[20] Ortenzi F, Marten R, Valentine NB, et alWhole of government and whole of society approaches: call for further research to improve population health and health equityBMJ Global Health 2022;7:e009972.

3. To facilitate and coordinate representatives of persons with disabilities and other relevant stakeholders for the implementation of all activities, initiatives, research and programs specific to healthcare issues of persons with disabilities as part of the health reform agenda (e.g. conducting access audits on physical and digital infrastructure, developing collaborative networks, etc); and,
4. To support MOH on communication and outreach efforts with organisations of persons with disabilities and other relevant stakeholders for any meetings, activities and related programs.

We request that the position of those 3 representatives be made as paid positions because:

(a) To demonstrate the government's commitment to embracing diversity and promoting an inclusive governance system;
(b) To recognise the expertise and leadership of those representatives appointed to the team;
(c) To honour the contribution of energy and time by the appointed representatives to the team; and,
(d) To provide economic security for the appointed representatives to enable them to focus on their tasks and the overall health reform agenda.

Principal Action 3:

Appointing at least three (3) representatives of persons with disabilities and care partners in each Technical Working Group (TWG) which will be established for the purposes of the health reform agenda.

These appointments are important to ensure the mainstreaming of the perspectives and interests of persons with disabilities and other relevant stakeholders in each topic, theme, strategic area and operationalisation. Through TWGs, these representatives can elaborate further on the recommendations listed in this recommendation paper as well as other best practices.

Similar to Principal Action 2, we request these positions to be made as paid positions as explained above. For a starter, each representative mentioned in Principal Action 1 can be allowed to join two different TWGs at maximum before transitioning to expand opportunities for wider participation of persons with disabilities and other relevant stakeholders within 1 year of TWGs establishment.

The three Principal Actions above practically and strategically promote the empowerment and meaningful engagement of the community to care for themselves and each other. It also

promotes partnerships between individuals, communities and the healthcare system in improving overall population health and a more sustainable healthcare system.

RECOMMENDATIONS

To ensure better understanding and consistency, we adapt the format used by MOH in the Health White Paper by listing specific recommendations according to the predetermined pillars, sub-pillars, and the phases of reform – short-term, medium-term and long-term.

It is very crucial to understand that every pillar and sub-pillar outlined in the Health White Paper is relevant to the well-being of persons with disabilities, senior citizens, their family members, care partners and other marginalized communities. As persons with disabilities, we are the single biggest group of clients that the Ministry of Health serves, and we have amassed extensive lived experiences[21] as patients, as persons with various disabilities, and as care partners. In traversing the full value chain of services from the Ministry of Health, we experience the services from different healthcare providers, for different health and well-being needs along with the barriers to access healthcare.

The proposed transformation of the health service delivery[22] is timely and we present our recommendations that take into account our disabilities and health needs. Post COVID pandemic, there needs to be a significant investment in mental healthcare by the government. Other than that, there is a need to invest in digital technologies which provides another option to persons with disabilities to access MOH's services. MOH must strive to ensure equity[23] in the way public healthcare is provided especially to those in the margins of society. More research into the experiences of marginalized communities, including persons with disabilities may help direct the most optimum way in dispensing MOH services to all.

It is extremely important that public health functions are accorded the support it needs from the HWP as it is the bedrock to a country's prosperity. We applaud the focus on getting inter-sectoral collaboration for health with other ministries and government agencies as attested by the Social Determinants of Health. We also hope that MOH's focus on pro-health behaviours will translate into a healthier nation and incidences of NCDs and other related health issues will reduce the strain it is putting on public healthcare and refocus healthcare to be more preventative instead of prescriptive.

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[21] Patient involvement in the development, regulation and safe use of medicines. CIOMS Working Group report. Geneva, Switzerland: Council for International Organizations of Medical Sciences (CIOMS), 2022.
[22] Global patient safety action plan 2021–2030: towards eliminating avoidable harm in health care. Geneva: World Health Organization; 2021.
[23] WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions. Geneva: World Health Organization; 2023. Licence: CC BY-NC-SA 3.0 IGO.

