

Inclusive digital health: Empowering people with disabilities

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The Partnership for Australia-Indonesia Research (PAIR) has launched a series of small-scale initiatives that employ a dual focus to shed light on the interplay between governance, policy and capacity building in key sectors. These initiatives are aimed at supporting four main research themes in the areas of commodities, transport, young people's health and young people's development.

The research adopts a dual strategy, focusing on both governance and policy, as well as capacity building, to reach its objectives. The study also takes into consideration important issues such as gender equality, disability and social inclusion.

This report provides policymakers with a rich source of information and up-to-date evidence that can inform their decision-making. The findings of these PAIR initiatives are essential reading for anyone interested in the future of these key sectors in Indonesia.

Warm regards,



Dr Eugene Sebastian
PAIR Program Director
The Australia-Indonesia Centre



EXECUTIVE SUMMARY

Digital technology can play an important role in increasing the accessibility of information for people with disabilities (PwD). Increasing the use of digital devices among PwD, particularly youth with disabilities (YwD) aged between 16 and 30, can improve access to health information and related services.

However, inclusive principles and practice are often neglected in delivering information and services. Many forms of technology and applications are insufficiently tailored for PwD in terms of information needs, usability and accessibility. There is also a lack of content tailored for the needs of PwD.

This project has three main aims. First, to understand information needs, preferences and challenges faced by PwD in accessing health information and services. Second, to explore current practices in planning and development of health information and service provisions through digital technology. Third, to provide recommendations to local stakeholders on inclusive practices in planning and development of digital health information and services.

The project was designed to involve a number of stakeholders including youth with disability, representatives of government, the private and non-government organisations (NGO) covering three key districts in South Sulawesi being Makassar, Gowa and Takalar. Using qualitative methods the project utilises focus group discussions, interviews and a participatory co-design approach. A combination of these qualitative methods can allow participants to have a strong voice and share their experiences, enriching the evidence-gathering and research process.

Our research reveals significant challenges faced by PwD in accessing digital health information and services. To overcome them, a framework for digital health inclusion is proposed, incorporating digital environment and health equity principles specific for PwD. A number of specific recommendations can be made. Our research allows us to make the following recommendations in terms of policy and project coordination.

Strengthen the digital literacy skills of PwD. We recommend training in digital literacy for people in the diffable community. A high standard of digital literacy can help PwD gain access to a greater range of health services. Improved digital literacy training could be achieved by working closely with educational institutions, disability organisations and technology experts to develop customised learning modules. Designers of policies or programs need to foster an approach that is focused on the needs of PwD ('user centric').

Strengthen disability and inclusiveness literacy among key stakeholders. Disability awareness and inclusive principles need to be incorporated into new and ongoing educational programs for healthcare professionals and other key stakeholders. This can contribute to an educational environment that is relevant and fully meets the needs of PwD. Cooperation with disability organisations to design education programs that emphasise digital health inclusivity is crucial in achieving this goal.

Develop inclusive digital health policies and programs. Meaningful engagement of PwD in digital health programs and policies can contribute to better health outcomes. We recommend the establishment of comprehensive guidelines for PwD engagement in the planning, implementation and evaluation of inclusive healthcare programs and policies. The involvement of PwD in the development of initiatives needs to be prioritised with a focus on fostering an inclusive and responsive healthcare system. Government health departments should develop partnerships with disability organisations and make this a priority for the planning of programs and policies.

Encourage collaboration between agencies to share disability-related data and insights. There needs to be more effective sharing of data between agencies and departments to identify and overcome a wider array of challenges experienced by PwD. This needs to go beyond economics and also examine social issues. A systematic and standardised data collection approach can contribute to more meaningful cooperation between agencies. Government leadership is required in this area, particularly in terms of resource allocation.



1.0. INTRODUCTION

Based on the WHO Global Disability Action Plan 2014-2021, there are more than one billion people with disability globally, accounting for about 15 percent of the world's population, or one in seven people. According to Central Statistics (BPS-Badan Pusat Statistik) data from 2020, about 22.5 million people in Indonesia have disabilities, representing five percent of the total population.

People with disabilities (PwD) face widespread barriers in accessing services, including healthcare, education, employment and social services such as housing and transport. These barriers contribute to disadvantage. In developing countries, PwD often experience poorer health compared with those without disabilities, as well as higher rates of poverty, lower educational and employment achievements, reduced independence and limited social participation (WHO, 2015). Among citizens aged 15 and over 12, 15 percent have a disability; 1.87 percent have severe disability and 10.29 percent have mild disability (Halimatussadiyah et. al., 2017). Their participation in the workforce is significantly lower – 20.27 percent for those with severe disabilities and 56.72 percent for those with mild disabilities – compared with 70.40 percent for people without disabilities (Gunawan et. al., 2017). Health disparities are also evident, with around 50 percent of PwD reporting health problems, 30 percentage points higher than those without disabilities. This higher prevalence of health issues indicate that PwD likely face greater health risks and/or have less access to appropriate health services (Cameron & Suarez, 2017).

The Ministry of Health in Indonesia has collected data on people with disabilities through the Basic Health Research (Riskesdas) in 2007, 2013 and 2018. The 2018 Riskesdas classified disability data into three age groups: children (aged 5-17 years), adults (aged 18-59 years) and elderly (aged 60 years and over). The data revealed that the provinces with the highest proportion of adults with disabilities were Central Sulawesi (40.6 percent), and South Sulawesi (34 percent). The prevalence of PwD in South Sulawesi is notably higher than the national

average, with districts like Makassar, Takalar and Maros recording the highest populations of PwD (Kemenkes, 2018). Discussion around health information and services for PwD has been limited, with a primary focus on social support, rehabilitation and welfare.

Previous PAIR research has identified that local stakeholders in these districts recognise the importance of addressing the health needs of people living with disability.

They face difficulties, however, due to a lack of people with the necessary skills to overcome these health needs. A recent survey by the *Jaringan Organisasi Penyandang Disabilitas Respon Covid-19* (COVID-19 Disability Response Network) focusing on the impact of the pandemic on people with disabilities in Indonesia (DPO Respon Covid-19 Inklusif, 2020) highlighted several issues. One significant concern was the inadequate information about COVID-19, primarily because mainstream media and internet sources were often inaccessible for some PwD. This problem presented an opportunity to explore the issue of health information and services for PwD, with findings forming the basis of inclusive policy and program development in the future..

Indonesia is one of the largest online markets in the world, with more than 171 million internet users as of 2020. As of July 2021, online penetration in the country stood at around 70 percent, with popular online activities including mobile messaging and social media. YouTube emerged as the most popular social network in Indonesia, used by about 94 percent of the online population. Additionally, mobile internet usage has been experiencing double-digit growth rates and currently stands at over 64 percent among the population (Statista, 2023). According to Central Statistics (BPS) in 2020, it was found that 14.14 percent of the Indonesian population already use computers, 62.84 percent own or use cellular phones and 53.73 percent have accessed the internet.

In South Sulawesi province, 14.87 percent of the population use computers, 65.14 percent own or use cellular phones and 50 percent have access to the internet. Data from *Survey Sosial Ekonomi Nasional* (Susenas) 2018, however, revealed a disparity: while PwD are increasingly accessing information through ICT ownership (laptop and smartphones), their access remains low with 35 percent, compared with 81.61 percent among those without disabilities. Internet access for PwD is even more limited, with only 8.5 percent having access, compared with 45.46 percent among the non-disabled (WHO, 2020).

Digital technology plays an important role in enhancing information accessibility for PwD. The increasing use of digital devices among youth with disability (YwD), aged between 16 to 30 years old, can significantly improve their access to key health services including access to consultations. Digital technologies, such as health applications, offer a range of services, including convenient access to information and consultation. Inclusive principles and practices are often forgotten in delivering these services, however, and many technologies and applications are inadequately tailored to the needs of PwD with a noticeable lack of content designed for PwD.

