## **Annual Report**

## 2022

**United Nations Internet Governance Forum** 

## **Dynamic Coalition**

on

## **Data Drive Health Technologies**

## DCDDHT

## 2022 DC DDHT Annual Report

### **Mission Statement**

Mission Statement of the United Nations Internet Governance Forum (IGF) Recognized Dynamic Coalition on Data Driven Health Technologies (DC DDHT):

The Dynamic Coalition on Data Driven Health Technologies facilitates a multistakeholder dialogue on the topic of the internet and e-Health, m-Health (mobile), internet of medical things and e-wellness technologies, so as to seek common ground on values, principles, ethics, norms, culture, standards, best practices and so forth.

Knowledge sharing and open communication between multi-stakeholders, with collaboration, assists innovation and delivery of quality eHealth Care products and services. Technology tools and devices, access by the internet, data sharing and use on the Internet, Medical Internet of Things and Wellness Internet, enable, the mandates of the United Nations Sustainable Development Goals (SDG), and in particular, Goal Number Three. SDG Goal #3 seeks to ensure Health and Well-Being for all, at every stage of life.

The Dynamic Coalition takes a global citizen centered approach on all matters.

## Acknowledgements

The United Nations Internet Governance Forum IGF Secretariat. has provided us with invaluable support through-out the year and we wish to thank in particular, Sorina Teleanu. We want to note DC member Robert Guerra for technical administrative support of the Dynamic Coalition (DC).

Stakeholder members support the administration of the DC and we welcome Dr Amado Espinosa (Mexico) and June Parris (Barbados) both former Internet Governance Forum (IGF) Multi-stakeholder Advisory Group (MAG) members to the team.

We thank our invited guest speakers for their invaluable contribution to the discussions we have had over the course of the year. We encourage our session participants to continue to deepen and enhance our public discussions with their insights. We thank members of other IGF Dynamic Coalitions for collaborating with us at our events

We wish to thank our new coalition members for joining us, and all our members for enriching our Dynamic Coalition's body of knowledge. We look forward to interesting discussions with all.

The Dynamic Coalition members were supported by their families, friends, employers and professors in their valuable work and we express our warmest thank you to all of them.

### 2022 DC DDHT Annual Report is Reported By:

Ms. Amali De Silva – Mitchell, Founder & Coordinator, Dynamic Coalition on Data Driven Health Technologies. February 10, 2023.

## Disclaimer

The views and opinions within this report are those of the writers and may not reflect the views and opinions of the United Nations Internet Governance Forum Secretariat, nor conform to IGF definitions, practices, norms, values and so forth.

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## 1. Executive Summary

United Nations Internet Governance Forum recognized Dynamic Coalition on Data Driven Health Technologies DC DDHT was very active in 2022. Although our sessions were attended in person at IGF Ethiopia, the DC provided for successful on-line collaboration from all parts of the world, for all DC DDHT sessions in 2022, making equal and universal access to meetings a reality.

The DC DDHT summer series of six hosted virtual public events, with an inaugural DDHT Keynote Speakers event, were very successful. It provided the content for the DDHT survey submission for the United Nations Secretary General's initiative, the Global Digital Compact, through the auspices of the Office of the Secretary-General's Envoy on Technology. We hope that our contribution will add value and support the conversations at the 2024 United Nations Summit of the Future. This body of work also supported the DDHT submission for the call for input on the topic of Digital Innovation, Technologies and the Right to Health of the UN Special Rapporteur to the UN Human Rights Council,

Standards specific to the medical internet of things have been in development by organizations such as IEEE, who shared their work with us at the Key Note Summer Series session. It was highlighted that ethics should be made center in the practical development the medical internet of things, as a failure of the internet or an associated technology could mean a loss of life or a serious medical services impairment with serious human consequences.

Strong messages came through from the DDHT sessions this year. Diversity and inclusion of all peoples, their spectrum of needs highlighted, that are not necessary part of a main-stream profile. Sensitivity to indigenous traditions were also highlighted at the DC session at the World Summit on the Information Society WSIS 2023 event. Granularity and diversity of internet service options, with secure cost effective inter-operability of internet technologies, are required for meaningful access. Accessibility for all is required to enable the efficient functioning of ehealth, telemedine and the medical internet of things.

Onboarding to the internet for access to the medical internet of things and telemedicine was a very interesting discussion that took place at the DC event at Eurodig. It involved delving in to the support role of the Good Samaritan, helping relatives, neighbors or the unknow person onboard to the internet, so as to get access to their medical services or to gain patient information. There is a need for non-profit community service organizations, with volunteer and financial support from all stakeholders, to help in this role of the Good Samaritan for the community. Training should be provided to the Good Samaritan so that the service can be provided effectively.

Our peers at IGF from the Dynamic Coalitions representing the disabilities community, impressed upon us, that, a medical internet of things or telemedicine that cannot be accessed

by the disabled is in vain. The need to develop tools for accessibility for all is critical. With artificial intelligence and robotics this mission would be attainable.

The issue of clean energy, power in remote areas and low waste was another set of messages that were heard clearly. The medical internet of things could mean a life service for some patients and continuity of power and service with no interruptions is critical. Hence meaningful power / electricity storage and off-grid generation is important to develop. Remote communities that may gain internet access through satellite technology are still vulnerable due to their inability in some regions to generate their own electricity power supplies. Meaningful internet access means developing solutions for the management of power sources for generation of electric power.

Developing success for the UN SDG 3 Health and Wellbeing for All is not limited to the medical internet of things. The Internet of Things for agriculture, water management, crisis management, education, business, transport and logistics are all but not the exclusive list of integrated partnerships for enabling good community health and thus leading to resilient economies for all. A secured internet is key to efficient functioning of collaborating systems and education for internet users is also key to enhancing a secured internet.

Climate change will impact the health of the global population in many ways such as flooding or drought that can lead to malnutrition or starvation which is a serious limitation for achieving UN SDG #3. As such, the health sector cannot work in isolation, and the need for collaboration locally and internationally, especially to support hard to reach locations is imperative.

The increase in respiratory disease, water borne disease, pandemics and so forth, will require the Medical Internet of Things (MIot), with the Internet of Things(IoT), to help mitigate the risks to the regional or global community. Bundling together of services can bring the development costs of MIoT down. Collaboration between diverse, traditionally independent financial stakeholders leads to pools of financial investment for the faster development of internet-based technology products to support resilient and inclusive societies and also supports the global Environment Social Governance ESG initiative.

## 2. Score Card on Policy Matters

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Theme	Event
Access to the internet and devices	IGF DC Summer Series
Accessibility & Disability, Inclusion and Diversity	IGF Ethiopia / WSIS 2022/ UNHRC
Accessing alternative medicine online	WSIS 2022
AI data bias	UNHRC
AI ML Robotics Emerging Technologies	VSIG
Costs / Affordability / Economic Cost / Government funding	WSIS 2022 / IGF DC Summer Services
Data records / fragmented data	IGF DC Summer Series
Data sharing and transmission for quality data systems - 7 rites	WSIS 2022 & DC Book part 2 2022
Decentralizing decision making	IGF DC Summer Series
Doctor to patient relationship and expectations gap	IGF DC Summer Series
Ease of device / system use such as speech to text for form filling	IGF DC Summer Series
ESG and healthcare branding	Book
Ethics	IGF DC Summer Series
Financing the Internet MIoT. Status of ehealth financing	IGF Ethiopia / WSIS 2022
Green eMedicine / Environment	WSIS 2022 / IGF DC Summer Services
Human Computer Interaction	WSIS 2022 & DC Book part 2 2023
Human rights issues	IGF DC Summer Series
	WSIS 2022 / Book /IGF DC Summer
Indigenous Health, Inclusion & Diversity	Series
Medical standard setting	IGF DC Summer Series
Onboarding to the internet / Good Samaritan supports patients	Euro DIG / IGF Ethiopia
Patient specific based medicine	IGF DC Summer Series
Practical applications of AI in healthcare triage	IGF Ethiopia / Summer Sessions
Privacy and 7 rites / rights for the passage of data between	
systems	Book / WSIS 2022
Rural issues / sourcing power / electricity	WSIS 2022
Satellite / community hot spots	IGF DC Summer Series
Social Media	WSIS 2022
Sourcing power for devices and systems	IGF DC Summer Series
Supply chain / alternative medicine	IGF DC Summer Series
Technical medical standards	IGF DC Summer Series
Telemedicine / doctor shortage - scaling medical services up	IGF DC Summer Series

## 3. Background to UN Internet Governance Forum, Dynamic Coalitions

Internet Governance was one of the most controversial issues discussed at the United Nations World Summit on the Information Society WSIS, held in two phases, in Geneva, 2003, and in Tunis, 2005. Cognizant of the fact that any Internet Governance approach should be inclusive and responsive, the WSIS requested the Secretary General of the United Nations to convene a new forum for multi-stakeholder policy dialogue.

The Internet Governance Forum (IGF) as a platform for discussions, brings various stakeholder groups to the table as equals to exchange information and share good practices. While the IGF may not have decision-making mandates, it informs and inspires those who do. It facilitates a common understanding of how to maximize Internet opportunities and address risks and challenges. (*Sourced IGF Website January 2022*)

IGF Mandate Paragraph 72 of the Tunis Agenda: 72: We ask the UN Secretary-General, in an open and inclusive process, to convene, by the second quarter of 2006, a meeting of the new forum for multi-stakeholder policy dialogue called the Internet Governance Forum (IGF). The mandate of the Forum is to: • Discuss public policy issues related to key elements of Internet governance in order to foster the sustainability, robustness, security, stability and development of the Internet; • Facilitate discourse between bodies dealing with different cross-cutting international public policies regarding the Internet and discuss issues that do not fall within the scope of any existing body; • Interface with appropriate inter-governmental organizations and other institutions on matters under their purview; • Facilitate the exchange of information and best practices, and in this regard make full use of the expertise of the academic, scientific and technical communities; • Advise all stakeholders in proposing ways and means to accelerate the availability and affordability of the Internet in the developing world; • Strengthen and enhance the engagement of stakeholders in existing and/or future Internet governance mechanisms, particularly those from developing countries; • Identify emerging issues, bring them to the attention of the relevant bodies and the general public, and, where appropriate, make recommendations; • Contribute to capacity building for Internet governance in developing countries, drawing fully on local sources of knowledge and expertise; • Promote and assess, on an ongoing basis, the embodiment of WSIS principles in Internet governance processes; • Discuss, inter alia, issues relating to critical Internet resources; • Help to find solutions to the issues arising from the use and misuse of the Internet, of particular concern to everyday users; • Publish its proceeding (Sourced IGF Website January 2022)

### Role of the Multistakeholder Advisory Group (MAG)

The Secretary-General of the United Nations established the Advisory Group (now referred to as the Multistakeholder Advisory Group - MAG). The purpose of MAG is to advise the Secretary-General on the program and schedule of the Internet Governance Forum meetings. The MAG is comprised of 55 Members from governments, the private sector and civil society, including representatives from the academic and technical communities. In addition, representatives of

former IGF host countries, as well as representatives of intergovernmental organizations, are invited to attend and contribute to the meetings and work of the MAG. The MAG holds face-to-face meetings, preceded by open consultations, up to three times a year.

