INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

Alliance Roundtables

COMMUNITY*CAPABILITY*CAPACITY

Fundamental Rights: (e)Quality of Life

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EXECUTIVE SUMMARY

The "Fundamental Rights: (e)Quality of Life" roundtable brought together a diverse group of experts from technology, design, healthcare, and innovation to discuss challenges, solutions, and organizational strategies relating to how technology and innovation can enhance and improve quality of life for people living with ALS/MND (PALS) and their caregivers (CALS) worldwide. Key themes included sustainable and equitable access to technology, and the importance of communication, collaboration, and community building. The report identifies the need for raising awareness, improving discoverability of available technologies, and fostering global collaboration to share resources and insights. It emphasises the critical role of technology in empowering PALS, highlighting that access to technology is not merely about functionality but about enabling individuals to feel like themselves.

The challenge of 'Sustainable and Equitable Access' involves creating solutions that are broadly accessible while addressing global inequalities. This includes ensuring representation for PALS and CALS through co-design practices and incorporating socio-cultural aspects for effective change. The matter of 'Communication, Collaboration, and Community' focuses on improving the discoverability of available technologies and fostering information and resource sharing among stakeholders. This includes sharing experiences, insights, and learnings across the broader community to raise awareness and open new avenues for technology transfer.

The report emphasises the importance of creating design solutions that meet the needs of the ALS/MND community, and the Alliance seeks to build this as a sustainable ecosystem based on open-source values, fostering collaboration and shared ownership among stakeholders. Three key initiatives are presented:

- 'Accessible and Affordable Voice Preservation and Communication through AI' focuses on incorporating voice banking and enabling communication and expression through augmentative and alternative communication (AAC) for an end-to-end solution available globally.
- The 'Platform for Collaboration, Knowledge Sharing, and Resource Management' aims to build a global marketplace to provide access to information, knowledge, and resources.
- 'Enhancing Quality of Life through Personal Insight' involves developing a personal framework for each person with ALS/MND and their caregivers to help

them understand where they are on their journey and identify specific areas where they will benefit the most.

A co-design approach is proposed which involves establishing local design and build sessions to better understand met and unmet needs and develop viable business case frameworks to help technology manufacturers, NGOs, and governments understand market size potential and the scope of the value opportunity.

Given the undeniable role that technology, including AI, will play in the future, a case is made for technology providers to collaborate with the ALS/MND community as an invaluable user-base to design and develop solutions built on inclusive design values and principles that have general applicability.

The report calls for collective effort, open innovation, and collaboration to address the challenges and harness the opportunities presented by technological advancements. It calls for us to reimagine assistive technology and what it enables, so that it does more than just provide capabilities to help a person with their functional needs but extends beyond that to provide presence, agency, and expression – all essential components to living a meaningful and purposeful life.

AGENDA

Agenda Overview	
Plenary Session (virtual)	Feb 27, 2025: 7:00am-8:30am ET (New York)
Group Discussion (virtual)	Group 1: February 27, 2025 – 9:00am-10:30am ET (New York)
	Group 2: February 27, 2025 – 7:00pm-8:30pm ET (New York)

Agenda Detail	
1. Welcome	Calaneet Balas
2. Why we are doing this and why it matters	Blair Casey
3. Context and background	Cathy Cummings
4. Data Sovereignty, standards, and innovation	Natasa Milic-Frayling
5. Patient Needs Framework	Jarnail Chudge
6. Working with established technology	Marla Calder
7. Experience using a new technology (voice)	Haide Jineth Briceño
8. Technology and needs in Africa	Philip Langat
9. PALS and CALS Perspective	Dr. Rick Nelms and Sue Nelms
10. Technology for people with disabilities	Bob MacDonald
11. Innovation and partnerships with academia	Dean Mohamedally
12. Innovations examples from India/Africa	Tigi Bhatnagar
13. Innovation through open collaboration	James Arney
14. Human design and technology	Bill Buxton
15. Wrap-up and next steps	Jarnail Chudge

Group Discussions	

Timeline

- 10 minutes: Debrief from the Plenary and introduction to the Discussion Group and logistics and housekeeping
- 30 minutes: Discussion in breakout groups
- 30 minutes: Summary from breakout groups and general discussion

- 5 minutes: Wrap up and close

Debrief from Plenary

The purpose of the plenary is to provide a diverse and varied set of views and experiences from different disciplines in technology, design, healthcare, human expression, innovation, access, affordability, etc. from a global perspective, with the intention of teeing up interesting, provocative, and illuminating discussions in the subsequent 2 group session.