Previous PAIR research in South Sulawesi found that youth with disabilities developed several strategies to deal with pandemic conditions and actively

responded to the challenges of COVID-19 (Nasir et al., 2021). Many respondents reported varied experiences, however, indicating that government support is minimal and often inaccessible to PwD due to ineffective communication and insufficient data about PwD. The objective of this project is to address the challenges faced by PwD by developing an inclusive digital health framework. This framework will inform stakeholders in the design and implementation of digital health programs and services. Specifically, this project aims to:

- Understand the information needs, preferences, and challenges faced by PwD in accessing health information and services.
- Explore current practices in planning and development of health information and service provision through digital technology.
- Provide recommendations to local stakeholders on inclusive practices in planning and development of digital health information and services.

This project looks at issues faced by PwD from a social rather than medical perspective. Our model works on the basis that people are 'disabled' by a society designed primarily for the able-bodied, leading to discrimination (Oliver, 2013). Health information provision for PwD should eliminate all barriers that impede access to information, creating an environment that enables equal access, including online information. The project was designed to involve multiple stakeholders and it covers at least three main districts in South Sulawesi including Makassar, Gowa and Takalar. The next section of the report outlines the research methodology, followed by a summary of project activities and results. The report concludes with recommendations and future directions.



PwD focus group discussion in Makassar

2.0. METHODOLOGY

This project involved an extensive research effort that included participants from a diverse range of stakeholders. These included youth with disabilities and representatives of government, the private sector and non-government organisations (NGOs), spanning at least three main districts in South Sulawesi. The project adopted a qualitative research approach, utilising focus group discussions (FGDs), interviews and participatory co-design methods.

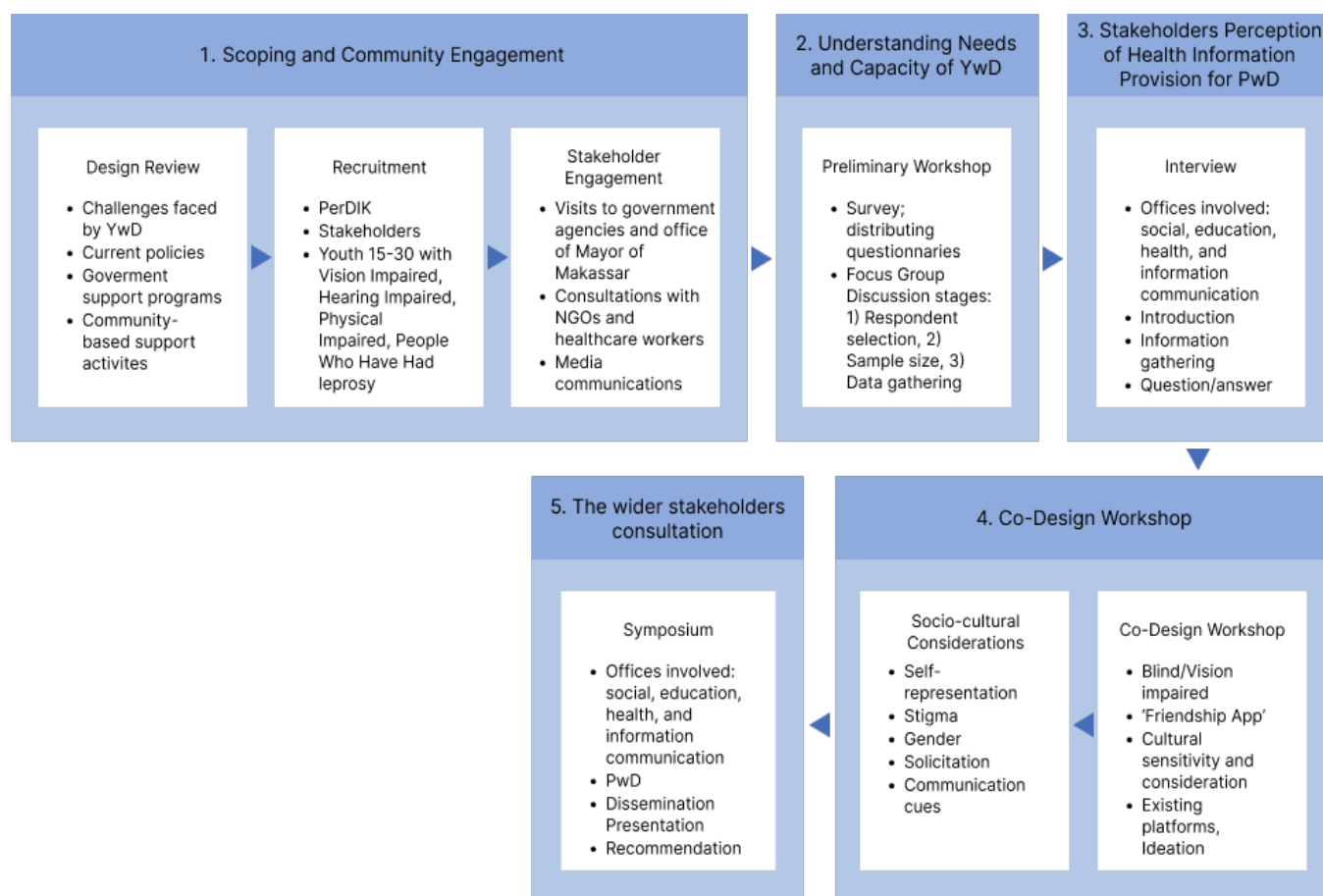
By integrating these varied methodologies, the project provided opportunities for participants to actively contribute and share their experiences during the research process. All interviews and focus group discussions were recorded and the audio recordings were transcribed verbatim. The interviews and focus group discussion transcripts were examined using ‘thematic’ analysis.

The research covered three districts (kota/kabupaten) in South Sulawesi: Makassar, Gowa and Takalar. A community engagement strategy was included early in the project. This strategy had dual purposes: firstly, as a means for participant recruitment and secondly, to promote stakeholder buy-in to the project recommendations. Extensive consultation with NGO partners was conducted to identify the most effective engagement methods.

We also consulted with health practitioners and experts, as well as service providers from government, the private sector and NGOs, about their perceptions of health information provision for people with disabilities (PwD). Additionally, we explored the needs and preferences of PwD. Understanding PwD health information needs, preferences and their ICT use is crucial. Through interviews, we gained insights into their information-seeking practices and the barriers they face in accessing information, particularly through digital media and the internet. In a participatory co-design of a digital health technology we elicited requirements and ideas to be considered in developing such tools.

The project was conducted in five stages: (1) scoping and community engagement; (2) understanding needs and capacities of YwD; (3) stakeholders’ perception of health information provision for PwD, (4) co-design workshop and 5) wider stakeholder consultation. (see figure 1). Table 1 shows the number of participants in each activity.

Figure 1. Diagram of research stages



Stage 1: Scoping and community engagement The first phase involved a desktop review exploring the challenges faced by PwD in Indonesia in accessing digital health information and services, current policies, government support programs and community-based support activities. This stage also included participant recruitment, program design and stakeholder engagement.

Stage 2: Understanding needs and capacities of youth with disabilities (YwD) The survey, conducted over two weeks in Makassar city and Gowa and Takalar regencies, aimed to examine data related to YwD to identify their characteristics, challenges and needs in accessing health information both offline and online. The questionnaire was conducted using the Kobo toolbox, a data collection, management and visualisation tool. It was administered in collaboration with our partners who worked as enumerators. Many of them live with disabilities, adding important sensitivity to our research. The measuring instrument was an online questionnaire filled out using the Kobo toolbox system, containing 40 questions divided into five main groups: demographic information, health facilities, telephone and internet use and health information needs including sexual health. Focus group discussions with YwD were conducted to explore PwD health information needs, information-seeking behaviour and preferences to inform the development of inclusive digital health information. Findings from the survey informed the focus group discussion (FGD) guideline development. Two FGDs were conducted in each district with six to 12 participants, discussing topics related to health and online health information sources.

