

# HEALTH LITERACY IN THE DIGITAL WORLD - REPORT

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## INTRODUCTION

According to the United Nations 2030 Agenda for Sustainable Development, the spread of information and communications technology and global interconnectedness has great potential to accelerate human progress, to bridge the digital divide and to develop knowledge societies. This realization birthed the WHO's Global Strategy on Digital Health 2020-2025 which indicated that the digital transformation of health systems is critical. It emphasized on 4 action points (1) commit - for the implementation of the global strategy on digital health (2) catalyze- generation of a cooperative environment that is conducive to the creation, introduction and scaling up of appropriate digital health technologies (3) measure- to create and adopt processes and metrics for monitoring and evaluation (4) enhance and iterate- to respond to feedback and adapt to emerging digital health technologies. Similarly, The APEC Conference on Digital Healthcare Innovation concluded that Information and Communications Technology (ICTs) currently linked to the fields of health and medical care can provide healthcare professionals with more extensive and efficient tools for healthcare delivery by applying digital health data, wearable & sensors devices and

smartphones apps to disease management, telehealth, and careful monitoring.

Digital transformation of health care can be disruptive; however, technologies such as virtual care, artificial intelligence, smart wearables, tools enabling data exchange and storage across the health ecosystem create a continuum of care that have proven potential to enhance health outcomes by improving medical diagnosis, data-based treatment decisions, digital therapeutics, clinical trials, self-management of care and person-centered care as well as creating more evidence-based knowledge, skills and competence for professionals to support health care.

The chair and moderator of the session, Einstein Rojas, board member, Philippine Alliance of Patient Organizations set context to the session topic **“Health Literacy In The Digital World: Patient Empowerment With The Right Tools And Knowledge”** by sharing the emotional, financial, and physical burden his family faced when his father was struggling with stage 4 laryngeal cancer. He delved into the importance of appropriate health literacy and accessibility to resources when coping with a medical emergency. The costs borne by a person who is

ignorant of the intricacies of his own body and illnesses can be up to 4 times that of a person equipped with the right knowledge regarding healthcare. With this in mind, Mr. Einstein invited 5 honorable speakers to discuss the following:

- Addressing misinformation- **Dr. Usha Rani**, Associate Professor and Coordinator, Manipal Health Literacy Unit
- Is digital a unifier or devisor- **Pru Etcheverry**, Director, Advocacy Answers, New Zealand



### Addressing Misinformation

Dr. Usha opened the discussion by defining digital healthcare misinformation, as health-related information claims that is based on anecdotal evidence, false, or misleading owing to the lack of existing scientific knowledge on the topic. She pointed out how people are quick to go on the internet to look up information regarding healthcare while paying ill attention to the source of the information. There are several questions that need to be pondered upon when researching the source such as, if it's an industry- Is it promotional? academy- Is it updated? agency/blogger- Is it paid/ Is it authenticated? She also stressed the responsibility borne by influential figures when promoting healthcare.

There are several factors that contribute to misinformation:

- Health literacy from the HCP perspective - **Prof Dr. Peter Chang**, President, Asian Health Literacy Association
  - Tools for Health literacy: Industry perspective - **Dr. Arshiya Zaheer**, Patient Engagement Lead, JCAP, MSD
  - Patient friendly communication- **Ms. Araceli Lanorio**, Patient leader, Neurofibromatosis Friends, Philippines
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- Social Media and Online Platforms:
    - Allows information to spread rapidly.
    - Algorithms on platforms may prioritize sensational content, that can amplify the reach.
  - Lack of Health Literacy:
    - Individuals with low health literacy may struggle to understand the data and complex medical terms or scientific jargon can be misinterpreted.
  - Cognitive Biases:
    - People may be more likely to accept and share information that aligns with their existing beliefs.
  - Anecdotal Evidence:
    - Emotional stories can override critical thinking.
  - Influence of Authority Figures

- Lack of Regulation:
  - Unverified or pseudoscientific content may be presented as legitimate health information.
- Fear and Uncertainty
- Selective Reporting and Cherry-Picking Data
  - Isolated or incomplete data taken out of context.
  - Having addressed the causes and disseminators of misinformation, Dr. Usha moved the conversation to the

consequences it has both at the community and personal level, some of them being hazard to personal safety, wastage of resources, and negative impact on mental health. One of the biggest hurdles in attaining health literacy is individuals facing difficulty comprehending diverse medical terminology, an issue that needs to be tackled via both an individualistic and joint approach.