The idea of establishing a Dynamic Coalitions Coordination Group (DCCG) emerged at the 10th IGF in João Pessoa, Brazil, during the first-ever main session dedicated to Dynamic Coalitions (DCs). The idea found broad support among members of the different coalitions, many of whom were exchanging views and good and best practices for the first time. The main task of the proposed Group would be, on one hand, to develop a framework for all DC with some common principles and recommended rules of procedure, and on the other hand, to act as a convener of coalitions in order to further the open and constructive discussions that took place in Brazil. The Group would work on obtaining organizational support in those areas where the Dynamic Coalitions may require support, look at areas of overlap and duplication and aim to create synergies among DCs. It was suggested that it also serve as a liaison to both the IGF Secretariat and the MAG. *(Sourced IGF Website January 2022)* 

# 4. The Dynamic Coalition on Data Driven Health Technologies, Within the UN IGF Framework

The Dynamic Coalition on Data Drive Health Technologies, DC DDHT, is a recognized member of the Dynamic Coalitions of the Internet Governance Forum IGF and as such, is a member of DCCG. DDHT also seeks to work collaboratively with the working groups of the United Nations International Telecommunications Union, the World Summit on the Information Society activities, as well as with other international, regional and national initiatives such as EuroDIG, Internet Society, ICANN and others. Members of the Dynamic Coalition also hold positions within these other entities.

The founding mandate of the DC DDHT has been as follows: The DC will discuss the issues and make recommendations to improve data quality and access to data, for building or remediating technologies and services to the global public, in keeping with the United Nations Sustainable Development Goal # 3: Ensure healthy lives and promote well-being for all at all ages. This will involve supporting technologies for the eradication of diseases; easing of blindness or hearing; enhancing nutrition; support of new developments for surgery; tele-medicine; public health education; public health management and so forth.

DC activities will include providing guidance and interpretations, risk management, advocacy and making recommendations for data standards, best practices and providing input in to other related and associated policies and legislation. DC Scope: Global, all health, associated industries, services, fields (such privacy, safety etc.) in the private, non-profit and public sectors. There are no exclusions of associated or cross-cutting policy or methodologies and it strives to be fully inclusive and diverse in approach to all matters, ensuring a multi-stakeholder approach.

## 5. Intersessional Work

2022 was a very active year for the coalition, with numerous public engagement events that helped source the content for the DC's contributions to the United Nations Secretary General's initiative, the Global Digital Compact, through the auspices of the Office of the Secretary-General's Envoy on Technology, and for the call for input on the topic of Digital Innovation, Technologies and the Right to Health of the UN Special Rapporteur to the UN Human Rights Council,

### **DDHT Summer Series**

### 1. Keynote speaker event

Invited guests were: Maria Palombini (IEEE) and Yuki Kudo (Journalist and University Educator in Law & Journalism from Japan)

DC member speakers were: Dr Amado Espinosa, Alex Buckham, Frederic Cohen, June Parris, Dr Joao Rocha Gomes.

This was a very rich session which covered topics such as standard setting, medical application development, user insights, environment, human rights and indigenous medicine.

Session recording is found at the UN IGF utube center at: <u>https://youtu.be/3qVwTc8wxc8</u>

Transcript is found at: Appendix 5

### 2. Work shop events

Five virtual workshops were held for the IGF community. The moderators were Dr Galia Kondova and Amali De Silva-Mitchell. These sessions were made up of small groups with indepth discussions.

### **Internet Onboarding Tool Box**

This is an initiative launched at IGF Ethiopia 2022, to encourage written contributions on the topic of on-boarding to the internet. This is to provide tools and insights to support users of the Medical Internet of Things to have a secure and effective online experience.

# 2022 Book: Health Matters, Technologies Driving Change in Healthcare, A Community of Thought. Part 2.

The book's chapters were written by members of the Dynamic Coalition over the course of 2021 and 2022. The complete chapters are available for download, at no charge, from the United Nations Internet Governance Forum, Dynamic Coalition on Data Driven Health Technologies webpage at: <u>Dynamic Coalition on Data Driven Health Technologies (DC-DDHT)</u> <u>Internet Governance Forum (intgovforum.org)</u>

In 2022 new written contributions for the DC book and a presentation were as follows:

- 1. Alex Buckham, Privacy Pack: Required steps to improve digital privacy
- 2. Frederic Cohen, Understanding Leadership: Between Partnership and Collaboration
- 3. Mark Datysgeld, *Digital health policies in LAC: Where do we stand and what can governments* <u>do?</u>
- 4. Amali De Silva-Mitchell:
  - 4.1. An introduction to privacy & DC DDHT, seven rites / rights for data management
  - 4.2. Opportunities for the Internet under the UN rights of indigenous peoples
  - 4.3. ESG and branding, the value for healthcare technologies on the Internet

### **Virtual School of Internet Governance**

DC DDHT member Frederic Cohen was invited to present the French language teaching session on Emerging Technologies at the IGF Virtual School of Internet Governance VSIG for 2022.

"VSIG in French – Session on emergent technologies

VSIG Group B Live Chat Session Emerging Technologies with Frederic Cohen - YouTube

It was a one-hour and eight-minute session on 23 November 2022 with Glenn McKnight for the Virtual School on the Internet Governance. This gave me the opportunity to present my work in the UN with DESA, IGF and DC DDHT. I presented web documents that relay it.

My previous professional and associative experience follows in this presentation. It summarizes my academic background in science and technology and my work for NGOs in the research and health sector.

I mention the writing of the culture portal on the Wikipedia encyclopedia in French in the late 2000s, then my support for humanitarian causes, such as participating in a fundraiser for UNICEF.

It is also about the fight against addictions, the legalization of medical cannabis, my commitment to the environment and finally my work at the Ministry of Research in France concerning robotics internationally.

In a following part, I present a summary of the collective book of DC DDHT in which I wrote two articles on cybersecurity and biotechnology with an analysis of the global governance in the economy. The sections on water and health are more detailed. I also address the topic of wireless solar space energy from devices.

In conclusion, the development of social policies in the world are discussed in such a way as to present an organization for the development of jobs in the public service sector.

The blog pages on the UN SDGs Action Campaign website, or the UN SDGs Festival are a current and dynamic illustration of this commitment."

Reported by Frederic Cohen

### **Collaboration with the International Telecommunications Union ITU:**

The DC hosted the WSIS 2023 session: Issues for Data Driven Health Technologies: A way forward for international collaboration and finding collaboration for indigenous communities.

Please refer to Appendix 3 for the detailed report on the session.

### The DC continues to support the work of International Telecommunications Union ITUs Partner2Connect community.

### **Collaboration with EuroDiG:**

This session brought together interested participants, to discuss the content for an internet use and applications onboarding toolkit, so as to support citizen's unfamiliar with internet practice. The role of the Good Samaritan in helping others onboard to the internet was discussed in some depth with detailed interventions from Lori Schulman of IGF USA, Aleve Mine of One World and DC members Alex Buckham, Herman Ramos and Frederic Cohen. The need for ease of use of the internet was stressed. The ethical use of data with the understanding of the consequences of basing decisions on data driven technologies without further human deliberations was highlighted.

The link to this very interesting session is found at: Dynamic Coalition (IGF) on Data Driven Health Technologies – Building an onboarding toolkit together – Pre 02 2022 - EuroDIG Wiki

### **United Nations Survey Submissions / Input**

The intersessional events that the DC hosted, provided the material for the following contributions:

- Submission for the UN Secretary General's Task Force on Internet Governance
  1.1. See Appendix 1: abridged version
- Global Digital Compact Survey: Office of the Secretary-General's Envoy on Technology.
  2.1. See Appendix 2: abridged version
- Digital Innovation, Technologies and the Right to Health: UN Special Rapporteur to the UN Human Rights Council
   3.1. See Appendix 3: abridged version

## 6. DC Session at IGF Ethiopia Meetings 2022, Public Engagement Events

1) The DC of DC's session with the UN Secretary General' Special Envoy for Technology.

DC DDHT member Herman Ramos represented the DC at this panel style session.

### 2) DC Session: Community Connection to Ehealth, Telemedicine & M-IoT November 30, 2022

Invited guest speakers were:

- Dr Joao Rocha Gomes Reflections on emerging technologies for ehealth
- Mr. Sean Dodge, RBC Capital Markets US Insight in investments in ehealth
- Ms. Lidia Best, President European Federation of Hard of Hearing People (EFHOH)
- Mr. Gerry Ellis of Feel the BenefIT

Please refer to Appendix 4 for the detailed report for this session.

## 7. Recommended Items from the 2022 DDHT sessions

These topic areas would benefit from further discussions for policy making

- 1. Diversity and inclusion
- 2. Indigenous values
- 3. Access (Ease of) and Accessibility
- 4. Good Samaritan's support / technical education
- 5. Health service delivery diversity
- 6. IT Ethics for medical applications
- 7. Artificial Intelligence applications
- 8. Bias and mis-information
- 9. Understanding reports generated from AI (human aspect)
- 10. Standard setting for medical applications and ethics
- 11. Data sharing ethics
- 12. Future oriented planning and visioning
- 13. Human rights medical context
- 14. Human computer interaction
- 15. Green technology and waste management
- 16. Electricity and power supply, storage and generation
- 17. Multistakeholder financing
- 18. Develop easily accessible spaces for stakeholder conversations on ehealth development.
- 19. Innovative uses of social media for delivery of health and wellness services

## 8. Vision for 2023 Work

The focus area for discussion is expected to be as follows:

- 2023: Robotics and the Medical Internet of Things
- 2024: Holograms, Virtual and Augmented Reality and the Medical Internet of Things

## However, all topics on healthcare and technology are always open for discussion and development throughout the year.

The Dynamic Coalition expects to develop Part 3 (2023) to the Dynamic Coalition Book: Health Matters, Technologies Driving Change in Healthcare, A Community of Thought 2022. Contributions are welcome.

The DC will also continue to collaborate with the ITU, EuroDIG and other Dynamic Coalitions, Best Practices Forums and so forth of the IGF.

## 9. Administrative Matters Update

Our DC membership is growing, and we have the pleasure of conversing with our new members on new topics through-out the year. The depth and breadth of conversation as been very informative, refreshing, mind-opening and intense. We believe that our DC's work, now commencing it's fourth year, is well established within the UN IGF family.

As always, the DC is open to and welcomes membership from the global public, through participation on the DC email list.

### Appendix 1

#### Submission for the UN Secretary General's Task Force on Internet Governance

September 2022

The United Nations Department of Economic and Social Affairs, Internet Governance Forum, Dynamic Coalition on Data Driven Health Technologies, strives to build capacity and economic resilience, through a multi-stakeholder approach to risk management and knowledge sharing, in the space of emerging technologies for healthcare and it's associated and complimentary technology spaces, such as information sharing, payments systems, supply-chain, regulation, best practices and legal affairs.

Technologies in the healthcare space are dynamic, growing fast and are at the frontiers of new technology development. This space is in need of excellence in multi-stakeholder risk management for thoughtful and humane approaches for best practice outcomes. The dynamic coalition has discussed extensively, with the public, the issues transpiring within the health technology space, at the ITU through the WSIS process, at IGF through a summer series program and at Eurodig.