Stage 3: Stakeholder' perceptions of health information provision for PwD Interviews with stakeholders were conducted in Makassar, Gowa and Takalar. Some of the stakeholders involved were representatives of service providers including health, education, information and social services, all having roles related to disability. The first interview with stakeholders in Makassar was conducted at the Makassar communication and information office hall, followed by interviews in Gowa Regency and Takalar Regency. FGDs were also conducted with healthcare workers from various fields, with participants recruited through invitations sent to community health centres and snowballing techniques.

Stage 4: Co-design workshop The co-design workshop aimed to elicit initial design requirements for an inclusive digital health platform. This stage used a participatory co-design approach, based on design thinking, an iterative, non-linear method focused on understanding users and solving problems.

Stage 5: Wider stakeholder engagement A post-research symposium was conducted with a wider group of stakeholders to gather feedback on initial findings. Various engagement strategies were designed, including media publication, video production, news articles, infographics and social media content.

Table 1. Participants number in project activities

Project Activities		Number of Participants	Place
Survey		149	Makassar City, Gowa Regency, Takalar Regency
FGD with PwD	Makassar	25	Four Points by Sheraton Makassar
	Gowa	12	Four Points by Sheraton Makassar
	Takalar	12	Grand Kalampa Hotel, Takalar
Stakeholders Interviews	Makassar	8	the Makassar Communication and Information Office hall building
	Gowa	8	Gowa Regency
	Takalar	8	Takalar Regency
FGD with Practitioners/Healthcare Worker		9	Swiss-belhotel Makassar

3.0. ANALYSIS AND RESULTS

We did a desk review to understand the challenges faced by PwD in Indonesia, as well as gauging current policies and programs on health information and service provision, particularly regarding digital health. We also observed, with help from our partner PerDik, the situation of PwD during COVID-19, focusing on how they accessed support during that difficult time. PerDik provided information on a range of initiatives.

Recent work on digital health

We conducted a rapid review of recent work on digital health design for PwD, revealing the following insights:

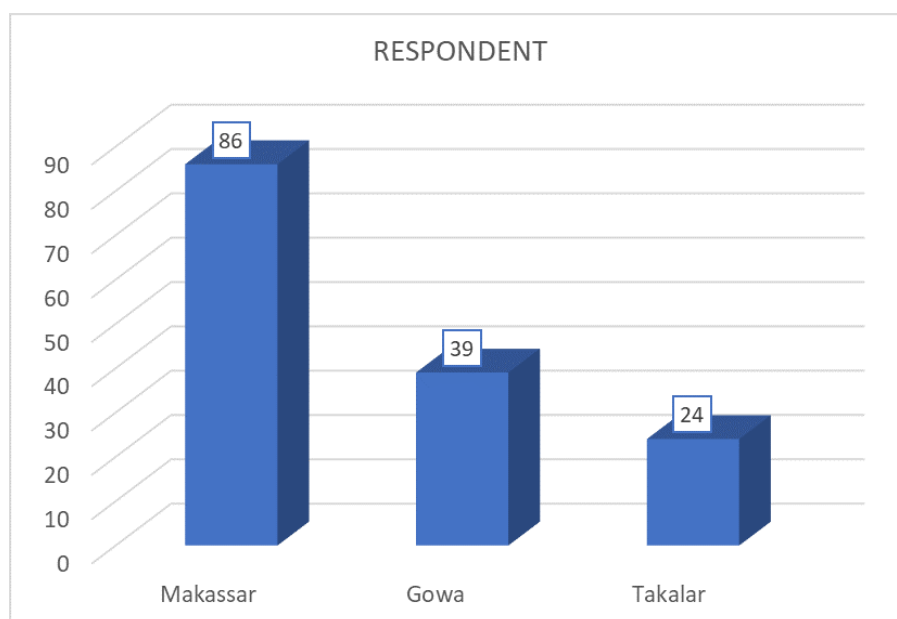
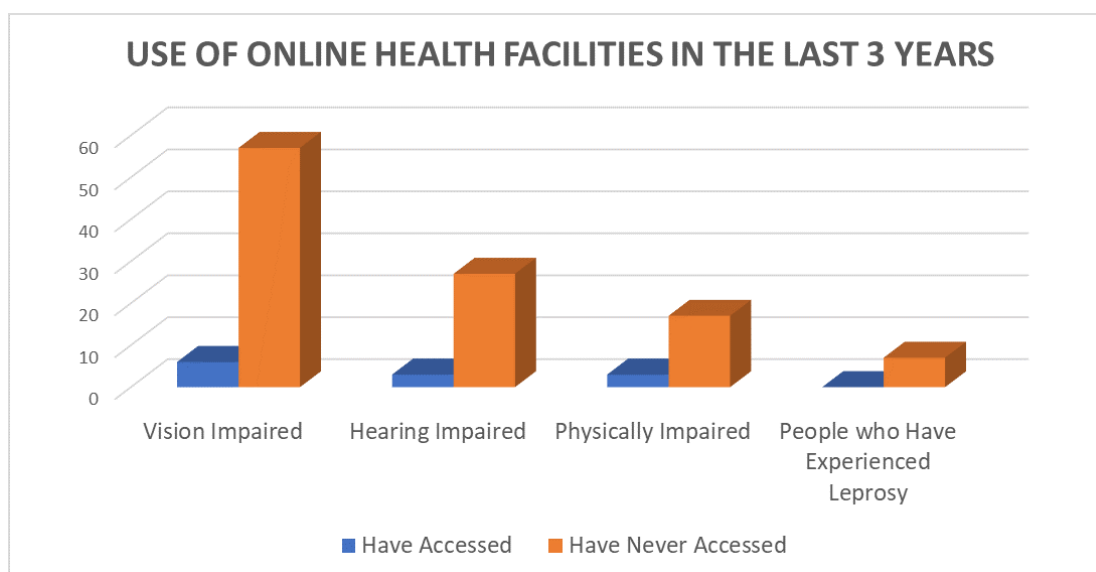
- Challenges for PwD in Indonesia are systemic. The country has yet to fully embrace principles of participation, non-discrimination and accessibility. People with disabilities often have limited access and opportunities to influence planning and development policy. Most development planning meetings in Indonesia do not provide facilities for people with disabilities (Pramana, 2018) Other significant challenges include social stigma, lack of funding for support, insufficient enforcement of existing regulations (e.g., employment opportunities), limited public sector awareness and inadequate/conflicting data.
- While some policies and programs exist to support PwD in Indonesia, they are hindered by a lack of reliable data. There is an urgent need for improved data and analysis. People with disabilities, particularly those with severe disabilities, often rely on family, friends and their social network for support. A recent survey by the *Jaringan Organisasi Penyandang Disabilitas Respon Covid-19* on the impact of COVID-19 on PwD in Indonesia (DPO Respon Covid-19 Inklusif, 2020) highlights several issues. These include inadequate information about COVID-19, primarily due to inaccessible mainstream media and internet sources. Half the disabled economy ground to a halt during

the pandemic, resulting in incomes collapsing by as much as 50 to 80 percent. Furthermore, this significant reduction in income was not offset by equitable distribution of government support. In response, disability activists and community organisations independently provided support to overcome these shortcomings (Saputra, 2020)