Efficient, sustainable and equitable health financing will provide for a better healthcare system. Malaysia is at an important juncture, where there is a need to increase health spending due to the rise in non-communicable diseases (NCDs), an aging population and diseases brought about by climate change. We have included ways to meet this increasing need for healthcare spending that is sustainable and ensures the right to comprehensive healthcare.

The final pillar that the HWP is built on is strengthening healthcare path and governance. It is hoped that with the impending restructuring of MOH, more emphasis on having staff who understands the needs of persons with disabilities must be made clear. Having inhouse experts should help transform the services offered by MOH to be more disability conscious. At the policy level, new laws and regulations that guarantee the rights of persons with disabilities are most needed, especially when it is based on evidence-based approaches.

If we ensure universal design principles, reasonable accommodations, and destigmatisation of disability, we ensure that access to all is provided to everyone in this country. Ultimately, a barrier free public healthcare should be the goal that the Ministry of Health (MOH) must work to achieve.

Hence, the lived experiences[24] and perspectives of persons with disabilities as well as their care partners can enhance the operationalisation of the Health White Paper.

> “The orthopedic department is illogically located down a hill making patients (mostly in wheelchairs/crutches) and their care partners need to dangerously traverse the hill using the road among cars to get their medication at the nearest hospital pharmacy. For patients who are not familiar with the hospital, if they come from the main lobby, they'll have to go down the hill to get to the orthopedic clinic, and then back up to the pharmacy to get their meds.”
>
> - A wheelchair user

Anecdote 1: Lived experiences of a wheelchair user at a state hospital

[24] Patient involvement in the development, regulation and safe use of medicines. CIOMS Working Group report. Geneva, Switzerland: Council for International Organizations of Medical Sciences (CIOMS), 2022.

Pillar 1: Transforming Health Service Delivery

1.1 Prioritising primary healthcare delivery		**Agency/ Ministry[25]**
Short Term		
1.	Integrate psychiatrist/clinical psychologist, rehabilitation service professionals and therapists as part of the primary healthcare (PHC) team at every district in all states across Malaysia by 2028; ensuring the sustainability of such posts in all PHC teams through adequate funding, support for further training, etc.	**MOH** JPA MOF
2.	Coordinate and consolidate the network of health-related services between MOH and social/care institutions under KPWKM	**MOH/JKM/JPOKU**
3.	Conduct an annual assessment of PHC teams' quality of delivery; by integrating relevant inquiries pertaining to primary healthcare services for persons with disabilities and senior citizens. Do include persons with disabilities in such assessments in the form of Accessibility Audit.	**MOH** JPOKU JKM OPDs
Medium Term		
4.	Conduct a 5-year review on the delivery of PHC services and the overall system for continuous improvements; integrating specific areas of concern relating to primary healthcare services for persons with disabilities. To ensure persons with disabilities are included in the review process. With such reviews, we can identify at the appropriate time, gaps in PHC services and proceed to provide sufficient budget, manpower and services to address such gaps.	**MOH** JPOKU JKM OPDs
5.	Enhance all health-related teleservices and home-based services, with a particular focus on the needs of persons with disabilities and senior citizens, and those with rare diseases or chronic conditions by adopting accessible technologies, providing support for care partners, flexible processes, etc.	**MOH** OPDs JPOKU MOSTI KKD
6.	Ensure accessibility, affordability and autonomy of patients, particularly patients with disabilities and senior citizens, are integrated as core principles and adequate safeguards are put in place as part of the	**MOH** Private HCPs OPDs