There is a need to think out of the box, go back to the future, be non-traditional, embrace popular as well as specialist opinions, partner and collaborate with diverse stake-holders and realize that although we put in to place the ideas that are commonly around at the time, developing visions for the future are essential as well, for good policy integration, especially with respect to infra-structure and capacity building, with the assistance of knowledge sharing and common high-level goal setting. Action plans to succeed long term, for the attainment of the United Nations Sustainable Development Goals, should be structured within a three-part timeline, supported by the internet policy, infrastructure and technology communities as follows:

- A. Immediate 1-2 years term of quick wins with leverage of existing technologies, with a focus on micro or small-scale efficiencies or deployments for capacity building
- B. Mid-term 3- 5 years term of planned outcomes for meeting UN SDGs 2030, with a focus on building within the community and standard setting
- C. Long term 6–15-year term plans for technology backbone, infrastructure building with partnerships and collaboration

Through extensive international community discussions over a three-year period, the dynamic coalition has identified a number of issues, that call from the public, for further international discussion. The DC wishes to highlight some of these issues at this time. The list is not exhaustive. The key-words and phrases noted below are packed with meaning, from the depth and breadth of the issue, to its inherent complexity, it's opportunities, benefits, risks and sometimes harms. The detail is not outlined within this short briefing paper, but found within the information sources developed by the DC. The DC recognizes the importance of building partnerships across the UN agencies and communities to facilitate successful outcomes within the healthcare space, using the internet and technologies as a partner, facilitator, enabler and motivator for building resilient economic societies for health and wellness benefit of all, per the mandate of the UN SDG #3. The list of issues, key words and phrase that demonstrate insights in to the health technology space and matters for reflection for the development of the internet, are as follows:

- 1) Universal telemedicine / access
- 2) Disabilities access
- 3) Growing populations and limited infrastructure supports
- 4) Standards for individual data privacy
- 5) Interoperability
- 6) Cultural issues
- 7) Power
- 8) Security
- 9) Racism and discrimination
- 10) Fairness and equity
- 11) Ageism
- 12) Women's issues
- 13) Children's issues
- 14) Disaster and rebuild back better
- 15) War
- 16) Translation services
- 17) Issues for indigenous peoples
- 18) Language and content barriers
- 19) Access to medication online pharmacy
- 20) Intellectual property sharing
- 21) Research results sharing
- 22) New technology blockchain
- 23) Quantum
- 24) AI / ML
- 25) Ethics for computer scientists
- 26) Misinformation, disinformation
- 27) Data collection standards
- 28) Data sharing standards
- 29) Issues for research and development
- 30) Financing
- 31) Access to devices
- 32) Green health
- 33) Understanding common issues globally and finding solutions together
- 34) Supply chain for medicines (pharmacy access)
- 35) Onboarding
- 36) Community supports; Village, Regional etc.
- 37) Skills, patient support and training
- 38) Dedicated legal frameworks
- 39) The good Samaritan's place

We want to thank the contributors to the DC DDHT event facilitation and discussions.

### Appendix 2

Re: Call for input on digital innovation, technologies and the right to health for call for input by the UN Special Rapporteur to the UN Human Rights Council,

Thank you for this opportunity to share a general statement and also specific responses to the questionnaire.

We are the United Nations Internet Governance Forum's Dynamic Coalition on Data Driven Health Technologies located within the United Nations Department of Social and Economic Affairs, (DDHT). We are comprised of an international multistakeholder team of doctors, healthcare professionals, economists, accountants, data professionals, technical professionals and so forth.

Our aim is to study, understand and share, the issues, risks and benefits, of the implementation of advanced technologies that use the internet, such as Artificial Intelligence AI, Machine Learning ML, Quantum Technologies QT and so forth, with a focus on healthcare. We engage the public through our events and conversations, which are open to the global attendance. We are global citizen and individual patient focused. Please refer to our website page for examples of detailed work and public consultations at: Dynamic Coalition on Data Driven Health Technologies (DC-DDHT) | Internet Governance Forum (intgovforum.org)

Healthcare is due to be significantly infused by AI systems in many ways, for the future. The opportunity for targeted, patient specific care at home, to reduce the burden on hospitals is gaining significant traction. This means that sensitive care, specific to all people's, but at a patient specific level must be developed so that it takes in to account economic, cultural and social differences.

One of the most significant issues for AI, ML and QT is the quality of the data input, content and management. Ehealth systems driven by advanced technologies also rely on simple traditional data collection systems, and the transition of this data to more advanced systems must be managed well. It is also commonly believed that Quantum Technology could change the current operational modalities for AI.

Data must be representative of the population it is serving. A data set based, for instance, on white skin tone population would not represent comprehensive outcomes for a population with brown skin tone. Unknown biases could be created, or whole groups of people left out or unintentionally included or data mis - interpreted. DNA combinations are complex. Hence, the learning data set for AI or ML is critical and must be inclusive of diverse populations for robust applications. Human input must also be incorporated to understand the nuances of any data outputs that require complex interpretations.

Building generic profiles of clusters or groups of peoples can also be intolerant of deviations, especially when multiple data sets are put together, with little planning and design, with perhaps false positives and false negatives outcomes. The data sets must be large if they are to provide generalizations.

The methodology used to develop statistics for quantum theory can perhaps be used as a sort of continuum of possible solutions, rather than by a so-called single truth. Hence, a range of outcomes can be entertained, rather than discrete outcomes.

The design of the AI system must include multiple stakeholder groups. Also, the system must be stress tested and AI system trust must be established. Inter-operability of devices and systems must be robust.

Data must be timely and up to date. It must eliminate inaccurate assumptions, at whatever the cost, so as to maintain robust data quality. The seven rites / rights of data (1) migration between systems should be adhered to. This means that a set of guidelines including privacy, fairness, equity, diversity and inclusion must be considered when data is shared between systems. A bottom-up approach with citizens' rights to control their own health data information must be the cornerstone of any AI system. This means that there

must be design and data transparency. An ombudsman who has the authority to keep track of AI health systems should be appointed. An equivalent office would be that of a privacy commissioner, with whom there should be close collaboration. Without these offices that take in public complaints, unfairness on a significant scale may result. The individual should have a voice so that no bullying entails.

It is important that ethics training is provided to all staff managing and operating the AI systems, whatever their level of work, so that they understand the issues of biased data and are thus able to understand issues, and especially those from small representative populations. There is AI speak as it were that is essential for quality AI based systems on the Medical Internet of Things.

Data must convert with meaning (semantics and syntax) between natural languages systems, that perhaps have identifiers embedded into the data that could trigger misinformation. Data is dynamic and the manner of data collection, storage, blending, elimination can all lead to different outcomes.

Data must take into account cultural, economic and other social factors. Geographic factors and geopolitical issues must be considered for data collection, analysis and reporting so that no one if left out for the achievement of UN Sustainable Development Goal 3, Health and Wellness for All. Collaboration between a multistakeholder group including finance for insurance, legal and social services must take place, so that marginalized individuals are not unfairly treated. Healthcare is a neutral service, open to everyone in an equitable manner.

The internet with AI has the potential to reach the remotest corners of the world or the least accessible areas due to a variety of reasons. This opportunity to service all, is an incredible opportunity for global health, but it must be administered in a fair, equitable and inclusive manner. It is all in the design of each individual component of the system and the quality of the data inputs and outputs. Simply relying on a machine with no human analysis could cause issues.

The individuals whose data it is, must feel empowered to own it, and have the rights to manage the data for corrections, privacy and so forth. There must be consent for data sharing across independent systems or the establishment of data anonymity for data sharing for AI builds, research and policy making. However, so that an individual's data does not get into the wrong hands, with a change of use and purpose, care and guidelines for AI system operators must exist. Principles of privacy must be adhered to, so that an individual's human rights are not impacted.

Our book Health Matters, Technologies Driving Change, A Community of Thought (1), our annual reports and presentations, which provide detail on a significant amount of work on this topic, are found at: https://www.intgovforum.org/en/content/dynamic-coalition-on-data-driven-health-technologies-dc-ddht

In addition, we also take this opportunity to submit responses to your specific questionnaire as well, that includes additional information to this letter. Please see attached to this email the questionnaire in word document form.

We thank you for the kind consideration of these points noted above and on the questionnaire.

#### Submitted by Ms. Amali De Silva-Mitchell

Coordinator UN IGF DDHT, on behalf of the members and affiliates of the UN Internet Governance Forum Dynamic Coalition on Data Driven Health Technologies

November 12, 2022

### **Appendix 3**

### Report for WSIS Forum 2022 Session Number 192

### Session title:

Issues for Data Driven Health TechnolOgies: A way forward for international collaboration and finding collaboration for indigenous communities.

### Session organizer:

United Nations, Internet Governance Forum Dynamic Coalition on Data Driven Health Technologies. Speakers were Anke Zimmerman, Frederic Cohen, Alex Buckham and Amali De Silva-Mitchell (also moderator, session reporter and coordinator of the coalition).

### **Relevance for WSIS Action Lines:**

The session related directly to WSIS Action Line #7 Health. However, for inclusive and resilient societies, the health and well-being of all citizens, is of great importance, to enable the successful outcomes for all WSIS Action Lines.

### Highlights of Covid 19:

The session show-cased how through the use of ICTs, rural or remote populations could connect for telemedicine and other health and wellness services. This was especially significant during the Covid-19 pandemic, when person to person contact was limited.

### Key achievements, announcements, launches, agreements and commitments

The UN IGF Dynamic Coalition on Data Driven Health Technologies published an online book Health Matters, Technologies Driving Change in Healthcare, A Community of Thought in 2021. The online book is found at:

Alex Buckham; Frédéric Cohen; Amali De Silva – Mitchell; Jörn Erbguth; Galia Kondova; Amala Arockia; Herman Ramos; Ashwini Sathnur; Emma Slade; Dr. Christine P. Tan; Dr John Lee Allen; Shabir Chowdhary; Vivien de Tusch-Lec; Eric Kostegan; Dr Laila Samady-Mustad; Dr David Holbrook; Ferus Hay; Dr Annalisa Jenkins and Dr Carina Tyrrell.

Part two of this book will be published in 2022 and is open for contributions at the time of writing of this report. UN IGF DC DDHT also invites interested organizations and persons to join the coalition.

UN IGF DC DDHT is also a member of the ITU Partner2Connect Community and has pledged to be an enabler of the work at the heart of that community. This is pledge is demonstrated through this session, and through the current work of the DC DDHT, in the development of a tool-kit to assist citizens to onboard to the internet. The toolkit will be presented at the UN IGF meetings in Ethiopia in December 2022.

#### Main outcomes

The session encouraged the audience to think out of the box when applying principles for diversity and inclusiveness to enable quality ICTs to the health and wellness sector. Indigenous, rural, marginalized groups are some of those unaccounted segments of the population who fall through the gaps in generalized policy making or product and service development in healthcare. Diverse types of health systems such as indigenous, ancient, non-traditional medicines may also encounter ICT non-inclusiveness, as they may service populations that are marginalized. This inclusivity of diverse users and practitioners is critical for robust public health intelligence systems.