At the Individual’s level, she talked about the implementation of the **ABCD** approach to addressing misinformation.



Figure 2

A joint approach includes implementation of legal policies, awareness campaigns, moderated use of the mass media, social support, and promotion of digital health literacy etc.

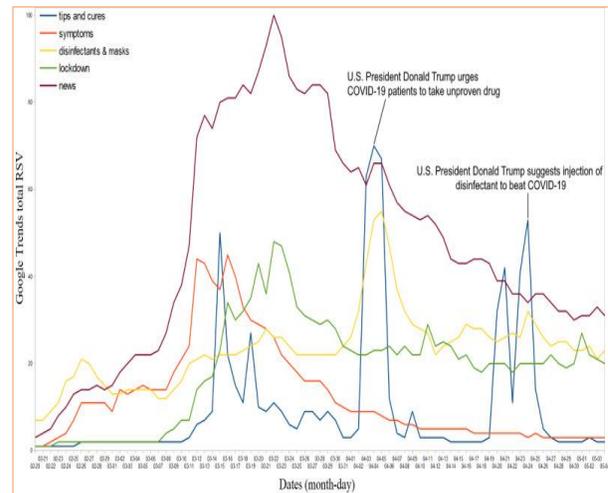


Figure 1- Top global web searches related to health, precautions, and COVID-19 news showcasing misinformation spikes due to the public statements of former President Donald Trump (RSV: relative search volume)



## Is digital a unifier or deviator?

Ms. Pru briefly spoke on need for digital awareness and her experience when she became a consumer of the healthcare system due to a medical emergency. She talked about digital literacy being a unifier as it helps in bridging geographical barriers, reduces costs and inefficiency, connects the community, and promotes inclusivity. However, not everyone has access to the advantages of digital tools. Sometimes even when the digital tools are accessible and affordable, they do not help the patients and can even work towards adding to the stress of the recipients.

The patient is often not in control over the healthcare services they receive. Furthermore,

not every patient is able to keep up with changing technologies, which makes it crucial for them to be placed at the center when designing digital healthcare tools. Digitalization is essential in today's healthcare system; however it is even more vital to value and embed patient experience, understand patient needs, and discern how patients would like to receive information to ensure equity, inclusivity, sensitivity, affordability and accessibility. Digital technologies provide valuable solutions for health; however, health inequity will be amplified if digital interventions are not being considered through a health literacy and health equity lens.

I came across the story of a school in New Zealand where the students were given free laptops to study at home during covid but were only able to use them during late in the night since the family members of the students were using it first for their personal reasons. Not only did it not help the students study, rather it severely affected their sleep and mental health. Sometimes decisions made by policy makers fail to serve their purpose due to the lack of inclusion of the voice of the right stakeholders, something that is essential in understanding needs of the patients and attaining health literacy.



## Health literacy from the HCP perspective

Prof. Dr. Peter Chang brought into discussion a physician's perspective on health literacy. He laid emphasis on the need to bring patients and HCP (Health Care Providers) at the same table when discussing healthcare to promote empathy, tolerance, and understanding in the HCPs. According to NHS (National Health Service-United Kingdom); 61% adults struggle to understand health information that contains

both words and numbers. He briefed upon the experience of losing several of his patients during COVID 19 due to healthcare services not being patient friendly and underscored the need to lower the barriers to make health services inclusive. To ensure proper dissemination and implementation of health literacy, intricate channels of communication are imperative amongst the HCPs, patients, families, communities, and social work.