[25] Lead Agency/Ministry in Bold and listed first

	collaborative framework between public and private hospitals on hospital care services across Malaysia.	
1.3 Intensifying effective public-private partnership		
Short Term		
7.	Institute accessibility compliance as a legally-binding requirement in all health-related procurement.	**MOH**
8.	Develop a comprehensive partnership framework between MOH, the private sector and organisations of persons with disabilities in the development, production and distribution of accessible healthcare technologies, products and services (e.g., production of accessible medicine labelling, creation of accessible healthcare mobile apps, and coordination for habilitation and rehabilitation services).	**MOH** OPDs HCPs
9.	Integrate specific objectives and indicators relating to the healthcare of persons with various disabilities and senior citizens into the performance standard across public, private and non-profit healthcare providers.	**MOH**
Medium Term		
10.	Strengthen the comprehensive partnership framework between MOH, the private sector and organisations of persons with disabilities in the development, production and distribution of accessible healthcare technologies, products and services (e.g., production of accessible medicine labelling, creation of accessible healthcare mobile apps, and coordination for habilitation and rehabilitation services).	**MOH** OPDs HCPs
1.4 Harnessing digital technologies		
Short Term		
11.	Integrate accessibility compliance as part of any new guidelines, standard operating procedures and related training on digitalisation based on the Web Content Accessibility Guideline (WCAG); involving representatives of persons with various disabilities and senior citizens during drafting such guidelines, standard operating procedures and training modules.	**MOH/MC** **MC/MAM** **PU** JKM OPDs
12.	Review and improve the accessibility of all websites and mobile apps owned by MOH to comply with the accessibility standards; collaborate with organisations of persons with disabilities to establish a team of digital accessibility auditors and advisors.	**MOH/MC** **MC/MAM** **PU** OPDs
Medium Term		

13.	Gradually shift to mandatory user consultation and accessibility compliance for all health-related technologies, products, websites and mobile apps developed by local and foreign businesses and inventors.	**MOH/MC MC/MAM PU** OPDs
1.5 Ensuring equity in healthcare delivery		
Short Term		
14.	Conduct accessibility audits on public medical institutions with direct involvement of persons with various disabilities and gradually improve the public health facilities according to the accessibility audit findings.	**MOH** JKM OPDs
15.	Conduct periodic assessments to systematically identify the availability and adequacy of habilitation and rehabilitation devices and other appropriate assistive technologies.	**MOH/SO CSO/JKM** JPOKU OPDs
16.	Codesign and piloting disability- and gender-sensitivity training programs for healthcare professionals by consulting and involving experts with various disabilities.	**MOHE** MOH OPDs
17.	Co-produce research and co-develop mechanisms for accessible communication support system with organisations representing persons who are blind and deaf, through among others, adopting centralised accessible mobile app for health consultation, training more sign language interpreters that specialises in health-related matters; directly involving Deaf community in the study and the development of such mechanisms. eg. Award winning DITE app[26]	**MOH** OPDs (Blind and Deaf)
Medium Term		
18.	Conduct accessibility audits on other medical institutions with direct involvement of persons with various disabilities and gradually improve the public health facilities according to the accessibility audit findings.	**MOH** OPDs
19.	Mandate disability-inclusion and multiculturalism modules in diploma, undergraduate and postgraduate medical studies, counselling, nurse training and allied health-related studies.	**MOHE** MOH MINDEF
20.	Institute mandatory disability- and gender-sensitivity training programs for healthcare professionals, through among others, by encouraging their participation in continuous professional development (CPD)	MOH **MOHE** MINDEF

[26] Health equity project for Malaysian Deaf community wins Nature inclusive health research award - https://www.monash.edu/medicine/news/latest/2023-articles/health-equity-project-for-malaysian-deaf-community-wins-nature-inclusive-health-research-award/_nocache

	activities; co-design these training programs with experts with various disabilities.	OPDs JPW
Long Term		
21.	Train and hire an accessibility officer at each State Department of Health to assess, monitor and advise on accessibility improvements of healthcare facilities in their respective states.	**JPA** JPOKU OPDs

> I can still hear with hearing aid so I prefer to go see doctor by myself and talk to Dr. I use a gadget with a wired earphone plugged into my ear. I ask the person who is talking to me to talk into the gadget close to his lips. That gadget then can suppress surrounding sounds and only channel his voice directly into my ears.
> My sis insist on going to see Dr despite my telling her not to. Dr talk to her, not me as expected. Dr refused to speak into my gadget so I didn't know what was discussed.
>
> - A deaf blind woman