The rights of users to their data and the use of data for the purpose it was intended for are important so as to maintain quality data, for especially new technology such as Artificial Intelligence. It is also noted that the ICT and supply chains must be fit for purpose, be suitable for relevant access, provide suitable control for the users to have input in to their own data such that it is relevant, safe to use, non-biased, up to date and stored and disposed of in an acceptable manner. Collaboration between regions on ICTs and robotics technology have allowed for increase in agricultural productivity, supporting nutrition and hence, wellbeing. It is always important to keep in mind the sources of energy used to power ICTs and work towards ensuring that it is green and efficient.

#### **Debated issues:**

The session was focused on showcasing the current uses, opportunities and issues for ICTs on the internet and the Medical Internet of Things. Diversity and inclusion were discussed through the importance for limiting bias for new technologies such as artificial intelligence, by inclusion of all data populations for health data intelligence including up to date (not stale data) from indigenous, rural and remote communities. Seven steps for managing the success of data passing through successive data systems called the 7 Rights / Rites of Passage for Data were presented.

The session highlighted the diversity and inclusiveness frameworks found in Canada with Gender Based Analysis (GBA) plus, and in the work by the National Health Service of the United Kingdom to overcome health inequalities. The British medical journal Lancet has researched on indigenous populations, and their work in Latin America was also noted. These works have been inspired by the acceptance of the United Nations Declaration of the Rights of Indigenous Peoples and the ensuing annual reports on the Status of Indigenous Peoples. These reports have highlighted the need for public health information systems to include the data of rural, tribal and indigenous populations so as to ensure complete national data sets.

An example of the use of the internet and social media for delivery of clinical homeopathic medicine was showcased. This particular international practice was developed fully, on ICTs and allowed access to homeopathy, to a geographically diverse global population. This access would not have been envisaged a few decades ago. The practitioner spoke of the freedom that ICTs

provided her practice, while the patients were able to access service from a location at a great distance to themselves in the world. This access was particularly important during the world-wide lock downs due to Covid-19 which restricted travel.

It was noted that homeopathy is the second largest medical system in the world and also the fastest growing in some parts of the world, such as Asia, Europe and South America. There are 200 million users of homeopathy globally. India has 100 million users and 200,000 homeopathic doctors, with 12,000 new doctors added per year.

Clean and affordable energy to power ICTs and other technologies was highlighted, not only for cities but also for rural areas. The need for an efficient and comprehensive transportation mechanisms for energy was noted.

Medicinal drugs from traditional medical practice, are available for use legally in Asia, Africa, Latin America and are gaining legal acceptance in the west. There is recognition of the use of social media by patients, global citizens and supply chains to access these medications. Some information and access systems, have history and are still in existence from ancient times, such as the old Silk Road. Safety and security of ICT systems in this use can be stressed by mismanagement with fracture.

In rural areas, farming supported by robotics and automation helped productivity increase by five percent, in an example provided of the technology transfer and support provided by China to African countries for the development of coffee and soya products. These beneficial partnerships and exchanges with ICTs for development work, are important to meet the United Nations Sustainable Development Goals (SDGs), as well as for WSIS Action line #7 on health, which include nutrition and well-being for livestock as well. Collaborating for disease safety, ehealth intelligence, product and service design solutions, using robotics and automation to increase production and quality to industrial levels for all, is an opportunity to bridge the gaps required, to create resilient economies.

However, the significant increase in global data collection means that data inequalities have increased as well. It is noted that the lack of strict adherence to privacy principles, during for instance the Covid-19 tracking, meant that the civil liberties for the population, may have been impacted. Care must be taken to ensure the quality of data collected. Also, data collected for one purpose may not be suitable for another purpose, especially when there is no consent from the data giver. For instance, when data is used by an unknow third party or fed into an Artificial Intelligence or Machine Learning system, unknow bias and error could result for the outcomes.

For quality ehealth, a quality internet that is fair and equitable is a must. Ehealth products and services. through the use of ICTs, is a catalyst for achieving the goal of the UN SDG #3 and for WSIS Action Line #7 by 2030.

#### **Quotes from speakers:**

#### Anke Zimmermann:

Technology has made it possible to reach across the globe

### Amali De Silva-Mitchell:

Excellence in data management, values the quality of the data exchanges between connected data systems (7 Rites / Rights of Passage For Data)

### Frederic Cohen:

Energy and the manner of powering of ICTs, must be part of the design

### Alex Buckham:

Milton Freidman was quoted: "only a crisis, actual or perceived produces real change". It was also noted that actions that take place, at such a time, are dependent on the ideas lying around at that time.

## Overall outcomes of the session and conclusions and visions for implementation of the action lines

The session encouraged the practice of diversity and inclusion with a "thinking out of the box and open minded" approach, while noting the need for keeping an eye on the past for bettering for the future. The global population is inherently diverse, and diverse medical practices are the history of the global civilization, just as language is. Both are critical aspects for establishing a diverse and inclusive health intelligence system for global society. Ehealth solutions must be inclusive, safe, trusted, un-biased, representative, complete, relevant, up to date, energy efficient, fit the purpose. The user in their location must have access to a quality internet. People and practice must keep an open mind to change and the rights of the user and environmental concerns. The full aura of the WSIS Action Lines and UN SDG mandates can be supported by these approaches.

Interesting insights can be delivered through the integration of the work of this session. The concept of treating "like with like" was introduced from homeopathy, which could be a beneficial technical model for data, system or service building or service bundling. Another concept presented was that of "dilution of homeopathic remedies", which noted that dilution did not necessary reduce potency of a medication and that mixing and refining could increase the potency of the medication. These concepts could be applied to machine learning, artificial intelligence and data management as well.

A call was made for systems and policy design bottom up, that include diversity, inclusiveness, environmental and social governance policies with effective waste management. The call for open, out of the box thinking was made when developing connectivity to all corners of the globe.

### Main linkage with the UN Sustainable Development Goals

The UN SDG #3 Good Health & Well-being links directly to this session. However, all other UN SDGs are either directly partnering, in concert with, or impacted by the effectiveness and path to development, of this goal.

### Suggestions for thematic aspects that might be included in WSIS Forum 2023

- Thinking out of the box, educating and collaborating on cultural norms for language, meta-data and so forth.
- Searching for similarities or patterns (reference methodologies found in Homeopathy) for ICT service delivery (bundling solutions for efficiency).
- Integrating human rights for diversity and inclusion in to the design process for ICTs
- Understanding the nature and extent of human data collected and used through ICTS
- Managing the environmentally sustainable power supply for ICTs
- Human Computer Interaction as part of the design process for ICTs
- Eliminating duplication and enhancing efficiency
- Waste management as part of the design process for ICTs
- Leave no one out, to the quality-connected last mile of the internet
- Collaborating with non-traditional medical practice for AI for Health
- Security and safety issues for the internet
- What are the issues for mass data gathering and sharing by unknown third parties?
- Alternative or non-traditional energy source powering of ICTs for rural or remote areas e.g., thermal energy, solar energy, small scale nuclear energy plants etc.

## Towards WSIS+20 and WSIS beyond 2025 please share views and challenges, achievement and opportunities and implementation of WSIS Action Lines to date.

The Corvid19 pandemic made the use of ICTs for everyone's everyday life a reality. The technology development cycle was boosted up by several years. The development of technical and ICT user skills became a necessity. The identification of the issues of the digital gap became critical for betterment, so as to achieve economic resilience. However, there is still a need for all sectors to finance the ICTs that enables the quality internet. Too much is taken for granted. Solutions to safe guard the internet from fracture with backups, alternate routing and technologies, is a must, which must also include resolving issues of connectivity for remote and hard to reach areas.

#### **Appendix 4**

## IGF Meetings 2022 Ethiopia: DC DDHT Session Report on Community Connection to Ehealth, Telemedicine & MIoT

The overall context of the session was based on the opportunities available for communities, from the international space to the village, to support each other in the development of ehealth systems. Fair and equitable internet access, is an opportunity to support a resilient ehealth service, so as to reach the United Nations Sustainable Development Goal #3, Health and Well-being for All. The need for the support of "good samaritans" who may be a neighbor with internet skills, or a compassionate internet philanthropist, is sought, so as to enable this end goal. The session commenced with a status update on ehealth, followed by a discussion of issues pertinent for onboarding a broader group of users, to the medical internet of things. The DC DDHT onboarding to MIoT tool kit was launched, with an invitation for everyone to contribute to developing this online information tool. A general question and answer period followed. The session was moderate by Ms. Amali De Silva-Mitchell *(DC Coordinator)* online and Dr Amado Espinosa onsite.

Dr Joao Rocha Gomes reflected on the use of emerging technologies for ehealth and spoke about the role of patient self-monitoring (*internet as a tool*). There is the need to increase the active engagement from the patient (*often through the use of the internet, for patient specific care*) for this self-help activity, which will lead to the resilience and opportunities for greater capacity for the ehealth system. He spoke of the use of AI to screen and profile patients for treatment options, saving time at patient intake (*more patients could be triaged*), again increasing the capacity and efficiency of the ehealth system.

Mr. Sean Dodge, Royal Bank of Canada RBC Capital Markets US, highlighted the tremendous growth in financial investment within the healthcare technology sector. He pointed out that non-traditional health care-based entities, such as a large consumer brand company, as well as a large database software technology company, were now investing in the space. He noted the changing behavioral profiles of patients, who were now rapidly seeking telemedicine options (40+%) that came in to active use during the covid pandemic, as their preferred engagement option with their healthcare provider.

Mr. Gerry Ellis of Feel the BenefIT and Ms. Lidia Best, President European Federation of Hard of Hearing People (EFHOH) spoke of their work on the ITU / WHO working group that, in June 2022, set up a universal standard for enabling accessibility to the internet, for all persons with visible and invisible disabilities. An inclusive internet is an internet that is open for use by all peoples (*diversity*) of the world, in a fair and equitable manner. The medical internet of things MIoT, can only be effective if it has ehealth systems (*including devices*) that are compliant with universal accessibility standards. They also noted that disabled persons should be provided with additional time to navigate the technology, such as the extension of time-outs on web page access and so-forth.

The general discussion that ensued was active and was based on a broad set of topics. It was noted that the opportunity for conversations and information sharing amongst stakeholders is important for the development of ehealth eco-system. The full length utube recording of the session is available for viewing on the IGF 2022 website. The webpage with access to the DC online book and tool kit is available at: <u>Dynamic Coalition on Data Driven Health Technologies (DC-DDHT) | Internet Governance Forum (intgovforum.org)</u>

- Key take aways:
- Accessibility issues are critical matters that must be addressed to enable universal access to ehealth
- Many stakeholders at different stages of the ehealth development life cycle need a space to access and collaborate on information
- •
- Action Items:
- Ensure all ehealth systems have addressed accessibility issues, and provide ehealth operators with the education to enable effectiveness.
- Develop easily accessible spaces for stakeholder conversations on ehealth development.