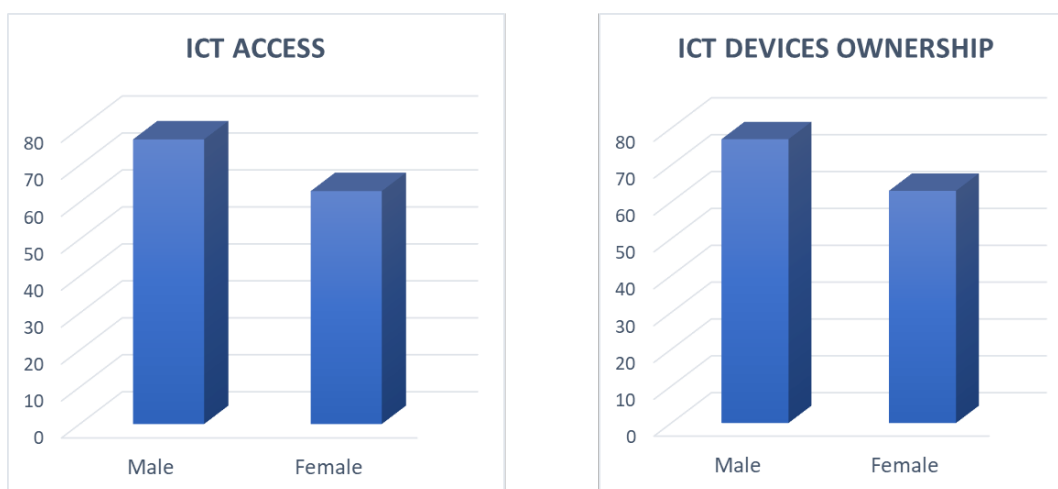
- Demographic changes have led Indonesia to be dominated by a younger generation that is highly technologically literate. This generation's skills in utilising sophisticated technology must be maximised. The latest APJII survey reports that 74 percent of the Indonesian population is now connected to the internet (APJII, 2019) This technological advancement brings opportunities to support digital health programs as the spearhead of health initiatives in Indonesia. The potential of technology in the health sector is immense. At the 58th WHO meeting, Resolution WHA58.28 was adopted, urging member countries to start planning e-Health development. The WHO also launched the Global Observatory for e-Health (GOe) to study its evolution and its impact (WHO, 2012) The use of telehealth is increasing annually, adopted by many health services. The effectiveness of e-health in delivering preventive and promotive health services has been proven in many studies. For example, e-health has been reported to help in areas like reproductive health (Gabarron & Wynn, 2016), obesity control, physical activity promotion, healthy diet encouragement, quitting smoking and managing alcohol consumption (Laranjo et. al., 2015)
- Digital technology has become an inclusive medium as it allows real-time delivery of services and information, not only for socialising but also for studying, working, travelling, health, shopping and community interaction without physical barriers. Digital technology can also improve quality of life by reducing social inequality, especially in its application in barrier-free health facilities (McCoy et.al, 2020) In some developing countries, however, the implementation of digital technology has not been fully realised, resulting in technology-based health applications still being underutilised as a means of promoting social inclusion for PwD.
- A primary concern is the interface design of digital applications. WCAG (web content accessibility guidelines) is one guideline for UI/UX designers in creating accessible web content, particularly for PwD. Adhering to these guidelines makes content more accessible to a broader range of PwD. These guidelines also ensure accessibility of web content on desktops, laptops, tablets, and mobile devices, benefiting users based on these guidelines (Kirkpatrick, et. al., 2018)

Youth with disability and access to health information

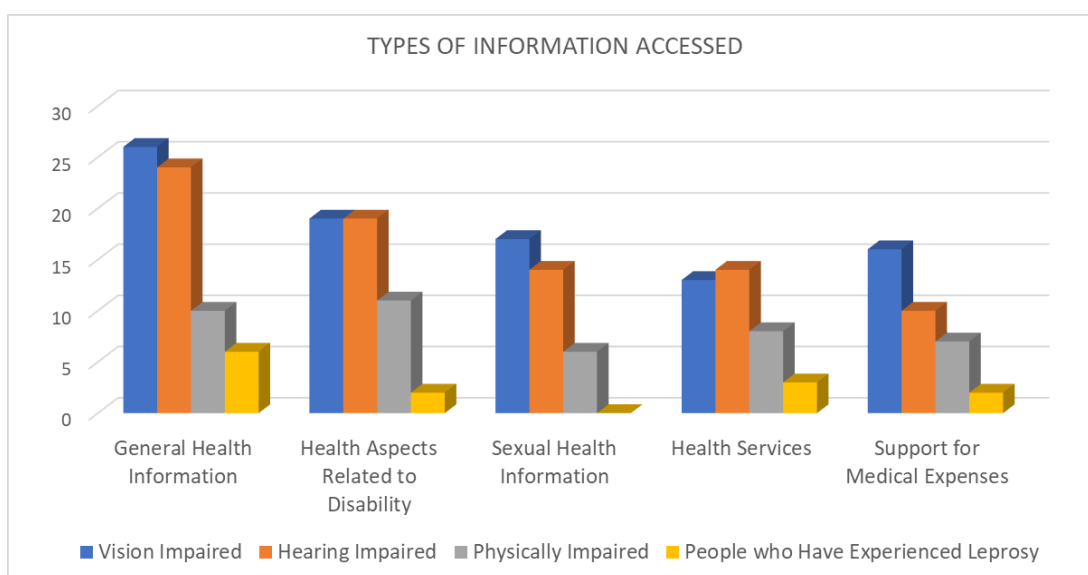
The survey provided important insights into health information and digital services for youth with disabilities. The types of disabilities included were visual impairment, hearing disabilities, physical disabilities and leprosy. Out of a total of 149 respondents, 58 percent were from Makassar, 26 percent from Gowa Regency and 16 percent from Takalar Regency (Figure 2). Of these, 60 respondents or 40.5 percent were not working. Some 50 respondents or 34 percent were still in school or were college students. Some 17 respondents were employed and the remaining 21 were self-employed.

Figure 2. Graph of the number of respondents**Figure 3. Graph of the use of online health facilities**

- Accessing health facilities** Only 10 percent of respondents have accessed online health facilities in the last three years. This includes six respondents who are vision impaired, while only three respondents each with hearing disabilities and physical disabilities have accessed such facilities. None of the respondents who have had leprosy accessed online health facilities in the last three years (Figure 3).
- ICT Access** Out of 149 respondents, 94 percent claimed to have ICT devices. This data also reveals no significant gender-based differences in accessing ICT: 54 percent of total respondents were male and the rest were female. This indicates that in terms of ownership and intensity of ICT access, male respondents are at 55 percent, only slightly more than female respondents (Figure 4).

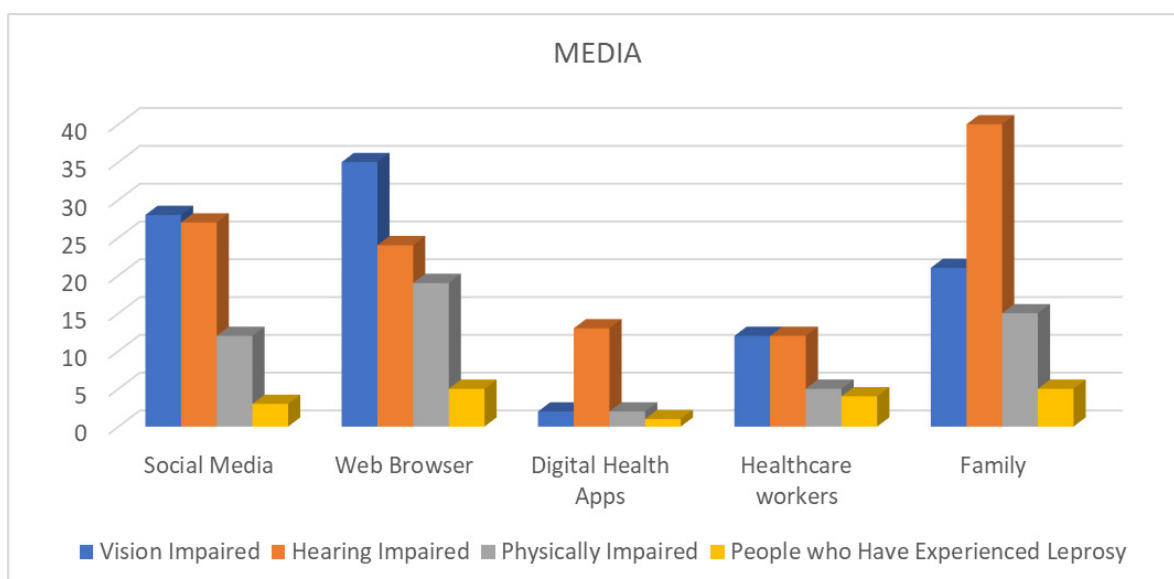
Figure 4. Graph of gender differences on ICT access

- Types of information** It was recorded that 40 percent of the total respondents accessed general health-related information, while just 30 percent sought health information specifically related to disability. Additionally, 23 percent accessed information both on sexual health and general health services, 21 percent sought information related to health care costs and information related to motivation was accessed by 32 percent of all respondents. General health information is the most frequently accessed type for those with vision impairment, hearing impairment and those who have experienced leprosy. For those with physical disabilities, however, the most frequently accessed information relates to health aspects of various types of disabilities (see Figure 6).