Goal: promote a stimulating discussion which will help identify and prioritise areas of involvement, and investment for the Alliance...in support of our mission and purpose

Key themes and considerations to guide the discussion groups

For the breakout groups, the following questions will help guide the discussion to ensure we cover the key areas which will help inform and shape the goals we set for the future.

Based on the plenary session, what stood out for you in terms of:

- The main challenges to address?
- Potential solution ideas which could make a difference?
- How do we organize in a way that helps us achieve the outcomes we seek?

BACKGROUND

There have been significant changes in the technology landscape since "The Spectrum of Possibilities" roundtable in June 2021. Since then, Artificial Intelligence (AI), robotics and autonomous devices, Brain Computer Interaction (BCI) are rarely out of the news. Coupled with the increase in capability and use of Augmented Reality (AR) and Virtual Reality (VR), the increasing popularity of home-automation systems, the investments in communication and voice-preservation technologies, and the growing familiarity of using our personal and home devices for tele-health consultations – all these represent new opportunities regarding the value and contribution they have the potential to make to improving Quality of Life for PALS and CALS around the world. However, in equal measure, they can be said to pose challenges and raise important questions about fair use, ethical handling of data, security and privacy, equitable access at a global level, and the impact they may have on our 'human-ness'!

Central to this roundtable was to tee up the discussion on how to marry the best of what technology has to offer while making sure it aligns with underlying values which seek to grow and augment our natural human capabilities rather than detract from them in some way! Our approach within the Alliance to this, has been to ensure the Patient Needs Framework is closely tied to and cross-referencing the findings and insights our Fundamental Rights survey furnishes us with, to ensure that what we do is aligned with the Alliance's overall mission and goals, serves our member organizations around the world, and makes a measurable improvement to the quality of life of PALS and CALS globally.

This is built on the values and principles which inform the work and approach of the Alliance daily. Our values of "human-centric" places emphasis on fairness in representation, inclusion, and accountability which help ensure we are driven by PALS and CALS; "knowledge-sharing" is focused on being transparent, timely, data which open and supports interoperability, which in turn makes it replicable, and finally, being "trustworthy" which comes down to being reliable, ensuring our compliance process are private and secure, and advocating for the re-use and sharing of information in support of research which is correctly attributed and acknowledged.

In an environment where there is significant global iniquity in access to information and care and affordable technologies, this roundtable was convened to bring

together not just representatives of our member organizations, but also a group of external experts in the field of data governance, systems thinking, human design, community builders, entrepreneurs and innovators so that we could come together and shed light on these issues and work to find a path forward where we could meaningfully make a difference and positively impact the quality of life of PALS and CALS across the world. As an 'organization of organizations', the Alliance is being increasingly challenged to provide leadership and direction to the broader community because of its unique perspective as a truly global organization.

In the sections which follow, we present an overview of the outcomes from the roundtable and go into greater detail on what that action plan may look like as we work together to realise them. This is followed by an overview of the expert presentations and summaries from the discussion groups.

It is our sincere hope we have done justice to the contributions of all our participants and partners and the diverse communities across the globe they represent!