### Appendix V: Transcript of Session: DC DHHT session on health matters

let's okay thank you very much for um the participants who are attending with us uh right now at this specific time um that was a confusion it seems um to the recorded time um on the website uh the units calendar to the time allotted to our event it's probably due to um different time zones and summertime and and so forth so so unfortunately we won't have all our speakers we will have a few more speakers who will speak today we'll make a recording and we will be posting that to the un website on the dynamic coalition with data-driven health technologies webpage and then with the other speakers um we will do a recording and post those um at that time as well so i have the greatest pleasure of um introducing speakers that we do have um and i am going to let them introduce themselves give us a bit of a background um to who they are and to share their views very openly with us on health matters health matters is very topical all over the world because of covid but now we are in post-covet and we are realizing the great benefit that telemedicine gave us all in terms of accident healthcare but we're also dealing with a global shortage of doctors and medical technology um we understand all over the world there were no investments in either the the medical staff themselves um or technology um over the past five ten years um the medical community has been raising uh flags for a long time but now uh the public we are becoming very aware um of the shortages and how it's impacting each one of us and our families and communities directly so we know that technology can be very supportive as we saw through telemedicine we know artificial intelligence machine learning and so forth can speed the process um and first possibly the administrative processes and then also help develop the health intelligence services as well that governments have and then the actual medical applications so in this dynamic coalition we focused on

doing good quality data sharing um our views um educating the public bringing together stakeholders so that we can have this discussion um really note the urgency to all parties um that we really need to get on with this work um we have a global population that's really expanding um you know in uh in increasing scales um we have issues of climate change coming in that are impacting emergency services and you know lots of more environmental impacts and so forth so we are in a time of rapid change we really need to be able to adapt very very quickly and so we hope that these insights from our speakers will really help all of us to develop um at a local national level regional level and then ultimate international level so i appreciate um this opportunity and i would like to introduce our first speaker i'm going to stop sharing my screen here um and please maria uh please uh please present your background and then your your views and opinions with us please sure so hello everyone and it's a pleasure to be here i'm delighted to be part of this really great panel discussion with the keynotes so my name is maria palombini and i lead the ieee which stands for the institute of electrical and electronics engineers um healthcare and life science practice i actually sit in the standards branch of the organization so many of you may be familiar with our global standard the 802.11 wi-fi standard as an ieee standard um so a lot of the great work we do here with our volunteers from all around the world in the healthcare life science practice is to really look at all these we're going to call them disruptive technologies although i'm not a big fan of that term um but um really looking at these emerging technologies breaking through in the healthcare life science field and the question is here for all the great opportunities and benefits that it can provide to in you know increasing patients outcomes um you know we have to really look at the responsibility of how they're adopted how we validate the data coming out of it and how we look at the sustainability and the activity of this data you know being re-integrated back into the the r d uh system right so it's a um you know ultimately our goal is how do we use these technologies in a way that can afford the privacy security and equitable sustainable access to quality care for all individuals um so that's the work we do here today i really want to talk about um you know there's a there's again so many technologies and everything you know a lot of my focus is on the value of patient data and is it only worth the value of its endpoint and what i mean by that is is we have so much patient data i mean it's just like tsunamis and treasures and whatever we want to call it and a lot of it just sits in silos it's non-active and if it's not active you know what value does it bring you know we've been on this high horsing data as an asset health data is an asset but if it's not utilized it's an invaluable it has no value to the health care system and so when we really talk about this you know we see some of the i would like to say more of the the types of technologies and applications where we're seeing like the you know the perpetrators of data kind of being held and sort of you know quashed into their little you know domain and that presents a real problem when we

talk about the longitudinal view of the patient you know a lot of it is we talk about patient from a point of view of ehr right your electronic health record your patient health record the patients you know medical geo uh social demographics you know social determinants of health you know genetic impact you know wellness all of these components should be included in the view of the patient because they all contribute to overall their like sort of continuum of care and so this sort of gets lost uh quite a bit because we are all hung up on this concept of validated data but really you know we talk about there's so much going on in these digital health devices we call them wearables iomts chips you know chips sensors whatever we want to call them you know and unfortunately they have a lot of proprietary models of communication and they don't like to integrate they're not interoperable the data is not portable um you know and all of this data that's being autonomously generated from the patient can really contribute integrating back into the patient's health profile so when we talk about clinical research right recruiting patients comorbidities like all of these things can be a better viewed if we had this data all operating and playing together again showing the patient's profile you know we've seen uh specifically i think when we talk about telehealth and you know we're seeing this explosive growth of rpms the remote patient monitoring devices you know we hear so many forecasts i'm sure you all too that you know globally this can be a hundred and seventy five point uh billion dollar market by 2027. i think that number changes every year because there's such a proliferation of these devices coming into the market so and this is both consumer and i say at a clinical level um and so the greatness about it is great there they can be accessible to those who can afford it who can access to it we still have a portion of patients who can't but that's a you know for further discussion but really at the point of the day is we're just talking about millions of devices capturing data about us where is it going who's using it as a patient we don't really even see it we get some dashboards and we get to play with it but how is that really helping us better manage our care so we have that challenge and now we're seeing again in the telehealth realm in this remote care room is this growing um you know movement towards hospital at home so we're hearing more about this obviously the pandemic sort of started to feed this idea but this was already in the works before the pandemic and this idea is bringing more care to the home so put aside the human side of it the education all the things that come with that we're talking about a seamless secure uh you know adherent bioinformatics highway this is what we're talking about here data going back and forth from the home into some let's call it healthcare ecosystem so as much as this can provide so much convenience to a patient who's immobile there is so much data being captured and generated again where is it going who has access to it from caregivers to clinicians to patients themselves and back into r d and i think these are all like really important points you know we hear there's so many stakeholders and you know who want to see things taken differently um you know we know that the the movement towards moving care outside of a physical facility not that that would always be abandoned we're just seeing a greater movement towards that thanks to technologies and you know that kind of thing but there's a real core question here about you know patient data governance like you know i don't i don't talk about

ownership of data because i think it's more philosophical concept but it's really like giving the right to the patient to be able to consent how their data is being used whether it's being put back into clinical research or to better help themselves um is a really important factor the ability for them to have their own longitudinal view of their care right like everything sits in multiple places um you know you can have you know five digital portals or you know some central healthcare systems holding on to your records and maybe you have a pdf scattered around here and there um it's just not i i don't think it's very conducive for patients helping themselves or even for their clinicians to help them so these are a lot of the core issues that we talk about here um at the ieee esa with our volunteers um you know we're starting to get into another concern with this data being used you know when we talk about ai at the edge um you know started to say hey we're going to start making decisions you know like on demand based on data being collected whether it's from a wearable some other technology you know without a human intermediary you know and that's a little concerning naturally because again we talk about validation of that data and how the algorithms are being designed and so on and so forth and these are really all important questions you know again for technologies that pose great benefits but we cannot lose sight of some of these core challenges that are like right right in front of us that need to be addressed in multiple different ways thank you thank you thank you very much for that uh broad overview of of what's happening um and um i'm just thinking um marie if you do you have a little bit of time uh with us that you've worked okay so let me see um because we have this confusion uh in terms of the time um let me see if there's another speaker after which we'll come back and and have a discussion which would be great so um let's see if i can um okay i'm then just going to present um a youtube um we have um a pre-recording from um our japanese speaker and i'm just trying to um get that going um yesterday hello this is speaking from japan one of the key speakers for the union related events but unfortunately i can't really participate simultaneously with you so i actually taking this video to share with you the situations that um have been taking place here in japan regarding the e or telemedicines i mean which is a topic of this um related conference or the meeting um i have actually studied law at the university of tokyo i mean faculty of law and the best i mean undergraduate and the postgraduates as well i have also um have got a master's of science emcee in economics from Ise underscore economics and political science where i have met one of the organizers hello well i mean this is actually i mean another education i have actually have done is running well uh defense i mean institute i mean of france i mean i and after working at jp morgan and mckinsey and company as a financial related corporate officer i have i mean basically working in the media industry both of

the broadcaster and newscaster and the communicator and also other also non-fiction books as well as the well and the current affairs and matters and as for the e-medicine here in japan there are many aspects i would like to point out as one of the difficulties of inaction or installments of this i mean immune system called telemedicine or in medicine or here in japan how it often causes online medicine one of the difficulty first of all is the kind of i mean the inhibition in mind on the side of the doctors especially i mean what that i mean here is that 80 of the japanese medical facilities or the doctors even though our system here in japan is quite similar to the uk regarding a gp but at the same time it's not at all like gp people are here in japan able to go to any doctors that they like to go to so i mean the doctors inhibitions took place in their minds because that's only 80 percent obviously japanese and medical facilities facilities are private and that means the installment costs of the healing medicine together with the kind of fear on the side of the doctors as if that they might actually lose patients and the kind of economic fracture black sounds become or became quite uh inhibition i mean in installments of the system and also and japanese and images and started quite late unlikely some of the european countries and which are quite i mean well depending on the images such as estonia for example um japan has started using the system i mean since 2020 i mean when the global pandemic copy 19 hit the entire world and in order to reduce the risks on the side of the patients as well as the doctors but still as of now the end of june the 30th of june 2022 we haven't actually seen a great change at all i must say because also many reasons i mean additional to the kind of family reasons that i have pointed out so far and the most important is i think it's a law i mean unlike the eu with a gdpr and the disposability which has been made and enacted since 2015 and together with the kind of data possibility i mean with this digital single identification system that they're trying to really enact japan is quite behind unfortunately on the matters of the legal i mean infrastructure like that and without that i personally think as a law major myself it is quite uh sorry to interrupt uh since you mooted yourself we cannot hear the video i believe regarding the situations of the patient doctor relationship here in japan um well and generally speaking doctors are quite respected everywhere all around the world i think but here in japan that some kind of a doctor some patient relationship is very very strong and unique in the sense that

we i mean change content to really call the doctor without sensei i mean i mean always really addressing and then in the matter like that so a kind of i mean decision making a kind of um well um doctor-patient relationship um situation may be quite unique in japan which could be a kind of i mean important decision-making factor when it comes to um in medicine i personally think because the kind of will not change certain change of the huge interest structure take place there is always i mean has to be a kind of voices of the general public which may not be so taken care of in my perception here in japan in no way comparison with another countries and some of the european countries or some other countries that i have actually i mean synthetism and next the importance is the kind of i mean and this is the divine so to speak the telemedicine or image it's a typical kind of means to make or give advantages for the elderly patients or the elderly people who might have not only kind of make protections or i mean global fun deliberated situations but um generally speaking um clinical i mean level of um well i mean illness certain kinds of i mean deficiencies and and as a tendency but they tend to live in uh not in cities but in a rural area so um the kind of people who are the most benefit receivers who is a medicine all the kind of people here in japan do not have smartphones that do not have any digital um infrastructure i mean number one is because of the i mean they're kind of not active in using those devices and secondly that is quite important it's uh the lack of penetration ratio of the internet or broadband or mobile network and when it comes to not really the population regarding to the area coverages well for example they satisfy the internet for example we see a kind of actions or a decision made by the testers i mean the ceo elon musk instead has done a great deal of penetration coverage of 30 some countries with the satellite internet which is quite ideal in my perspective in my analysis for the country like japan where the doctor's shortages do exist in the rural areas while the cities like turkey or also current culture have bought enough doctrines so there's a huge job not only in the distal equipment and this infrastructure but at the same time the available doctors in a kind of wide variety and also i mean entire coverage of the entire genre of medical services such as for children also just for dentists such as for well internal medicines etc so that is another problem