Anecdote 2: Lived experiences of a deaf blind woman

Pillar 2: Advancing Health Promotion and Disease Prevention

2.1 Strengthening public health functions		**Agency/ Ministry**
Short Term		
1.	Include representatives of persons with various disabilities in the development and implementation of public health communication and outreach strategy; ensuring universal accessibility as an inherent core in all communication or outreach activities and contents (e.g., producing easy-read materials; video with subtitles, audio description and Malaysian Sign Language interpretation; image with alternate text).	**MOH** OPDs
2.	Ensure the national health data network to include specific data on persons with various disabilities and senior citizens, including persons with rare disorders or chronic diseases, by disaggregating those data according to age group, gender, geographical area, monthly income, etc.	**DOSM/MOH** JPOKU JKM

3.	Provide research grants specific to organizations of persons with disabilities, including social enterprises managed by persons with disabilities, to conduct research on public health topics which are significant for persons with various disabilities in Malaysia.	**MOF** MOH OPDs
4.	Establish a collaborative and partnership network between the Ministry of Health, public and private medical institutions and organizations of persons with disabilities in all states and territories across Malaysia for data collection and integration, as well as public health program planning and implementation.	**MOH** Private HCPs OPDs NGOs
Medium Term		
5.	Assess the level of accessibility and effectiveness of the public health communication and outreach strategy for all Malaysians, including for persons with various disabilities and senior citizens; consult persons with disabilities and their representative organisations during the assessment process.	**MOH** OPDs
6.	Sustain the ecosystem of financing and distribution of research grants specific to organizations of persons with disabilities, including social enterprises managed by persons with disabilities, to conduct research on public health topics which are significant for persons with various disabilities in Malaysia.	**MOF** JPOKU
7.	Sustain the collaborative and partnership network between the Ministry of Health, public and private medical institutions and organizations of persons with disabilities in all states and territories across Malaysia for data collection and integration, as well as public health program planning and implementation.	**MOH** OPDs Private medical institutions
Long Term		
8.	Train and hire experts on public health issues pertaining to persons with various disabilities, particularly experts among persons with various disabilities themselves, to serve in the National Disease Control Centre.	MOH **JPA**
2.2 Improving inter-sectoral coordination and collaboration for health		
Short Term		
9.	Appoint representatives of persons with various disabilities, senior citizens and care partners to the inter-ministerial committee on healthy ageing and elderly care.	**MOH** OPDs

10.	Include specific targets relating to persons with various disabilities and senior citizens as part of shared KPIs across ministries and agencies.	**Government** OPDs
11.	Appoint representatives of persons with various disabilities, senior citizens and care partners to the Health in All Policies Task Force.	**MOH** OPDs
12.	Ensure direct participation of organizations of persons with disabilities in the inter-sectoral framework at the community level.	**MOH** OPDs
2.3 Incentivising pro-health practices and behaviours		
Short Term		
13.	Provide a WCAG compliant portal on any food-, health-, cosmetic-products that are found to be dangerous, or are identified to be taken off from consumption.	**MOH**
Long Term		
14.	Develop an open and accessible database platform, by complying with the Web Content Accessibility Guidelines (WCAG), containing information pertaining to ingredients and their measurements, as well as possible side effects for all health-, food- and cosmetic-related products; financing and promoting accessible technologies which enable the general public, especially persons with various disabilities and senior citizens to obtain information pertaining to ingredients and their measurements, as well as possible side effects for all health-, food- and cosmetic-related products.	**MOH** MAFS KPDN
15.	Develop and promote accessible and inclusive sports and recreational programs for persons with various disabilities through collaboration with private entities and non-governmental bodies across Malaysia.	**KBS/NGO** JPOKU OPDs

> “I am resentful, because the clinic staff have to lift my mum from her wheelchair rather than providing a portable ramp
>
> - A physically disabled care partner ”