ROUNDTABLE OUTCOMES

Based on the 3 key themes of **Challenges**, **Solutions**, and **Organization** (and **Change**), we identified the following:

CHALLENGES
These can be categorized into 2 main areas:

SUSTAINABLE AND EQUITABLE ACCESS
- How do we create solutions that are equitable for the community while there is such deep inequality and imbalance between the 'have's' and the 'have nots' at a global level?
- The need to ensure representation at a global level for PALS and CALS through co-design practices (as embodied in the phrase "Nothing for us without us!") for both project and product design and development, and in research and development of clinical treatments.
- The socio-cultural aspect for effective change is more than just making technology accessible but is to do with raising in-country awareness and shifting cultural attitudes (e.g. stigma), advocating for public policies and support),

ensuring the infrastructure is capable of supporting it effectively, and how this will differ from place to place in the specifics, but the general items hold true universally.

- The need to address the challenges of equitable access and affordability, in a global context, through the exploration and development of new economic models of value which help ensure solutions which are economically viable and scalable. This includes the importance of implementation and sustainability of any proposed models or solutions; and will need to cover appropriate measure from a business and a social point of view.

COMMUNICATION, COLLABORATION, AND COMMUNITY

There is a fundamental lack of awareness, regardless of country, of the available technologies and solutions. The need to improve the 'discoverability' of the available information and data, as well as providing the necessary education and training for PALS, CALS, and allied health professionals, as well as communicating the importance of clinical trials, policy wins, and new approaches to care.

- Related to the above, is the need for information and resource sharing and collaboration among all the different stakeholders. This will help avoid duplication of efforts and encourage the creation of local and global networks e.g., the idea of sharing equipment within and across countries to improve access and reach more people at the point of need.
- Sharing experiences, insights, and learnings across the broader community. There are countless local initiatives and innovations currently taking place around the world, but no means for that to be shared to raise awareness, and open new avenues for technology transfer.

SOLUTIONS

The following is not intended to be a complete list of all the ideas and suggestions which came up in the roundtable, but rather, provide an overview of the key dimensions and characteristics of what will comprise solutions and approaches which stand the greatest chance of being successful.

- Opportunity for the Alliance to orchestrate by bringing together the building blocks that are out there, by being the catalyst or facilitator. E.g., in the case of technology transfer (e.g., University College London (UCL) student projects), the Alliance might serve as an-in country guide for deploying technology solutions into other countries (from which they originate.)

- o Emphasis on creating design solutions that meet the needs of the ALS/MND community. These could be having local design and build sessions to incorporate met and unmet needs. This would involve both sharing knowledge and guidance on how to facilitate co-design session, producing templates for "no-cost" workshops, prototyping, piloting and research.

- Can the Alliance help produce a framework comprising measures for a business case (e.g., addressable market of PALS/CALS across different geographies) with dimensions related to Quality of Life (e.g., access to care, social relationships, self-expression) to help manufacturers, NGOs and governments understand unmet market size and the scope of the value which can be provided.
  - o This would help position accessible technology as an opportunity to attract investment and drive innovation from established technology companies and new entrants too.
  - o Employing the principles of 'inclusive design' and recognizing the ALS/MND community as presenting a series of extremely challenging use-cases, this could be presented as an invaluable testing ground for AI-driven real-time assistive communication tools. And the underlying business framework can help showcase the personal, social, and economic impact of such solutions based on an established need.

- Making global community discourse more continuous, through a combination of events but also through providing technologies, or using currently available ones, which will help to raise awareness and support greater collaboration and sharing. While global collaboration is deemed critical, many innovative solutions often emerge from necessity in smaller, local contexts, e.g., in Kenya, frugal innovation has led to creative assistive technology built using repurposed materials.
  - o This can be seen as a systems where ideas, solutions, and workarounds are collected, categorized, and redistributed globally. A "GitHub for Accessibility," where people from around the world can submit and refine blueprints for adaptive technology ultimately helping create and foster an ecosystem of shared, accessible, and affordable innovation.

- Could the Alliance be the trusted authority overseeing a resource marketplace? Both in terms of providing access to information and knowledge, but also as a

forum to provide, manage and share ideas, research, resources (including manufacturers and solutions) and guidance.