Figure 5. Graph of types of information accessed

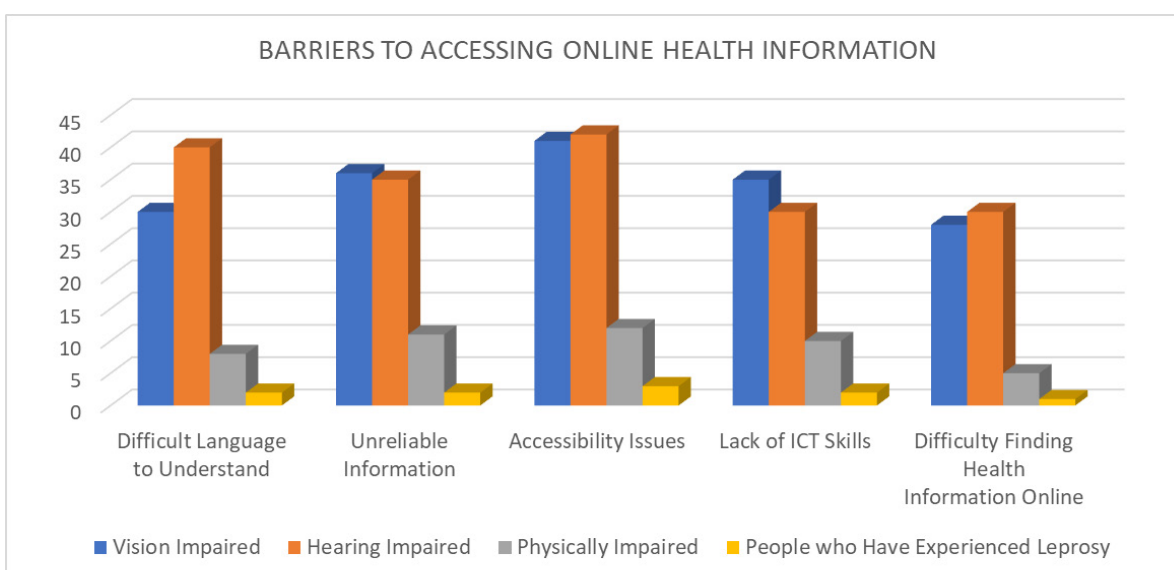
- Media** A total of 43 percent of respondents used social media to find health information, while 52 percent used a web browser. Just 11 percent accessed health information through digital applications, 20 percent sought information from healthcare workers and 50 percent turned to family for health information. For those with vision impairment and physical disabilities, social media and web browsers are the most frequently used media for seeking health information. In contrast, people with hearing disabilities often seek health information through their surrounding environment, specifically family.

Figure 6. Graph of media used in accessing information



- Barriers to accessing information** Some 51 percent of the total respondents admitted that understanding the language of health information was difficult. Other barriers included 53 percent citing distrust of information, 61 percent facing accessibility problems, 49 percent lacking skills in using ICT and 41 percent experiencing difficulties in finding information. Based on types of disability, the primary obstacle in accessing online health information is related to accessibility issues (see Figure 7).

Figure 7. Graph of barriers to accessing online health information



Understanding needs and capacity of youth with disabilities (YwD)

Focus group discussions (FGDs) were conducted with PwD in Makassar, Gowa and Takalar. The FGDs aimed to directly discuss health challenges and solutions with PwD, how they find general health information (including offline and online sources), the types of information they seek online, their use of online sources for health information, their familiarity with online health services and their level of comfort with these services.

Discussions took place in the three regions mentioned above. FGD participants were young people with various disabilities aged 18–30 years. The groups included people with sensory disabilities (blind and deaf) and people with physical disabilities (paraplegia, cerebral palsy, amputations and people who have experienced leprosy).

This project also held FGDs with PwD in Makassar, Gowa and Takalar. The FGDs explored directly with PwD, their health problems, how they handled them, how they find general health information (online and offline), what kind of information they seek online, what online sources they use to obtain background information, how they use the information, are they familiar with any online health service or information source online and how familiar are they with online health services and information sources.

Access to offline health services

The majority of participants reported frequent health issues but rarely visited clinics, hospitals, or healthcare centres. The reasons are:

- Deaf participants faced barriers such as a lack of accessible information and the absence of a sign interpreter or healthcare workers who understand sign language. Some attempted to access health services without a sign language interpreter, resulting in misunderstandings between people with deafness and healthcare workers.
- Blind participants reported never visiting health services independently due to the need for mobility orientation when visiting new places. The absence of mobility orientation programs for the blind led to reliance on family or non-blind companions to access health services, although such support is often unavailable. Another issue was the distance between their homes and healthcare facilities.
- Participants with physical disabilities mentioned inaccessible buildings, such as the absence of ramps for wheelchair users, registration tables that are too high and lack of handrails for those using crutches or prosthetic limbs.
- People who have experienced leprosy faced stigma related to their history of the disease, often being stigmatised as contagious even after recovery.

Disability organisation perception on health information and service provisions

Little information on digital health could

be extracted from key participants from disability organisations in the three research areas. Of the seven disability community participants, none could provide an example of digital health information obtained from the local government.

“As an independent leprosy association of Gowa district we have not ever received any health information or socialisation. We get support from an international organisation from Japan (Sasakawa Health Foundation) to disseminate leprosy awareness in villages. From that program we also recorded data on leprosy patients we met and search for treatment solutions for them. We have never received an initiative, for example, from the Health Office or the Information and Communications Office regarding this digital health issue. It was us who started the initiatives through support from other parties.” (P2, PwD CBO, Gowa)

The only general health information came from the mainstream media, especially regarding COVID-19 and vaccinations. Even then, the information does not meet the necessary accessibility principles. In addition, there are no examples of good practice involving the PwD communities by regional organisations such as the health office or the communication and information office in designing accessible information for the inclusion of PwD in the three research areas.

“Our deaf community organisation have never been invited by any government office to convey the needs of the deaf’s rights.” (P4, PwD CBO, Takalar)

Accessing online health services

The use of digital health services has been a lesser priority for people with disabilities in Makassar, Gowa and Takalar, as confirmed by the FGD results.

Each disability group cited various reasons. Blind participants mentioned that digital health applications have not been perceived as an urgent need to download and install on their gadgets. Additionally, those with visual impairments prefer to search for information manually through Google or watch video podcasts on YouTube. However, like others who have tried digital health service applications, they encounter features that screen reader applications cannot read.

People with deafness report finding the information in digital health service applications too complex.

There is also a lack of access in these applications for interpreters. People with physical disabilities and those who have experienced leprosy do not encounter significant obstacles in accessing digital-based health services. However, those who have experienced leprosy note the lack of current information about leprosy in digital health service applications.

Sexual and reproductive health Sexual and reproductive health remains a taboo subject among people with disabilities. Most participants feel embarrassed to talk about it, even though they acknowledge the need for information. Most also expressed discomfort with consulting about sexual health through digital health service platforms, mainly due to a lack of trust in doctors providing consultations through these applications.