Anecdote 3: Lived experiences of disabled care partner

Pillar 3: Ensuring Sustainable and Equitable Health Financing

3.1 Increasing investments for health		**Lead Agency**
1.	Legislate a ring fence element for any and all pro-health taxes (including summonses) that are identified as behavioural change agents for the utilisation of the MOH in future government budgets.	**MOH MOF**
2.	Improve healthcare budget by increasing the tax base especially from the hyper rich (property tax, sales revenue, inheritance tax, capital gains tax, etc).	**MOF**
3.	Include persons with disabilities in any and all health financing committees to ensure the needs of persons with disabilities are guaranteed.	**MOH OPDs**
4.	Expand the scope of tax rebates and exemptions for donation from individuals and small businesses to health services rendered to persons with disabilities.	**MOF**
Medium Term		
5.	Increase public health funding from the government to 5% of GDP in line with other upper middle-income countries.	**MOF MOH**
Long Term		
6.	Increase public health funding from the government to 8% of GDP in line with other upper middle-income countries.	**MOF MOH**
3.2 Ensuring population receive comprehensive services that are affordable		
Short Term		
7.	Ensure that people with disabilities, pre-existing conditions, mental health issues, people with rare diseases & undiagnosed conditions, and people with ongoing non-communicable diseases (NCDs), needing habilitation and rehabilitation, the elderly and palliative care are not excluded from accessing healthcare by any and all parties that are tasked to handle the healthcare financing. There needs to be a guarantee from MOH that the above are honoured.	**MOH**

8.	Guarantee that the fees imposed to access public healthcare are maintained at the current rate for all, to continue with our aspiration to maintain our universal healthcare.	**MOH**
3.3 Ensuring effective and efficient healthcare spending		
Short Term		
9.	Allocate sufficient funding on ensuring MOH facilities (government owned health institutions) are accessible to all by implementing universal design & equipping MOH facilities, Healthcare Providers (HCPs) and information sharing with relevant accessibility features. Ensure MOH facilities and access to services is extended to care partners, family and friends of PWDs and patients.	MOH **MOF**
10.	Diversify the universal coverage of health protection and support to all in Malaysia by including sexual and reproductive health (SRH) coverage, mobility, sight and hearing aids, payment for sign language interpreters, rare disease treatments and medications, medical implants, as well as dental related care, palliative care and habilitation and rehabilitation services.	**MOH** MOF
11.	Include persons with various disabilities in any and all monitoring and conformance committees tasked to ensure all the recommendations presented in this document are conducted with the needs of PWDs being central to the relevant recommendations.	**MOH** OPDs
Medium Term		
12.	Allocate sufficient funding on ensuring MOH facilities (government owned primary health institution) are accessible to all by implementing universal design & equipping KKM facilities, HCPs & information sharing with relevant accessibility features. Ensure KKM facilities & services access is also extended to care partners, family & friends of PWDs & patients.	MOH **MOF**
Long Term		
13.	Incentivise general practitioners (GP), allied health institutions, and dentistry clinics on ensuring their facilities are accessible to all by	**MOF** MOH

	implementing universal design & equipping their facilities, HCPs & information sharing with relevant accessibility features based on Act 586. Ensure the facilities & services access are also extended to care partners, family & friends of PWDs & patients.	
14.	Develop and sustain a financing system to minimise system downtime and ensure reliable access to healthcare services through, among others, investing in robust and scalable technology systems that can support the increased demand for digital healthcare services.	**MOF**

> It is difficult to find speech therapist, those available are far away from us. We need to go out early, it usually takes 2 hours plus finding parking another 15-20 minutes. Therapy time only for 1 hour. The next appointments take 2-3 months waiting time. In the beginning my daughter's progress was very encouraging, but now she has regressed as she missed 3 years of therapy during MCO. Am looking for a private therapist but it's so expensive!
>
> - Parent of a child living with rare disease