which has been really making the situations idealistically but realization of the ideal or telemedicine here in japan quite difficult i mean as a situational analysis in mind and point of view and lastly but most importantly i would like to point out the medialitis the media is actually telling people i mean transparency wise the government also well um i don't know if my recording or this video has been quite or can be quite useful or not but i'm actually i'm putting it open to the public on my youtube channel and under name nikki kudo that's a guy from yellow give her income k for kilo i'm from india for echo my last name kudo is k and for killer eu uniform d for delta and for oscar and if you have any questions and you're welcome to give comments to my youtube channel i mean under my name and as you like anytime and i may be able to answer precisely or more accurately to your needs and well i do hope that tell me i was able to well i can be able to be a part of the small contributions in spite of the fact that um i'm not able to participate in this exciting and important learning conference i do hope that any confidence in the meeting will be so successful and we will keep on really working together in order to make the entire world a better place to live and also a better place for all those idealistic and ideas and ethos and equality and uh well fairness and justice and i choose and all those idealistic and realizable or should be realized by you to be um sincerely from the bottom of my heart to be realized thank you very much indeed for your final attention and i do really look forward to connecting to you all again very soon and in person and simultaneously yourself thank you for watching so so thank you very much to uh mizuki kudo uh that was a lovely presentation um and she has advised all of us that we can connect with her [Music] i think that was the end of that [Music] i know miss kudo is also a pianist so i'm just thinking okay um so i think um looking pretty good here here okay so i'm sorry for that managing my technology here but i think yuki's also pianist so i think that's what we heard from her as well perhaps um so i'm just looking to see if we have any of our other speakers here um and um otherwise i'm going to there we have our members here frederick cohen and

alex buckham who have messages as well and i am going to turn the floor first to alex buckham please alex would you like to share uh a few minutes of your thoughts with us sure no problem thank you molly um hi everyone thank you so much for joining today it's a real pleasure to be here um as amari just mentioned my name is alex buckham and i work in the human rights sector uh currently i work for two ngos focusing on promoting and protecting human rights in the gulf and i've been a member of this dc for over a year now principally because amongst my areas of expertise and interest are issues about state surveillance what's known as surveillance capitalism and sort of corresponding privacy rights issues so in many respects um technological innovation shapes and some would argue even defines society um and with regard to healthcare the area that we're all here today to discuss it's absolutely critical to continue to pay close attention to the impact that this potentially useful technology uh can have on our human rights um health services could according to professor robert of the university of california use ai technology to conduct quote an enormous amount of research more accurately with better information prognosis and recommendation close quote given the vast amounts of data that health services currently have in their possession a point that was raised by a previous speaker various kinds of ai digital diagnosis tools as well as ai software systems which scan patients records to assist in the development of future drugs and treatments are but two of many examples of the types of digital technology being used in the health sector however to take the uk's national health service as an example companies such as google apple amazon and facebook now of course meta demonstrating clear interest in partnering with the nhs to gain access to its data has raised serious concerns regarding for example these companies seeking to monetize sensitive health information in their advertising efforts dr allison pollock a consultant in public health medicine based in newcastle in the uk as previously stated quote all the surveys of the public show they want their data used only for public benefit and quote they have very serious concerns about the commercialization of their data and if it's being exploited for profit in 2019 a leaked uk government document revealed details about secret uk us post-brexit trade talks in which the us was clearly pushing for quote free flow of data as a quote top priority including health data of course also in 2019 the uk government's department for health and social care released a response to a series of freedom of information requests from privacy international regarding the use of nhs content by amazon's virtual assistant alexa privacy international alarmed that the agreement quote seems to clearly allow the latter to use information provided on the nhs website for a handful of purposes including advertising or marketing incidentally in a 2019 rockcore survey of about 4 000 people um only 11 were willing to share their data with a tech company like amazon or facebook it's previously been revealed that a number of menstruation apps sent personal data about women's sex life to facebook without those people's consent facebook and google also received information from apps covering smoking cessation and depression again without users consent so in response to claims by big tech

companies that every precaution necessary is being taken to protect users health data and broader right to privacy martha stender a berlin-based tech ethicist fellow at the viandrina european university in frankfurt argues quote even the most sophisticated anonymization techniques given enough data points um it may become possible to de-anonymize individuals in future this is a standard sort of um quite successful rebuttal to arguments about metadata that the states have put forward in the past when trying to defend mass surveillance um issues about the role big tech is playing and further seeking to play in health care have only been exacerbated during the covert 19 pandemic of course in their paper uh storing and de benji poi volley apologies for any mispronunciation there raise a number of key points one of which pertains to the increased reliance of european governments on companies such as apple google and facebook in tackling the pandemic which raises quotes serious questions about their power relative to tech giants is for instance striking the public health agencies wishing to adopt google or apple's exposure notification technology as part of digital contact tracing efforts appear to have little if any choice but to accept the terms and conditions the companies impose others have raised concerns about big tech becoming quote the new gatekeepers of the enormous health data sets that they are helping to compile with no concrete guarantees these data sets will be openly accessible in future as well as the possibility of apple google and so forth dictating which research questions are asked and setting research agendas more broadly two final points naomi klein has previously made the case that with regard to narratives about the success of contact tracing apps they ultimately quote erase the role of a functioning public healthcare system of the fact that it was a well-staffed public health system that allowed human tracing and tracking of the virus which means a human being best of all a human being in your community somebody who you might trust who speaks your language close quote to assist those in need of medical aid she argues that the ever increasing use of surveillance apps and tele health to the ultimate benefit of companies such as apple google and amazon is quote removing humans from the equation look at the big looking at the big picture tech giant's increasing involvement in health sectors around the world poses serious risks to a variety of human rights including our most fundamental right to privacy if tech companies practices are not kept in line with international standards our health data could be used for a number of problematic efforts pertaining to state surveillance and surveillance capitalism i do apologize for how depressing that was but thank you nonetheless for listening thank you molly thank you very much alex thank you for bringing us up to speed on all those very important human rights aspects that very important as we as we develop legislation internationally um to keep all those uh points in mind um so that we have as a speaker talking about fairness equity personal control of data and and so forth so very important um i am i think we have a number of dc speakers um you know participants here so i'm going to just go down a list of people i'm going to ask frederick please uh for any comments that he would like to share with us please first hello everyone thank you for the invitation

today we were talking about an important issue for public health is what is about our air quality it was very well known that air is a good transport some virus like the kovid and there are also very much more virus that could be very really dangerous for public health and the future of the humanity what people have to do is is very important is to to get an important distance between each other not to contact and to communicate these very dangerous diseases so we were talking about our air quality and an important thing to know is that uh the pressure in the atmosphere could make changes like the wind which could uh get away some ridiculous things but that could be really dangerous for everyone what what is another thing to say is that the technology in the urban era here is a really easy to regulate with an important partnership and an important trust over it for the one who who get action over the wool systems there is a connection between pipe work to transport water and road trafficking because of the pressure the fluids are exchanging between them not not to make a waste of energy to make noise or smell smell is an important signal to identify to recognize what could be dangerous for everyone's health on earth also we can remind that our air quality in pressure was very much illustrated in japan by some super heroes in comics and then it's very well known for anyone but it's difficult to get it serious when it's made with pictures and as the quality of the education for young people is in danger so we have other other schematics issues to to design what could be physically embedded in all in all these issues and um polymer statistics mathematics sources are a particular space to communicate and to talk with each other then serious people like regulators or elected personalities some some change makers in policy making with the u.n in partnership should provide an important trust over the world to make change happened we were talking on drug wars and it's not about laundering is a dangerous issue for the global economy the manufacturers everywhere in the world but

really most in china are informed of the importance of these issues i think it's not to be polluting by all by everyone in the world and we had the example of the nuclear weapons which were confused in water after the accident in japan for fukushima the chinese government is also communicating about how to clean this dangerous water and to find a solution that could protect the environment and the the sea domains also we are supporting foreign jews health the eu the you know dc campaign coca instead coffee instead of coca that could support the economy in different regions in the world like in latin america or in africa but mostly europe that is really embedded into cultural issues that could be dangerous for public health because this product is transmitted too much and [Music] the kovi 19 pandemic was an occasion to fight against the supply chains [Music] of the drug war the presentation of mr wong-ji in afghanistan was was also an important turnover in the history not to continue this cycle of traguer wave laundering and pollution for everyone in the world so what we keep in mind is that our solution to design a healthy urban space in modern life could continue with the waving it is produced in the pipe work their battle between hair and water transmitted [Music] from the pipe could be managed and in france now provider for water is regulated by the chinese company of computing tencent which is one of the basics which remain is in a competition in front of gaffers for the western countries but also with the russian ones what is what are glonass for example also use to to to get satellites in the space to to get in mind but arrest is important to have because there are sometimes important challenges and sometimes things are not like mostly produced some goods from a

counting like issue to london other problems like difficulties to work which is a repetitive task like beating the heart or the brain activity then signals could be made in the with the paperwork to communicate sometimes but also to support a human activity and get action when difficulties are coming so the topic of climate action which was very well illustrated with by gilbane is also an important thing for armies in the world and we keep in mind that the competition into the security countries into the city into the countries of the city can still should be should be managed with the support of the international community the situation there is also complicated but some curves could be shared through others to make prevention when some discussions have to be made and then the u.n could be a part of the solution there is no problem to communicate to everyone with the support of the governments who take part for the security okay thank you thank you frederick it was very interesting to hear about all this air quality and very very topical um you know there's going to so much of climate change and the impact on health care um and and we always i know you know a few decades ago we were talking about air quality and then kind of forgot about it and we're now talking about um you know things like earthquakes and and storms and and things like that but uh that air quality thing i think is very important especially um in the workplace um you know they're talking about these big um you know we had big office buildings and how to clean the areas but then when we step out as you say we're meeting that air quality issue as well right so um you shared with us some very interesting insights you shared with us that integration between supply chains and going on into into defense as well and so forth so thank you for those comments okay um now i'm going to ask uh jiao dr zhao are you um are you with us and would you like to share some thoughts hello uh hello everyone it's my first meeting and it's great to meet you even if virtually um but uh but yeah i'm happy to share some thoughts i have not uh prepared anything in particular but uh but of course i can definitely start by sharing my backgrounds so i'm a medical doctor based in portugal junior one uh i practiced for one year uh here in portugal during the colby time uh at least the initial peak of it because we're still going through it uh but then i made a career shift so i joined a company in germany um called ada health which means whose main product is a symptom assessment checker so basically our users can introduce the symptoms uh in that platform and they will be provided with um some conditions based on the likelihood ratio uh of the input that they gave to the app and of course that the questions that