Stakeholder perceptions of digital health service for PwD

Stakeholder interviews

The interview data produced the following results:

Strengthening literacy related to disability and inclusiveness

Most interviewees have minimal knowledge and literacy related to disability, accessibility and inclusive concepts. There is a significant need to strengthen understanding related to accessibility and inclusiveness for people with disabilities.

Periodic and integrated disability data collection There is a need for regular and integrated data collection on disability. Such data can be used by the government, private sector, NGOs and the general public. Most stakeholders from the four offices in these three regions reported they have no available data relating to disability.

"...So for now, we have not been intensely getting information related to disability data and lack information on public access or other media." (S8, Makassar)

"There should be data, but as far as I know there is no disability data..." (S7, Gowa)

"Regarding the type of disability, if it is directly related to us here, we have never had any activities related to disability services." (S7, Takalar)

Some also confirmed that the current data was obtained from PwD who visited their offices. As a result, the availability of this data remains incomplete because there was no formal data collection from this service.

"Oh yes, related to that, yes there is. It is not specific here, the main thing is what service is provided." (S5, Takalar)

A lack of data in these offices can be problematic for people with disabilities. Health services may lack the resources to meet the unique healthcare requirements of individuals with disabilities. Understanding, addressing and advocating for the needs and rights of individuals with disabilities relies heavily on data. Lack of data makes it difficult to design healthcare programs to cater for diverse disability needs. Furthermore, the absence of comprehensive data can hinder the development of inclusive practices, advancements in accessibility technologies and the effective implementation of policies and accommodations for people with disabilities (PwD).

Involvement of PwD in inclusive policy making

Almost all respondents from agencies stated that their

involvement of PwD and related organisations in the formulation of inclusive policies has been less than ideal. This lack of involvement is evident from the work programs, where few consider the presence and needs of PwD in society.

"Related to involving people with disabilities in these needs. Once again, I say it's still not optimal, sir." (S3, Makassar)

Another respondent mentioned that involving disability organisations could encourage the study of the needs of PwD in accessing digital health information. This approach is supported by local government regulations concerning the involvement of PwD in drafting policy. An example is in the preparation of the Bupati's (Regent's) Regulation, which originates from Regional Regulation (Perda) No. 2 of 2019, concerning the protection and services of disability rights.

"Analysis of needs first from both the government and disability organisations. People with disabilities must be able to convey their needs so that more people care, especially the government and stakeholders who can make changes and policies." (S7, Gowa)

Improving disability needs analysis Based on the results of the needs analysis, it appears that this activity is still not optimal. Some respondents also still perceive that the needs analysis primarily relates to economic problems faced by individuals with disabilities.

"Actually, this activity had been carried out, but almost three years ago. It has not been carried out anymore." (S1, Takalar)

"The program provided does not only consider the disability aspect, but also the income of the family." (S4, Takalar)

Respondents also mentioned that the current needs analysis is limited to accessing public facilities for PwD. They argue that supporting this accessibility concept requires collaboration from other agencies, considering that the program will fall within the scope of regional government organisations.

Collaboration between agencies in providing health information

Participants from four different offices in Makassar, Takalar and Gowa emphasised the importance of cooperation in supporting the provision of health information. Collaboration between agencies, particularly the health office, social service, education office and the Ministry of Communication and Information, is crucial because these stakeholders each have unique roles in supporting and designing the publication of essential information. One

respondent mentioned that health information dissemination has been conducted, although not in a digital format.

"There is indeed the work program of the puskesmas (community health centre) so that in a few months there will be more health checks. Weighing, measuring height, teeth, eyes, giving deworming medicine to drink, providing toothbrushes." (S1, Takalar)

Participants also said that special attention was needed regarding the minimal role of digitalisation in disseminating health information for people with disabilities. Platform development can be done by involving users and related agencies to meet the need for information.

"We need programs to support access to health, education and social information. Collaboration and partnership are needed that have partnership values. There needs to be collaboration in platform development." (S8, Makassar)

There was also provision for health information collected by the office that did not reach people with a disability.

"Actually, in Makassar City, there is a kind of mobile car that helps check the condition of the community. But I also haven't seen its role for people with disabilities." (S4, Takalar)

Analysis of the needs of users who are people with disabilities and system developers The interviewee argued that developing a health information platform for PwD is both useful and challenging. This complexity arises from the need to identify the many different types of disabilities during a needs analysis for users with disabilities in future developments.

"It is hoped that the health information provided to people with disabilities is balanced, it's not the content that is important but the method, the content is the same for both disabled and non-disabled, but if the waves are not the same, the information will not automatically arrive." (S5, Gowa)

Issues related to the many types of disability in digital platform development The many types of disabilities present a major challenge when developing digital platforms. Several participants also noted a lack of tools to facilitate reading and writing for PwD.

"In fact, the first thing that must be considered is that they must have cellphones first." (S1, Takalar)

Challenges faced by developers and agencies in digital health inclusion Digital health agencies acknowledged there are challenges in terms of a

lack of money and a shortage of skilled staff. In some districts/cities, however, there is a readiness to develop applications or digital platforms, making the best of what is available. Currently, these entities are waiting for collaboration opportunities and regulations/policies from the government to maximise the efficacy of the planned program.

"What I see is this (the infrastructure) is ready, but the applications and content are not there. Because this is quite urgent, we need policies and institutions." (S8, Makassar)

One participant from the Ministry of Communication and Information also emphasised that the agency can be relied upon to propose and develop the concept of digital health for persons with disabilities.

"Not only disability, all things related to digitisation, the Ministry of Communication and Information (Kominfo) will be at the forefront. Kominfo is ready if asked to be a pioneer by the Regent in providing digital health care for people with disabilities." (S8, Gowa)

Regulations and workshops on designing a conceptual model of inclusive digital health care

Respondents expressed the need for collaboration between agencies to improve regulations within regional work units (SKPD). This collaboration is essential for creating annual work programs that incorporate inclusive digital health concepts.

"Disability issues need multi-sector collaboration. If necessary, the involvement of all regional work units (SKPD) with their respective roles. The aim is to achieve the vision and mission of a disability-friendly Gowa. This will be homework in the preparation of the RPJMD to be the attention of the regional work units." (S7, Gowa)

The design concept to be developed should not only be based on content but also methods and the provision of accessible infrastructure. Health literacy and the role of disability organisations are considered significant based on participants' perceptions.

"The development of health information media for people with disabilities does not focus on content but on methods, involving health workers such as cadres, providing accessibility infrastructure, real databases, and the involvement of disability organisations is very important." (S5, Gowa)

Other respondents said that prior to designing an inclusive digital health conceptual model, it is necessary to have a workshop.

"There needs to be technical guidance first then proceed to the development level. Because there are some people with disabilities who only have Android phones but are limited in terms of access because they may not be able to read." (S8, Takalar)

A. Healthcare worker perception of health information dissemination for PwD

Nine health professionals from five different workplaces and seven health professions participated in the focus group discussions. Five key themes emerged: Unequal distribution of special facilities for disability priority services, limited involvement of PwD in health programs/services, lack of understanding of healthcare workers and practitioners about inclusive health services for PwD, healthcare workers' perceptions of the increasing workload with the presence of digital health services and healthcare workers' expectations about access and features of digital health services.

From the data, we obtained the following results:

- Unequal distribution of special facilities for disability priority services
There are no priority health care facilities for PwD in Makassar. However, healthcare workers indicated there was a priority queue, to reduce waiting time, for PwD along with other priority patients such as people who are elderly or pregnant.
.
"They have a service line, so for those with disabilities, the same as the elderly, they have their own queue number and they shouldn't be given long queues." (N1)
- The patients also receive accelerated access to obtain health services and assistance during the process.
"so the service line is accelerated... if they meet a doctor as soon as they register, they are immediately escorted to the doctor, they will be accompanied, starting from when they arrive until they meet the doctor for taking medicine until they go home and then they are released by the officer" (N2)
- There are also healthcare workers who say that there is no priority access for people with disabilities in their health services, however, and that the queue counter is the same as for general patients.
"Regarding the special route, for now there is no special route for patients with disabilities." (N3)
- If the patients are not old or they are sufficiently fit (apart from their disabilities), the patients will be treated just like any other to avoid patients thinking they are being treated differently.