- o For example, this could help redistribute tools that are appropriate to the local geography or share resources that are no longer being offered in a particular region, but which might be deployed elsewhere. Importantly, this would be a 2-way exchange between the Global North and South! A framework for cross-regional knowledge exchange could make these insights more accessible, e.g., low-cost prosthetics made with 3D printing—could inform best practices worldwide!
- o This would be aligned with the varying levels of tech literacy across different age groups and the barriers this creates for accessing technology and act as the basis on which new solution ideas can be developed (e.g., the potential of using cell phones as a primary platform for innovation, given their widespread availability.)
- o This would not only help share resources, ideas, and solutions, but also how to identify and prioritize emerging innovations and ideas from around the world.

- Ensuring that solutions are appropriate for the region. In the case of technology transfer, it is important to consider local norms and practices for any deployment to be successful.
  - o Accessibility solutions often fail, not for technical reasons, but because they do not align with cultural and social contexts. Instead...imagine a hyper-local approach where local makers, using AI, 3D printing, and low-cost hardware, build custom assistive devices on demand. These hubs could empower individuals to create, repair, and adapt solutions specific to their needs. The challenge would be to support a scalable model where expertise, materials, and community engagement converge!
  - o Repurposing off the shelf technology and tailoring it could provide a cheaper way to develop technology solutions for PALS and CALS.
    - ▪ This approach is demonstrated, for example, through gaming technology such as Xbox adaptive controllers which have been repurposed for assistive applications. The example provided of using the sensors in robotic vacuum cleaners, (originally designed for mapping spaces), could be adapted for smart wheelchair navigation in mapped environments such as a person's home, shopping centre, transport hub, etc.

- Potentially, some of the ideas mentioned above could provide a platform for
- This approach has already shown success in unexpected ways. For instance, systematically identifying and modifying mainstream technology for accessibility, ensuring these adaptations are easy to implement at scale, e.g., providing 3D printed solutions via open source. Or, organizationally, creating networks and communities which have aligned interests for mutual benefit based on the value being exchanged e.g., linking university students requiring real-world project experience as part of their coursework, with therapists to design custom solutions that extend reach and are affordable.
  o What role could Generative AI play in this which in turn will improve the sensitivity of current models and help remove some of the inherent biases they contain?
  o Can our patient framework provide a structure to base guidance on assessing, researching, designing and tailoring solutions for PALS and CALS?

- Ensuring all these, (and others!) solution ideas are easily discoverable is critical for their success and impact. Additionally, ensuring they are designed to provide recommendations based on personalised needs, over which the end-user has full control of their information (condition, location technology in use), to provide relevant tools, guides, access to resources, etc.

ORGANIZATION (AND CHANGE)

Here, we outline the organizational and operational attributes which came up in the roundtable in terms of considerations to include in the approach to implementation, and the change that will be required to help bring about the outcomes we collectively seek to bring about. From the Alliance perspective, given our limited resources, what are the areas that it makes sense for us to focus on and where and how do we work with the broader network of the member associations around the world in the most effective way?

- Collaboration is at the heart of what happens next! Taking the idea of the "Renaissance team" That no one individual can do this on their own, but when people come together and bring their areas of expertise, areas of passion, areas of knowledge and experience, then it is clear we can accomplish so much more together.
  - The "Renaissance team" would consist of a range of diverse experts, from AI researchers to local community makers, are imagined coming together to co-design solutions. When aligned with an open-source model where accessibility experts, caregivers, and people with ALS/MND contribute iteratively, much like software development communities do, can provide a model for scalable and sustainable access to impactful and affordable solutions. E.g., an AI-assisted accessibility toolkit, where "maker" communities from around the world build upon and refine each other's designs in a continuous feedback loop.