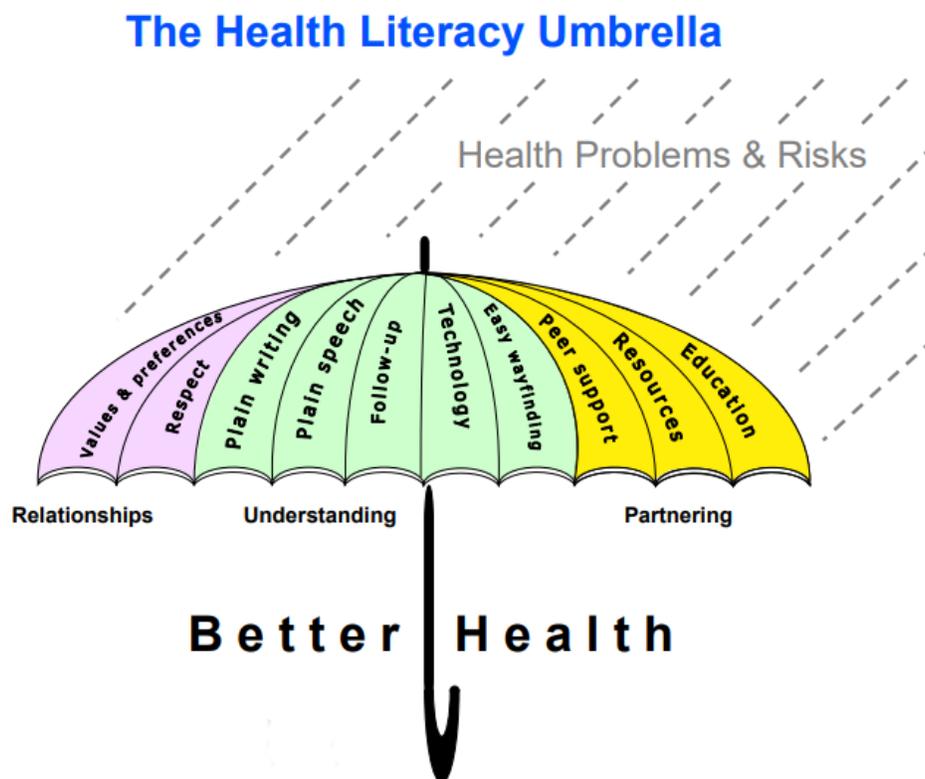


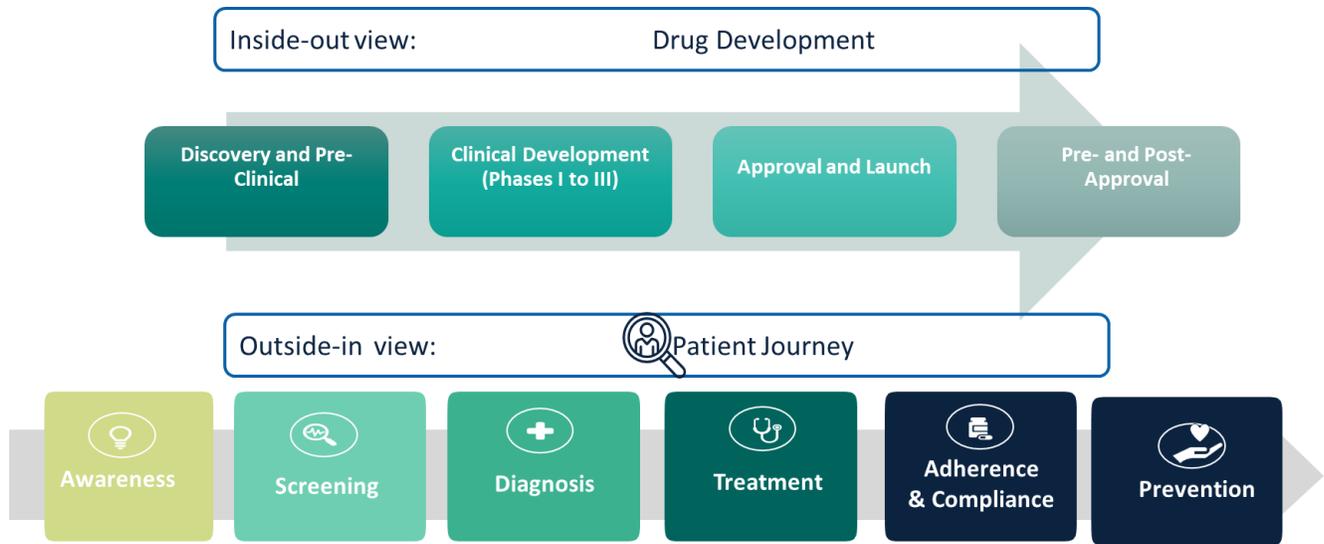
Figure 3- Developed by the Health Literacy in Communities Prototype Faculty: Connie Davis, Kelly McQuillen, Irv Rootman, Leona Gadsby, Lori Walker, Marina Niks, Cheryl Rivard, Shirley Sze, and Angela Hovis with Joanne Protheroe, July 2009. IMPACT BC.