"For example, in terms of age, if someone is old, we must put them first. So in terms of age, the patient still looks really fit, so we don't (prioritise) them. Because we don't mean to differentiate them from other general patients... because they don't want to be treated like this, they end up feeling different. So, they can sit together with other common patients." (N4)

- Limited involvement of people with disabilities in health programs/services
The participation of PwD in health programs is limited, and the number of PwD is small, so there are few programs that involve PwD.

"The data for the disabled have not been fully collected at this time, because we are at the community health centre, we are not yet too concerned about it. There may not be many activities for disability people there, because the numbers aren't that big, so we focus on other health problems that are considered from a health perspective, so that's pretty much what we do." (N9)

Healthcare workers at the community health centre said that patients with disabilities prefer not to involve themselves directly for treatment or activities in community health centres because they think by doing so the process will be much faster.

"They prefer to bring a companion instead of coming alone. It seems that they prefer to be accompanied, even though they may actually be able to be independent, just to make it faster, for example, if they want to take a referral. For example: they will ask their companion to be with them and let their companion talk. So regarding independence, people with disability rarely come alone." (N4)

Participation and engagement with health workers is limited because even when requesting a referral letter to visit a hospital, the patients or family choose not to involve the patient directly.

"Usually if for example they have matters in a community health centre or if they are sick, sometimes they are too lazy to come to the health centre directly, usually their family will come. For example, if a patient asks for a referral or something, the family just needs to bring a letter. So there is no need for patients with disabilities to queue anymore because the family does the work." (N3)

- Lack of understanding about inclusive health services among healthcare workers
It is apparent that among health workers and practitioners there is a lack of understanding about services for PwD. Communicating between health workers and those with disability often involves using basic gestures..



Focus group discussion underway in Makassar

“Gestures, more like gestures. We can only use very general body language, for example: if we want them to drink, we show it like this and if we want to refer to eating, we show it like this.” (N7)

In communication, the health workers also rely on family.

“The communication is with the companion because it is really difficult for us to dig up information directly from them.” (N6)

Communicating and engaging with patients are usually aided by health cadres who know about patients with disability conditions. A health cadre is a worker who comes from the community and is chosen by the community and then trained to work together for the community voluntarily to deal with health problems in the community.

“Usually we got the information from the cadres, for example the health problems of the patients. Because with the cadre, the patients will inform the health officer, after that we as health offices will go directly to meet the patients.” (N8)

Due to the lack of skill in communicating with patients with disability, healthcare workers suggest that training is needed to maximise interaction, communication and deliver information to patients with disabilities.

“So I think there needs to be knowledge or skill for special services like that. Such as knowledge and skill related to visually impaired patients. Soft skills, basic soft skills for health officers. Maybe training on communication so that at least the health workers know. Because communication can have different understanding from one person to another.” (N7)

“To focus more, I think because my job is related to health promotion, I hope the health services given can be supported by communication training for health workers that is specifically for disabilities. Actually, by that, it can also support the delivery of health information to patients.” (N3)

- *Healthcare workers' perceptions of the increasing workload with the presence of digital health services*
Technology, information and digitalisation are developing rapidly and this has impacted the health sector. There are now digital-based health services that facilitate services without requiring face-to-face meetings.

Doctors surveyed stated that digital health services are indeed easy to access, but are not necessarily effective if they have to be done in conjunction with operational working hours. This is because there are likely to be difficulties in dividing the time in providing services directly and online. There is also concern that if digital health services are used outside of operational hours, it may reduce a health practitioner's time for rest and spending time with family.

“Something like that probably might be hectic, right? Maybe it's because the health workers will not have time to rest. I am not saying we do not want to. But we need to consider our working hours are up to this hour and our time for family is up to this hour.” (N4)

Additionally, it is presumed that the adoption of digital health services will lead to a greater workload for healthcare professionals. This situation would result in their attention being split between providing on-site patient care and attending to individuals seeking services online.

"We have busy schedules at the health centre, then if we add more things to do especially at the same time, if we set the schedule together with our work schedule, it will be challenging who will be served first, our cellphone or our patient. It will also take a long time. For example, there is a chat from a patient on the cellphone, then we are also seeing patients, so our focus will definitely be divided. And if we are at home it is not possible, because we need to arrange time for family." (N1)

- **Healthcare workers' expectations about access to and features of digital health services**

Health workers made several suggestions for improvement. They mentioned that it is better if digital health platforms are in the form of websites that can be accessed with a barcode without having to download an application. Digital health services that require users to download applications are considered difficult, because not all users have sufficient storage space.

"Nowadays it is pretty cool that we can just use a barcode. we scan directly and it appears. because if you download it's a problem too. Because there are various kinds of applications now, TB friends, Peduli Lindungi. So, the problem is there, if we ask them to download the app, they say their storage is full, so we just use barcodes, faster access." (N6)

"Yes, it would be even better if there was a barcode, even more efficient. then it can be shown with video. Depending on what information you need, the video is there." (N8)

Several health workers recommended features that should be available in a digital health platform for people with disabilities, such as the ability of health

workers to provide their own information and a brief introduction about diseases and maintaining a healthy lifestyle.

"For example, the input is that we as healthcare workers can write or provide information on the platform, for example, if patients want to look for health information, they can do it independently. They can scan using their cell phone and from their cell phone can have a voice saying this information and that information." (N4)

"So, for example, reproductive health information exists, they just need to click and play or listen alone, then there is information about mental health or reproductive health and so on." (N6)

"And don't make videos that are long, just simple ones, that means just introductions, such as those related to diabetes or tuberculosis, clean and healthy lifestyle and like how the symptoms and treatment are. But the video must be short, because if it's long, it's usually boring" (N5)

Several health workers mentioned the delivery of information can include short video, audio and animation features so the patients can find it interesting.

"Maybe.. I think people are more interested in animation. Sometimes people are more interested because it's funny, compared to things that are too formal, right? Sometimes people are more interested in the animation." (N1)

"If I can suggest, it would be great if there is a video. Sometimes, people are too lazy to read, so with the video, there will be voice or audio at the same time." (N5)



A PWD focus group discussion in Takalar

Health workers also expect patients to use the digital platform to register before attending community health centres. The data of patients can be synchronised with their queue number and the health workers can be prepared with information about a patient's condition before they come to the community health centre or clinic.

“ a platform that can be accessed from home, from school, or from patient's companion, so that the patient's complaint can be sent from his home. Patients can register themselves. The patient's companion also can provide data on patients' complaints so it doesn't take a long time when they come to the community health centre, so it will be more efficient... In addition, patient data can also be synchronised between the main complaint and their queue number at the Puskesmas. Therefore, we can know the condition of the patients so we are better prepared, whether these people who will come need a wheelchair or we need to prepare what they need.” (N6)

Youth with disabilities and digital health platforms

We wanted to understand how PwD would interact with a digital health platform based upon their experiences. To find out more, we used a participatory design. A participatory design is a multidisciplinary approach that relies on the participation of users to enhance understanding of their needs. In a user-centred design, the extent of user participation can vary, with user inclusion potentially spanning the entire design process (Sarmiento-Pelayo, 2015). A co-design workshop is a tool that enables participants to generate, test and refine ideas. These workshops often use storytelling scenarios or case studies as a grounding context for creative brainstorming, ideation and prototyping.