- Sustainable eco-system built on open-source values of working transparently and inclusively and inviting contributions from the broader community. This applies both to technology solutions and to the underlying business models and frameworks which provide a value exchange amenable to all contributors, has clear policies and guidelines on attribution, re-use, governance and supporting guardrails. It is designed to be cost effective and equitable and harnesses the expertise of people with lived experience.
  - An excellent illustration of this came up regarding organizations working in the same domain but with complementary areas of expertise deciding to come together because they recognised that instead of competing, they have the opportunity to improve and enhance what they currently provide. Further, by putting their efforts and resources into that rather than into duplicating functionality of a seeming competitor it

demonstrates how a different approach, a different mindset, benefits both those organizations from a financial and resource utilisation point of view but ultimately benefits the broader community as well.

o Another example is the Alliance's 'Secretariat as a Service' capability which is helping and assisting new members in the Global South set up and establish their organizations by providing them with resources, templates, and processes which minimise and reduce start-up costs.

- The governance and oversight that will need to be put in place will be best served by creating an appropriate "Advisory Council" (comprised of community representatives, but also 'external' folks with relevant areas of expertise, to both broaden and deepen the selected work areas.)

ALLIANCE STATEMENT AND ACTION PLAN

The following criteria have been applied to determine the areas of focus for the Alliance regarding its innovation and technology strategy:

- It must reflect the unique position the Alliance has as an organization with a global remit.
- It must be community driven with involvement, participation, and support from both the Alliance members and the broader technology community working in this space.
- Be able to draw on this collective capability and apply the insights, knowledge, skills and experiences to meaningful effect.
- Have a clear understanding and agreement of the role and capacity of each contributor.
- Not duplicate efforts already underway but draw on and extend them where applicable.
- Demonstrate strategic vision and leadership for the benefit of the broader community.
- Providing education to support the community on the broader implications of using technologies such as AI, brain computer interaction (BCI), and the considerations around governance, compliance, data-use, personally identifiable information (PII), costs, etc.

The following figure shows a square with Complexity and Effort on the horizontal axes with arrows going from left to right to indicate increase, and on the vertical axes are Value to Quality of Life and Priority with the arrows going from bottom to top to indicate increase. Taking this, and applying the different criteria above, the 'sweet spot' is shown as an ellipse in the upper middle of the square reflecting high value to quality of life and priority, and medium in terms of complexity and effort. Hence, the sweet spot is the indicator of where the Alliance's initiatives must reside.
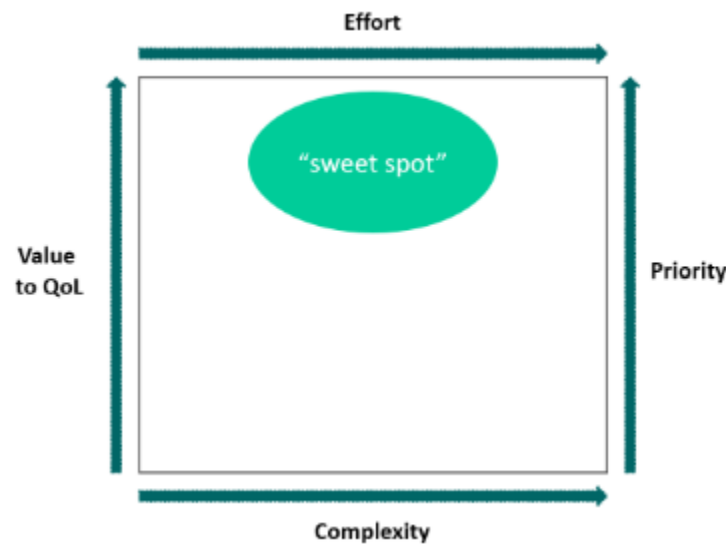
Based on the above, and from the analysis of the roundtable, the following 3 initiatives will be undertaken by the Alliance. Each fall in the sweet-spot and no-one is more important than another since they collectively form the portfolio of projects we will engage in. Each one will have its own cadence and proceed at a pace that is most appropriate for it, hence they are represented as 3 separate, but interconnected, workstreams running in parallel with each other. Further, the portfolio approach allows the delivery of benefit and value to take place in near-, medium-, and long-term.