## Tools for Health literacy: Industry perspective

Dr. Arshiya Zaheer brought the next perspective into the discussion by talking about the industry's role in health literacy. She walked the audience through the steps taken to integrate patient voice at each stage of the industrial process. As depicted in figure 4, there are several stages in the drug development process:

1. Patient involvement is pivotal to discover unmet medical needs via data mining at the **discovery and pre-clinical** stage.
2. "Patient Friendly Clinical Trial Protocols" are necessary for better recruitment and retention of patients in the **clinical trials**. These protocols are written in simple language, with the help of visual aids, for better understanding of research.
3. Digital tools such as QR codes, informational videos, infographics, AI chatbots, etc. are used during **approval and launch** to ensure inclusivity of all stakeholders.
4. Numeral adherence tools, compliance tools, and informative websites are used **post-launch** for the retention of stakeholders, while also ensuring the availability of data such as the right dosage, appropriate follow-ups, side-effects, and make of drug. One of the biggest barriers faced while trying to integrate patient voices in the industry is the absence of collaboration between the pharmaceutical agencies and the patients, due to lack of trust and ignorance. To ensure the inclusivity of patients and stakeholders at all levels of the drug development process, they need to be equipped with the right knowledge using various health literacy tools, which emphasizes the need for collaborations between the industry, government, patient groups, caregivers and the patients themselves. It is important is to understand the language and requirements of the patients and provide them with coherent information in a layman language to ensure they are up to date with the advancements in the healthcare system. Shared decision making through digitalization of health literacy is of essence to ensure the right information is dispersed using the right means to the right people via the right modes of communication. Dr. Arshiya spoke on "gamification" of information, a strategic method to enhance the mode of distribution of scientific data by creating experiences similar to those when playing games in order to motivate and engage patients. Using creative ways such as gamification, not only ensures patient engagement, but also skips the technical jargon associated with educational materials conventionally available in the healthcare sector.



*\*Adapted from Innovative Medicines Initiative Framework and Duke / CTTI's Patient Groups & Clinical Trials Project*



### Patient friendly communication

Ms. Araceli Lanorio, took upon the closing topic of the panel by discussing various patient friendly means of communication. She addressed the question of what defines communication as patient friendly for both literate and non-literate individuals. Use of visual aids, digital technology, clear and simple language, and access to interpreter services are

some of the means to ensure culturally sensitive and inclusive patient education materials. Digital health literacy has a vast scope in equipping the public with the right knowledge, community building, promoting communication, addressing FAQs, simplifying scientific terminology, and increasing accessibility to a broader audience.

<p><b>SCIENTIFIC ABSTRACTS</b></p> 	<p><b>CLINICAL TRIAL COMMUNICATION</b></p> 	<p><b>RESEARCH CONCLUSIONS</b></p> 
<ul style="list-style-type: none"> <li><input checked="" type="checkbox"/> SIMPLIFIED COMPLEX TERMS</li> <li><input checked="" type="checkbox"/> FOCUSES ON IMPORTANT FINDINGS</li> <li><input checked="" type="checkbox"/> USES EVERYDAY LANGUAGE</li> </ul>	<ul style="list-style-type: none"> <li><input checked="" type="checkbox"/> CLEAR EXPLANATION OF PROCEDURES</li> <li><input checked="" type="checkbox"/> POTENTIAL BENEFITS &amp; RISKS IN SIMPLE TERMS</li> </ul>	<ul style="list-style-type: none"> <li><input checked="" type="checkbox"/> SIMPLIFIED SUMMARY OF OUTCOMES</li> <li><input checked="" type="checkbox"/> ACCESSIBLE TO BROADER AUDIENCE</li> </ul>

Figure 5- Ways of making scientific abstracts, clinical trial communication, and research conclusions easy for everyone to understand.

Patient friendly communication is like having a friendly chat with a caring neighbor, not a confusing talk with a science wizard.

## WAY FORWARD

1. Conduct a survey amongst patient groups and organisations to understand the gaps in health literacy. Possible publication of a paper and presentation at the AHLA conference 2025.
2. Develop a modular training format for improving health literacy with a focus on digital health.
3. Conduct a webinar series on health literacy and the need for patient friendly communication with relevant stakeholders (hospital heads, HCPS and policy makers)
4. Develop interactive health literacy tools for one therapy area using gamification, interactive design and cartoonisation.
5. Develop a podcast series on good practices of communication with five HCPS.
6. Social media campaign (one month) on misinformation and disinformation and the need to verify information.
7. Partnership with Prasanna school of public health and joint proposals for promoting health literacy in the Asia Pacific Region

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