are asked back in the assessments are always taking into account um the the input or the information provided by the person in the beginning so for example if they say i have a headache uh they will be asked how long is that adequate lasting from are there any uh modifying factors to that condition any associated factors so obviously it's a very interesting field for me having that interest in technology and also bridging with the knowledge that i had from from medical from the medical studies and the initial stage of medical practice um but of course there are some limitations to these technologies and this is maybe where i want to to make my first point be another um tool or another app that we have on our phone to be there and to be used once a year whenever we we are in a more acute stage there are many uh apps for monitoring of chronic conditions that are not used by the patient in the chronic states and they are only used when the patient actually feels the need of having some extra support so they actually fall we have an expression in portugal to to to describe these things they fall in an empty bag so they are not used for the purpose that they are created for uh at all um and and under this line there's also another interesting aspect that started in germany called digas which is the the prescription of medical apps as an aiding tool for the treatment of the patients uh this is um this was introduced in germany first it is already been developed a similar approach in france recently and in portugal it's starting to being debated at this stage so i would say that yes some of these apps may provide some aid or some support to the patients but all of the entire system either in france or germany implies the validation of these apps to trials that are a must they are a need so these technologies before being put up to use for the patients they need to be validated first and this is another thing that should be regulated uh beforehand um in europe particularly there there are some working groups that i'm aware of uh also regarding data which we are in the first communication uh the european out data space is being discussed at the moment and i would say that it's key uh to manage the interoperability of data between member states and even within the country so allowing the person to travel to a different country have access to their medical records and actually be able to to use the medical records in a different country or so that the healthcare authorities can actually make use of that data this is another key aspect but it's a still a discussion that is going on and we don't have regulation yet for this nonetheless i i would say that it's another interesting uh point to be assessed um but but looping back to the to the applications and uses of technology what we have seen also over the last years is that there there's a steady increase in the healthcare expenditure um in comparison to the gdpr in the majority of countries and i'm basing myself on oecd reports at least that's what i always try to follow they are not fully representative of course but they provide this overview of yes the upcar expenditure has been increasing and it's not because our populations are getting older or that the needs for chronic management of conditions uh are getting increased yes that happens too but that only accounts for about five percent of that increase

the vast majority um of course not a vast majority not over 50 but 40 percent uh it's driven only

based on technology and i would say that the call is also on how can we actually use technology not as uh not as a mere

incremental performance booster for uh our healthcare practice but also as a disruptive way of performing healthcare so not only improving the outcomes but also reducing the costs and this is also the work of some newer companies that are not necessarily dependent on or that are at least more flexible up to move around in the regulation gaps because yes this is i know that this is the elephant in the room probably but there are still a lot of gaps in these fields um and usually these these younger companies are able to provide some systems that are um yeah able to tackle both these things and i would say that this is the next step for us in terms of uses of technology so not only how can we improve diagnosis how can we improve treatments with technology but actually how can we make things cheaper because yes telemedicine is being used but we still need to maintain the infrastructure to provide the regular appointments for the ones who don't make use of telemedicine and we have seen this particularly during all the times there was an increase in the appointments for telemedicine of course not it's natural but what we are seeing right now is that we are looking back to the regular system in which telemedicine is no longer the norm uh which is also understandable taking into account the cultural aspects of our populations the lack of digitalization of our uh of our families of our citizens um but it's also important to to keep in mind that yes we need to uh to implement these changes uh we need to regulate them um and it also comes from uh from a top-down approach because yes the if we only have something like this to offer if it's cheaper economically and if if it's more accessible also because we're not only talking about economic costs we're also talking about the possibility of people who don't live near near these facilities to actually have access to healthcare it's interesting because i remember having a discussion with with some medical doctors in portugal that could not foresee this as a problem a problem at all because our geography is very specific we are a tiny country uh we have healthcare facilities decently or at least close uh to the majority of populations we still have this problem but if we think at a global scale and we need to think like that uh we don't have facilities to to provide uh medical access quickly to to all the population uh so this can also be a tool that can be used uh to bridge uh to bridge that gap and uh and yeah i would say that on a final note um the key is is also to regulate because what we are seeing uh also recently in recent years is that many companies coming from europe there are regulator under gdpr actually use that as a flag to enter into other markets and to validate their own respect for for data privacy um and to actually have access to a free highway access to other markets um so uh and on this note i would say that it's important to breach ai systems uh so that yes not only to stop the companies from acting on this field but actually to validate what they're doing as something that is of relevance to provide trust to the populations um and above all this is the most important thing at all because at the end of the day we want to make a day out of our patients better and we work for them so so the ultimate goal should be that to increase their trust also the topic on data is extremely relevant and i'm very

keen on on discussing some more in the future about it but but i would say that that's my key takeaway regulation is key so that then we can leverage the technologies um and yeah once again it's great to meet you and i'm looking forward for the discussions thank you thank you very good welcome to idc as well and we look forward to it and you touched another point i'm an economist an accountant so you touched on a point there about um cost and uh i'm also a little troubled to hear that telemedicine is going down because i think um that was something that especially with the doctor shortages that we've seen in many countries that allow people access to medicine right so i don't know how we encourage going back or keeping that going but i think that's something we need to maintain for sure in the immediate term to meet that shortage and then develop everything else as well so thank you for that um i'm now going to ask june paris june um would you like to make some comments hi i'm june paris i'm a nurse sorry my grandson's in the background yeah i'm a nurse um yeah it's i would love to see um um telemedicine i would love to see um this thing making things better for patients but in my experience i've worked with telemedicine i've worked with a company called remed where you have apps um to look after patients and and but you still the patient still needs you the patient still needs you right it's and not everyone has access to computers and and um internet and they're not in internet literate um what but it's getting expensive it's healthcare has been getting very expensive um even if you pay medical insurance it doesn't cover the costs of what we have to do to have surgery it's like certain i'm talking english because i worked in england thirty thousand pounds of a surgical procedure and you're paying a premium even if you're paying insurance it still doesn't cover that cost so i have no idea how we're going to change this staff a lot of staff are leaving there's hardly any doctors now doctors are leaving nurses are not people are not registering to to study nursing because it's difficult it's really hard and and the pay is not that good so i don't we'll have probably have to use robots or something like that in the future to look after patients i i don't i really can't see how this is going to be solved unless everybody puts their heads together and tried to budget governments will probably have to budget more towards health care i don't know but as i said i've been looking into this for a number of years at least 20 years and i can just see the cost is rising i did my own budgets i had my own budgets and i had my own we sold you know i don't know i'm not sure how it works in canada but we supply and we buy um healthcare i had to supply health care and i had to purchase health care and that comes out of your budget every year and you have to reach a certain level of um you you have to reach like 75 of your patient whatever it is you've got to do to get paid from the nhs for that service that you're providing and it's very difficult i spent hours and hours without just working without even getting paid just to get that work done just to get that computer work done just to get all my data in it's you it's like and you don't you don't get paid for a lot of that work that you're doing so you'll see why doctors and nurses are just not they don't want that profession anymore um at the end of the day um because you're sitting in front of a computer in fact you sit in front of a computer so much that sometimes you don't even see the patient so you see it has its advantages but it also has its dis advantages i wish that

i could just not go on a computer sometimes and just care for the patient um so yeah um so i'm seeing it from my point of view but i've also because i've done all i've done research for this company called remed i put it in the chat i i did the research for them and they were setting up so i've seen it from their point of view as well um they haven't if you could follow their links they're really doing well with supplying patient care to hospitals in england and private practices and and gp practices and all that and they're spread in india they're in india they're in the caribbean they're all over the world and that's a company that i worked with in um a long time ago and i actually did research for them to set up that component and that that program so yeah so it's not i've been talking about it for a long time so i hope i didn't say too much thank you no no that's wonderful i'm just so happy that we're uh getting this uh experienced people um on board on our dc and and you know obviously each one of you are experienced uh in in various areas and we need to sort of dig deeper into into those areas and and discuss further and and write papers and and then obviously share our insights with the public and um and uh igf uh the technical community if that will support them i think it'll be very good especially if they can understand better from the i.t side what they need to develop you know whether it's interoperability or whatever um you know and especially i think things like tools such as um you know speech to text and stuff like that um we are really hearing about that you know that background work the doctors have to do um we're hearing that although a lot of paperwork and even my own friends are talking about so much paperwork and that keeps them away from the patient as you were talking about and so forth so um those things i think technology can really help in many ways so you know um i think that would be something that we should brainstorm together and and uh you know pitch that work um forward um you know to be heard by those people who have the money basically to to grant uh you know for the betterment of services and so forth so um thank you june for that we have dr amado um online mother would you like to present for us it was going to be one of our speakers would you like to share yes of course thank you very much for the opportunity yes yes screen you can share your screen you can share your slides if you wish yes yes i can look for them and yes i want to first of all congratulate you for the organization of this meeting emily i think that's a very very important for the igf and for the different groups to have the opportunity to discuss so such an important topics like you have already mentioned here and i think this is a certainly a very a very good opportunity to to in life people about the reality in different in different areas where we are trying to accomplish these innovations in terms of digital health in digital uh into the different uh environments uh what i want to to mention uh shortly is actually about how the uh different applications of digital health are

taking place in in mexico in latin america and how can we actually take advantage of them in order to to learn a little bit a little bit about uh this is a presentation which we uh i i need uh i i cannot share this screen emily i don't know if you have to to give me yeah anya anya please igf secure could you make uh dr mado a host please so that you can share yes just a second thank you thank you anya you are most welcome man i think you are able now amada please try yes yes it's working now okay um here we are in uh well what we we want to to very briefly introduce to you is how we are working here in latin america in terms of um deploying this um this in this this new paradigm of the data of the healthcare system which is called digital health as such at the different communities right now as you know the the um the population here the indigenous population in latin america is large enough it's very representative in terms of the culture in terms of the what is called the traditional medicine that that they practice there and actually there are very different languages not just in mexico which we used to have the uh as taken in the mayas but also in south america where the influence of the uh inca culture was very strong and is still nowadays no matter no matter that today the uh the mixture between the or original indi indigenous people with um new commerce is called mestizos but also in terms of the of the groups that already that still have their own uh the their own conception of health in how the relationship with the nature should be should take place the pathology that we real what that we find in these communities is a a very similar to the urban communities like that means chronic diseases are very heavily present there but also in other diseases like arthritis or musculoskeletal disorders because of the different conditions of the weather in which the the people suffers suffers under these conditions and if they have the opportunity to have remote support from specialists or from the institutional healthcare organizations it's very important for them to to have an opportunity to have access to this kind of knowledge in medical support and certainly the economic conditions in which they built those pollutions live that means really outside from the uh small towns or or

small cities where you can find a regular hospital or you can find some specialists there but for them it's very difficult to to to move there because they they have to walk four six hours before they reach one of those towns and they they almighty we can't hear you yeah we still can't hear you still can't hear you please did we did we lose dr mado there anya um i can uh oh no yes it seems maybe he is reconnecting probably okay right so just give him a minute to reconnect these just a bit of administration after dr amado i have a name here crunchy bhagav would you like to speak after dr amada has spoken and i also have delphi ramirez as well um please after dr amargo has uh connected reconnected and and spoken then um we'll open the flow to you as well please okay thank you we can see the presentation again amanda perhaps you can go back a few slides because i think we missed a couple of slides from your presentation this is the slide we we also at the end um we don't hear you dr mother here now can you hear me yes yes thank you very well yes please okay in yes i was mentioning to you that um for for many years those communities have suffered the their own pathology which is related to their cultures together with foreign pathologies which arrive with people coming from outside to to live with them and to mix with them and nowadays paho in in the world health organizations are are trying to to look forward how to help those communities through different initiatives in order to make the in order to accomplish the the the goal number three which is related to the universal health coverage which um in which they are looking for a holistic approach of health that means to take into consideration their own culture how do they perceive life in the purpose of life and how do they have the how do they become responsible for their own health and also how they how can they remain an or even an original culture with the advantage of having access to the healthcare institutions already in place at the uh urban urban cities and at urban societies and also they are looking after the reciprocity