The co-design workshop, attended by YwD who are blind or vision impaired, focused on one type of disability to allow specific characteristics to emerge. Participants engaged in activities including discussions on the cultural sensitivity of sexual health, examination of existing platforms and ideation. The workshop provided meaningful insights into participants' lives concerning social networks and relationships, as well as socio-cultural factors that may inform the design of such platforms. These insights include:

- Many PwD are often isolated due to limited mobility and other barriers, with their network typically confined to family, relatives, and friends met at Sekolah Luar Biasa (SLB), or special needs schools.
- There are ingrained stigma problems within families and communities, often impeding opportunities for PwD to find partners and start families.
- The topic of sexual relationships, including finding partners, is perceived as sensitive. Many participants hope to find partners but are uncomfortable with others knowing, suggesting the platform should be framed as one for finding friends rather than a dating platform.

- Participants expressed a preference for self-representation that reveals their disability only when another user shows interest.
- Platform should be designed for PwD and non-disabled users but should include interaction and communication guidelines for different types of disabilities.
- Accessibility of features and content is of the utmost importance.

Wider stakeholder dissemination and buy-in

A symposium was held on September 30, 2022, at the Swiss-Belhotel Makassar. This event involved stakeholders from various government agencies relevant to services for PwD, including the Health Office, Social Service, Communications and Information Office and Education Office. The event was attended by representatives of PwD from several disability organisations, along with representatives of health centres and healthcare workers/practitioners. The team presented their tentative findings from the survey, focus group discussions and interviews, along with some recommendations.

The activity commenced with an opening speech from the Makassar government, represented by an expert assistant in the field of Makassar city development.

The symposium also included a discussion with participants. Participants were enthusiastic, with many expressions of appreciation coming not only from stakeholders but also from representatives of disability organisations. The event was also seen as an opportunity for PwD communities to meet and discuss their needs with stakeholders, particularly in health services. One participant, a parent of a child with a disability, expressed gratitude for being involved in this research process. She said it provided her with an opportunity to clarify information directly with stakeholders, especially regarding her daughter's engagement in government-driven activities and issues related to the database of PwD.

The symposium involved the following:

- Increased understanding between agency actors and the disability community.
- Dissemination of results and recommendations.
- Interactive discussion to understand stakeholders' perceptions of findings.
- Conveying stakeholders' expectations for collaboration between sectors on programs and activities to support PwD.

4.0. FINDINGS AND RECOMMENDATIONS: TOWARDS A DIGITAL HEALTH INCLUSION FRAMEWORK

Based on our findings, we present a preliminary framework of digital health inclusion to support the work of leaders and developers in the industry, health systems operations and academia. This framework adopts the health disparity principles incorporating the digital environment domain developed by Richardson et al.(2022) with a particular focus on PwD. Digital domain of health encompasses factors that impact various health, functionality, and quality of life outcomes and associated risks. These determinants involve aspects such as the availability of technological resources, digital literacy, and community infrastructure. The influence of the digital domain of health extends across individual, interpersonal, community, and societal levels (Richardson et al., 2022). We map the findings at the individual, interpersonal, community and societal levels.

- **Individual-level determinants.**

Determinants at this level include digital literacy, digital accessibility, digital self-efficacy and digital acceptance. Digital literacy is defined as the ability to find, access and evaluate information using digital platforms. Participants with sensory disabilities, especially those who are deaf, face barriers due to a lack of accessible information and the absence of sign language interpreters. Blind participants prefer manual searches and face challenges with screen reader limitations in digital health applications. For example, deaf people struggle with the complex language used in current healthcare applications. Inclusive user interface design is crucial for increasing usability for those with low digital literacy. Digital self-efficacy is the belief in one's ability to solve technological problems. Our participants exhibit varying levels of comfort with digital health services. Addressing limitations in digital self-efficacy involves improving the compatibility of digital health applications with assistive technologies. Digital acceptance refers to understanding and



A PwD focus group discussion, this time held at Gowa

attitudes toward the use of digital technology, including awareness of technology, perceived usefulness and trustworthiness. Participants express discomfort with using digital health services for sensitive topics like sexual and reproductive health, indicating potential trust issues. Addressing attitudes towards use involves building trust and ensuring that digital health services are designed with sensitivity to the unique concerns of individuals with disabilities.

- **Interpersonal-level determinants.** These are factors describing the relational aspects linking individuals to both digital health technologies and one another. These include the availability of digital health information, interdependence, PwD-technology-healthcare worker relationships. FGDs with PwD revealed concerns about the availability of information related to leprosy. Interdependence is evident in the reliance on family or experts for health information access. The relationship between PwD and healthcare workers also requires attention. Lack of awareness in communicating with patients with disabilities has been seen as barriers in providing health service. Designing digital health platforms with a focus on preserving and enhancing the patient-tech-clinician relationship is vital.
- **Community-level determinants.** These include disability-friendly digital health infrastructure and government technology infrastructure. Disability-friendly digital healthcare infrastructure refers to community access, particularly for PwD, to health systems through applications and online content design (WCAG standard) to enable self-sufficiency, participation and collaboration. Government technology infrastructure encompasses infrastructure and broadband access, quality, and affordability. Health systems should partner with other agencies including disability organisations and organisations with training expertise in digital health development.
- **Societal-level determinants.** These encompass local policies supporting digital healthcare adoption, availability of disability data from regional agencies, and social norms. Social norms dictate beliefs and philosophies influencing who develops digital tools, what is developed, how it is used and by whom.

Table 2. A framework for digital health inclusion

Level of Influence			
Individual	Interpersonal	Community	Societal
Inclusive design of user interface for increased usability for those with low digital literacy (Digital Literacy)	The availability of digital health information	Disability-friendly healthcare infrastructure (design standard)	Local Policies supporting digital healthcare adoption.
Technological equipment availability and accessibility	PwD-Tech-Healthcare worker	Government Tech Infrastructure	The availability of disability data from regional agencies
Digital self-efficacy	Implicit Tech Bias		Social norms
Acceptance of digital health applications globally (Digital acceptance)			

Recommendations

Strengthen the digital literacy skills of PwD. We recommend training in digital literacy for people in the diffable community. A high standard of digital literacy can help PwD gain access to a greater range of health services. Improved digital literacy training could be achieved by working closely with educational institutions, disability organisations and technology experts to develop customised learning modules. Designers of policies or programs need to foster an approach that is focused on the needs of PwD ('user centric').

Strengthen disability and inclusiveness literacy among key stakeholders. Disability awareness and inclusive principles need to be incorporated into new and ongoing educational programs for healthcare professionals and other key stakeholders. This can contribute to an educational environment that is relevant and fully meets the needs of PwD. Cooperation with disability organisations to design education programs that emphasise digital health inclusivity is crucial in achieving this goal.

Develop inclusive digital health policies and programs. Meaningful engagement of PwD in digital health programs and policies can contribute to better health outcomes. We recommend the establishment of comprehensive guidelines for PwD engagement in the planning, implementation and evaluation of inclusive healthcare programs and policies. The involvement of PwD in the development of initiatives needs to be prioritised with a focus on fostering an inclusive and responsive healthcare system. Government health departments should develop partnerships with disability organisations and make this a priority for the planning of programs and policies.

Encourage collaboration between agencies to share disability-related data and insights. There needs to be more effective sharing of data between agencies and departments to identify and overcome a wider array of challenges experienced by PwD. This needs to go beyond economics and also examine social issues. A systematic and standardised data collection approach can contribute to more meaningful cooperation between agencies. Government leadership is required in this area, particularly in terms of resource allocation.



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6.0. STAKEHOLDERS

- Communication and Informatics Department, Gowa
- Communication and Informatics Department, Takalar Regency
- Education Office, Makassar
- Education Office, Gowa
- Kaluku Bodoa Public Health Center
- Maccini Sawah Public Health Center
- Public Health Office, Gowa
- Public Health Office, Takalar Regency
- Social Services Office, Gowa
- Social Services Office, Makassar
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