Pillar 4: Strengthening the Health System's Foundation and Governance

4.1 Strengthening the roles of MOH through restructuring		**Lead Agency**
Short term		
1.	Strengthen the functions of the section on persons with disabilities under the Family Health Development Division; recruit at least two (2) officers with disabilities to support its activities.	**MOH** OPDs
2.	Review current governance system and mechanisms relating to healthcare provision for persons with various disabilities in Malaysia through consultations with persons with disabilities and their representative organisations.	**MOH** OPDs

3.	Review and enhance the functions of the Institute of Public Health with regard to issues relating to persons with disabilities; harmonising the working relations between the section of persons with disabilities under the Family Health Development Division and the Institute of Public Health.	**MOH**
Medium Term		
4.	Appoint an expert with disabilities to lead the section on persons with disabilities under the Family Health Development Division; sustain posts for officials with disabilities to be hired to the section.	**JPA/OPDs** MOH
5.	Establish focal points in relation to affairs of Persons Living with Rare Disorders and/or Chronic Illnesses.	**MOH/PWLE**
Long Term		
6.	Establish the National Institute for Rare and/or Chronic Illnesses.	**MOH**
7.	Train and hire at least one (1) person with disabilities to become the liaison officer at each State Department of Health to coordinate health-related programs and initiatives for persons with disabilities between MOH and state departments.	**MOH**
8.	Establish the National Centre for Spinal Cord Injury Research and Rehabilitation Services.	**MOH**
4.2 Improving policy, law and regulations		
Short Term		
9.	Review and amend the Personal Data Protection Act 2010 (Act 709) to ensure adequate data protection in the healthcare sector, including introducing specific provisions and rigorous enforcement mechanisms that are tailored to the unique requirements and best practices by adapting relevant provisions from the Health Insurance Portability and Accountability Act (HIPAA) in the United States.	**AGC** MOH
10.	Codify the protection of patients' data from the risk of potential misuse by any entity within and beyond Malaysia's borders into the law, particularly in the context of international data exchanges.	**AGC** MOH
11.	Review and amend laws and regulations relating to prevention and control of infectious diseases, such as Act 342, by involving representatives of persons with various disabilities, senior citizens, and	**AGC** MOH OPDs CSOs

	care partners so the laws and regulations reflect their rights and needs during health emergencies.	
12.	Review current policy gaps and develop an inclusive and comprehensive national health policy that includes all relevant aspects of healthcare of persons with various disabilities (e.g., accessible healthcare infrastructure, rehabilitation services, mental health, rare and chronic conditions, accessible health education, etc) by consulting persons with various disabilities and their care partners.	**MOH** OPDs AGC
13.	Involve from the start persons with disabilities and care partners in all stages of review and amendment of all health-related laws and regulations.	**AGC** MOH OPDs
Medium Term		
14.	Review and amend the Telemedicine Act 1997 (Act 564) to address the challenges posed by technological advancements in telemedicine services, such as teletherapy; focusing on accommodating emerging technologies and services by providing clear regulatory requirements and establishing a "standard of care" specific to teleservices.	**AGC** MOH
4.3 Strengthening the healthcare workforce		
Short Term		
15.	Map out the gap of expertise relating to healthcare services for persons with disabilities.	**MOH** OPDs
16.	Provide funding to train more psychiatrists, clinical psychologists, allied health professionals, rehabilitation professionals, therapists, pain management experts, rare disorders and chronic illnesses experts in Malaysia.	**JPA** MOH
17.	Develop specific subjects relating to persons with disabilities and multiculturalism for diploma, undergraduate and postgraduate programs across all specialisation; involve experts with disabilities in the development of such subjects.	**MOHE** MOH OPDs
Mid Term		
18.	Sustain the scholarships and job posts for psychiatrists, clinical psychologists, allied health professionals, rehabilitation professionals, therapists, pain management experts, rare disorders and chronic illnesses experts in Malaysia.	**JPA** MOH