in terms of the relationships with another groups which means it's not only about a single in the universe community but also another ones who have similar realities and that's why we are looking forward to to have access to the patient's clinical history in which we can accomplish to grab at least the most important uh demographic in physical data from the communities in order for us to have an idea how those how do these communities behave in terms of health and how do they have access or can have better access to the health institutions because it is not only a matter of translation to translate into the native dialect but also how can we take into consideration their own values their own perspectives of life and this kind of inputs can be accomplished in a holistic clinical database that we can build together with those communities our societies nowadays we we are working in the technical communities together with these indigenous communities and we are having um also some initiatives which are very interesting in terms of how to use uh not only the software but also the telecommunications in order to make sure that these these groups have not only access through the mobile phones which they not er we cannot guarantee that they are going to pay the monthly fee or that they are going to have a ongoing access to the data but we can we are pursuing to to build local um stations where which can be communicated through the satellite satellite network which we do have in place in mexico in order for them to test at least that these hotspots have access to the internet in an ongoing basis and if they have some [Music] healthcare problems they can attend this community place where they can have access to a healthcare institution or to a healthcare professional who can keep them provide them advice and take a advantage of a database that we are trying to to construct at different communities one of the programs which is uh nowadays not only successful but became very important is a program which is called aims me and star in mexico which it's a program which started at the at the early 80s where small clinics were placed at these small communities indigenous communities and now nowadays we are trying to guarantee that those clinics do do have access to the to the internet to the satellite network and we we already have a very simple easy to use clinical database which takes into consideration some of the aspects that i already explained you about

how can we really help how can we really use technology to help people to better understand how can they have an ongoing personal uh personal health file we call them in spanish a uh that means the healthcare story which in which we do have the most important uh in relevant points like immunization weight uh if they if any chronic disease has been detected and so on there is very simple one and also to establish the mechanism in order to to help them to understand how to take advantage of telemedicine it's not only to have the the equipment there i have visited peru bolivia ecuador where mainly in bolivia they have a very important telemedicine programs which has which have not been able to to be improved because the community really does do not have does not have a the the conviction that there is something which which goes goes along together with their own values in in the way in which we allow the technology to be perceived by those communities as a part of their own resources then we can be more successful in this direction and also to generate prevention strategies that means to help people to understand that prevention is much much more important that than a treatment a professional treatment and that if they take advantage of these programs they can really help their communities to improve no matter how their cultural cultural principles are in well that's that's pretty much my message just to say that technology is really becoming part of the healthcare environment in those communities that in latin america is a very important region where those communities with a different mindset in terms of cosmic values or the perception of life and how to handle with the institutions official institutions it's sometimes challenging we are looking forward all together to to come out with a very possible in practical solutions which really help those people to have a better quality of life thank you very much thank you amada that's very very interesting the whole landscape in mexico it's something we hear very often so just very interesting discussion from japan uh to to hear about um the whole situation there and issues and and the work you're doing in latin america so thank you very much people wondering what the witches banner was there this was originally going to be uh presented at itu there was some communication uh difficulty there so um dr mata has uh you know very you know has has delivered this to us i'm just very very pleased to hear

about um you know uh all the activities going there so thank you very much um i'm just looking at the time and i think we had um one um uh participant who had to leave but we have i think a gentleman mr delphi ramirez would you like to share some comments with us seeing that okay that's fine so i think that sort of wraps things up but i would like to go back to um our speakers and ask them if they would like to share any um additional comments uh maria i'm not sure if you're still with us um would you like to just in having listened to all of other conversation here is there something else that you perhaps would like to add um you know i think what i really enjoyed um from hearing from the other speakers is you know first of all the diversity of the perspectives was really important not only from their you know discipline from where they work but as well as geographically you know we can't we know that this healthcare data research you know rights is a global challenge we know but we also see that there are some intricacies depending on where you are not only geographically but where you are in the healthcare chain so i think it's really important for us not to say one solution is going to apply and help all we really need to take if we're going to take this real concept of precision medicine and precision care and targeted care we we have to take all these uh perspectives into consideration thank you thank you excellent yeah that's that's exactly it and as um dramatica was saying that holistic um healthcare approach right that's uh that's uh based on values and targets to the region and so forth exactly yes and and then the complexity that we have nowadays with all climate change and it's so much change uh going on right now where the old normal was was very flat in many ways but now it's not just cold it's just we've got just everything else from population growth to climate change to to add into the matrix of issues that are going on yes so is there anybody else who would like to add i'm just going to open the floor and just um you know just speak up i think that's probably the way we can go maybe i i don't want to make a short remark related to what june was saying of course of course technology in in at any time of the human history has had both aspects of the of the same issue i mean i can imagine when the when the wheel was invented it was just for uh specific um specific objectives related to the good of the society but also they they use the will for for other purposes which were not the best that that we can think about and technology certainly is a challenge nowadays not only because it is not very well understood by every like all the communities but also it is not very well managed in terms of the legal and ethical frameworks that are surrounding it in the technology is running at the such a pace in which the institutions cannot really catch up with it in in certainly we don't have certain kind of challenges but i think

this this kind of groups of these kind of discussions it is very important for us to to realize that we are protagonists we are the main players trying to build up this new this this new percep perception of life or building up this new paradigm of healthcare in which we really give patients physicians nurses uh authorities uh uh the the people responsible for funding third-party payers that are called in the u.s we we are giving them the opportunity to double check analyze big data we will we are also trying to put in place how to couple together the data coming up from the genomic uh sequentiation from the um social determinants of health we are trying to put together also the um advantages of of the everyday medicine based on evidence and personalized medicine and so on then i think it's worth to try we certainly have to be very very aware of what we are doing in which direction we are moving ourselves but certainly taking advantage of new technologies should should be for the good dr our societies things yes thank you very much yes exactly i i totally agree with you yeah yeah so I'm just going to um there was a message that came up from delphi would you would you like to comment please to let's just turn your speaker on um i i we're seeing messages um uh anya could you give delphi the opportunity to speak please i think you are unmuted now delphi no amalie if you take a look at the chat she did say oh yeah i assumed she was he sorry that uh oh she doesn't okay they don't have a mic so i i'm just trying to read the message it says um mike is not working okay so i i think it says something like aspects in health understanding health in two fields population and individual should charge both aspects um by teaching data i'm saying something like that um then said both aspects also are keen in helping health practitioners doctors nurses to approach new paradigms in in society so that was some delphi thank you duffy okay um so i think are there any further comments please please um yeah you can please request uh the floor i think anya may have to um turn on your mic for you or something but maybe you can indicate that in the chat and then she can turn that on for you i i think everyone are unable to unmute themselves but i'm happy to i can request you know for for participants on youth but i can't unmute automatically anyone okay i i think then that everyone has an opportunity um is that are there any other comments from anyone please okay so if there isn't then we'll say um well so this was a really an excellent session um we we missed out on a few speakers um because of the timing issues but we can have um another grand session again uh in the fall hello um and i think uh we can have you know just have a have another wonderful

conversation as we did today uh i just learned so much from everyone um the diversity the regional diversity stakeholders that we've had here um talking and sharing the experiences so i really appreciate this um i invite anyone who isn't part of a dynamic coalition please join our coalition and um i think uh you know there's a lot of work to do um and and and it's uh you know formulating all the ethics and values and food systems requires a coming together um to discuss um a lot um so um we really appreciate if you join us we can develop some policy that we can put forward uh i.t based but also if you think uh it should go forward to some place like you know we are in a very suitable place to do that because we are under desert so um you and jesus so um i think we're in a very good place to have a very good and someone said a holistic conversation um so so let's do that and uh i appreciate all of those of you who joined us uh maria thank you for joining us um and thank you for our new new dc members as well thank you so much and for our existing dc members you are the heart of who we are um so thank you so much and marie i hope you could join us as well uh into the future further discussions with us as well absolutely so thank you very much and thank you anya for arranging all of this for us thank you thanks to everybody thank you very much thank you bye thank you everyone thank you thank you i'm ali thank you thank you very much you

# Appendix 6 & Member activities:

Reported by Frederic Cohen

## DC DDHT - Outdoor Experiences 2022

## UN inter-agency affairs for international cooperation and cyber-officer

Since my email invitation from Under Secretary-General Liu Zhenmin to join DESA programs in 2020, my participation in the IGF - DC DDHT has become my main activity. It includes monthly Zoom calls and collective preparation for the IGF annual Summit.

In the same participatory mode via the internet, related activities appear in my schedule, with the UN ITU - AI for Good conferences for which I receive invitations from Guillem Martinez Roura on the topics of robotics and health.

The opportunity also arose to join by invitation by email seminars and conferences of the Financing for Sustainable Development Office of UN DESA, such as the Investment Fair. I also receive several newsletters for these events. It was the same with the P2C Annual meeting I attended online.

I also use social networks to follow UN Geneva conferences or the UN DESA Global Policy Dialogue Series. The UN Water Conferences are also on my agenda.

I also participated in the recording of a talk of about an hour for the Virtual School of Internet Governance (VSIG) with Glenn McKnight. I presented this one in French. It was about emerging technologies. It is published on his YouTube channel.

## CNAM Paris University (France), School of Engineering in Robotics and Automation

At the same time, I am pursuing university studies in automation engineering and robotics at the national level. I have already acquired many disciplines from this institution, the CNAM center in Paris, France.

For this, I wish that my work in the UN and its referencing with the IGF Secretariat be recognized as the equivalent of a professional activity for the graduation at my School of University Engineering.

Steps in this direction were taken during my meeting with the advisor of the employment agency of my city through his follow-up, considering a different categorization in his summary.

### Activism with the Global Green Party and associations on healthcare and climate control

I frequently follow the news in China via the Internet because its role in the global economy seems essential to me. I also think I can get closer to the DESA management by reading the information provided by the Ministry of Foreign Affairs in China, as well as by the Chinese State Council, which addresses cyber-governance on an international approach.

It is also an opportunity to contribute to Wikipedia by adding a few translations to its Chinese dictionary.

Also, I participate at the national level in politics with the ecologist party and in the socialist alliance. In this context, I express my commitment to the United Nations, which I represent, for example, by having participated in a campaign team during local elections.

I keep links via the internet with associations fighting against addictions that demonstrate annually in Paris according to a well-known route near the Bastille. The first is to defend access to medical cannabis, which is being developed through experimentation in hospitals, and to open CBD shops that offer cannabis without THC, a molecule prohibited in cannabis in some countries around the world.

I publish this online with Facebook but also on the act4sdgs.org site that gives an award periodically for the UN System in a community. In this context I received the invitation from the winner to mobilize Paola Andrade to connect and support her action with the SupVivors and Ecuador dice no mas to demonstrate the resilience of people who have been victim of sexual exploitation and abuse.

#### **Reported by Frederic Cohen**

Amali De Silva – Michell contributed to the (1) Pew Research Center & Elon University's Imagining the Internet Center. Future of the Internet (Project): The Metaverse in 2040 and (2) Pew Research Center's report: Experts Say the 'New Normal' in 2025 Will Be Far More Tech-Driven, Presenting More Big Challenges

### Members At Large

Several DC members continue to participate with the working groups at the UN ITU and other IGF groups. They also pursue their personal, work and academic interests in this field.