19.	Review and continuously enrich subjects relating to persons with disabilities and multiculturalism for diploma, undergraduate and postgraduate programs across all specialisation; involve experts with disabilities in the review and improvement processes.	**MOHE** MOH OPDs
Long Term		
20.	Encourage more persons with disabilities to engage in health-related professions, including as paraprofessionals, through financial support, the adoption of bridging courses, etc.	**MOH** JPA
4.4 Stimulating research, innovations and evidence-based approaches		
Short Term		
21.	Review, update and expand the collections of research publications and other related materials under the Clearinghouse for research on Disability, with specific focus on locally-produced resources and research.	**MOH**
22.	Institute patient public involvement approach as part of research grants requirements in all health-related studies; ensure all studies conducted using government grants must be made publicly available and published in accessible formats.	**MOH/MOHE/MINDEF** MOF OPDs
23.	Provide specific grants for organisations of persons with disabilities, including social enterprises managed by persons with disabilities, to conduct research on health issues facing persons with various disabilities and older persons.	**MOF** OPDs
Mid Term		
24.	Integrate inclusive participatory research methodology for health-related studies on persons with lived experience, especially studies relating to persons with disabilities, as part of the national health research strategy.	**MOH** KPWKM
25.	Sustain the financing and distribution mechanism for grants for organisations of persons with disabilities, including social enterprises managed by persons with disabilities, to conduct research on health issues facing persons with various disabilities.	**MOF** MOH

CONCLUSION

We implore MOH to seriously consider and **integrate the Principal Actions and recommendations** presented in this paper:

Principal Action 1:Establish continuous platforms for rights-based consultation with persons with disabilities (PWDs), organisations of persons with disabilities (OPDs), the disabled community, their family members and care partners as well as other relevant stakeholders.

Principal Action 2: Appoint at least three (3) representatives of persons with disabilities and care partners into the MOH Health White Paper Council.

Principal Action 3: Appointing at least three (3) representatives of persons with disabilities and care partners in each Technical Working Group (TWG) which will be established for the purposes of the health reform agenda.

We look forward to more engagement and the inclusion of persons with disabilities, senior citizens, care partners and other marginalised communities, as well as their representative organisations in the Health White Paper Council as well as the Technical Working Groups which will be established soon, so that the recommendations and perspectives of these groups will be heard and integrated meaningfully.

Appendix

Accommodations for representatives of the disability community

In ensuring the representatives of the disabled community are able to conduct their duties in reforming the healthcare system of Malaysia, reasonable accommodations must be made for them. Below are some examples and should not limit the accommodation type required by the representatives as disabilities are diverse and exist on a spectrum of severity. The representatives will be able to inform on their accessibility needs as and when required.

- Structural: ensuring all meetings are conducted in spaces that are disability friendly. Flexible hours and work from home options. Providing access to hybrid meetings. Ramps, curb cuts and unblocked pathways are available in the work and meeting locations. Providing free flow drinking water (other than coffee or tea)
- Communication: provide alternate text and video descriptions, ensure sign language interpreters are available during meetings, town halls, focus discussion groups, etc. Ensure meetings are recorded and transcribed for later viewing or reference
- Enough time is given to the representatives in preparation to attend meetings, town halls, focus discussion groups, etc.
- Ensure the representatives from the disability communities are diverse and not restricted to visible disabilities only.

Key Principles from Patient involvement in the development, regulation and safe use of medicine, CIOMS Working Group report[27] relevant to Persons with Disabilities engagement

Key points 1. The patient voice offers a valuable perspective throughout the development of a medicine. It should be fully incorporated into the decision-making process.

Key points 2. Patients have expert knowledge and understanding of their diseases and conditions. This means they have equal credibility as those who are scientific and medical experts.

Key points 3. Reimbursement of expenses and compensation for patients' time and contribution should be considered.

Key points 4. Consider training of all stakeholders during the planning for patient engagement activities.

Key points 5. Every effort should be made to maintain patients' independence.

Key points 6. Balanced information, transparency and open communication are key. Written agreements should be easy to understand and complete.

[27] Patient involvement in the development, regulation and safe use of medicines. CIOMS Working Group report. Geneva, Switzerland: Council for International Organizations of Medical Sciences (CIOMS), 2022. doi: 10.56759/iiew8982