1. Accessible and Affordable Voice Preservation and Communication through AI
2. Platform for Collaboration, Knowledge Sharing, and Resource Management
3. Enhancing Quality of Life through Personal Insight

ACCESSIBLE AND AFFORDABLE VOICE PRESERVATION AND COMMUNICATION WITH AI

- Voice is deeply rooted with our identity; through it we express emotion and make connections. Incorporating voice banking and enabling communication and expression through augmentative and alternative communication (AAC) for an end-to-end experience-based solution.
- Using open-source AI models designed to work offline and on low-powered devices to ensure affordable access.
- Supporting multiple languages and enabling the capture and use of local idioms and nuances in language.

PLATFORM FOR COLLABORATION, KNOWLEDGE SHARING, AND RESOURCE MANAGEMENT

- Build a global platform with an infrastructure designed to support the people that are involved or want to get involved in the ALS/MND community.
- Focus on architecting a system which will work with a range of different domains to provide benefit across areas such as active research projects, researcher database, knowledge sharing, voice-banking resources, etc., relying on resources and data from regional, national, and international sources.
- The aim is to establish a functional and intuitive framework for each person consulting the system in helping them figuring out the aspect they are missing or may be curious about within the ALS/MND community.

ENHANCING QUALITY OF LIFE THROUGH PERSONAL INSIGHT

- Built on the work underway on understanding the patient experience of a person with ALS/MND through using Maslow's framework related to the hierarchy of needs, aligned with the insights from the Fundamental Rights survey, the scope of this project aims to bring individual needs to the fore for each person to enhance and enrich their quality of life based on stated and unstated objectives and desires (offering the potential to transform the experience and journey for each person.)
- This research focused project will comprise the design and development of an individualised and personal framework for each person with ALS/MND and their caregivers to help them understand where they are on their journey and identify the specific areas where they will benefit from the most. Example areas include voice-banking, hygiene, nutrition, creative pursuits, spiritual development, etc.

The following table presents an overview plan for these workstreams. It is intended to provide the basis of detailed discussion with the various working groups which will be established for each of the 3 project areas. A key component is the interdependency between a number of activities and their applicability to other workstreams.
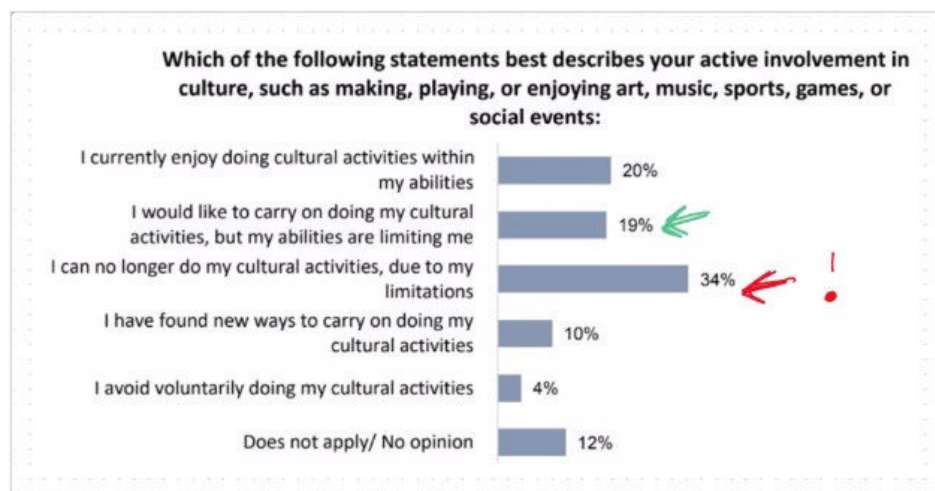
The Human Experience: framework for enhancing quality of life for greater well-being and increased sense of 'fulfilment'

| Strategic initiatives	Year 1	Year 2	Year 3
Accessible and Affordable Voice Preservation and Communication through AI	• Research AI models for suitability • Identify partners and establish value exchange • Horizon scanning of emerging technologies • Pilot	• Extend pilot to worldwide coverage • Ecosystem design and development	• Incorporate new features for richer experience • Build new capabilities • Share and disseminate to other domains and sectors
Platform for Collaboration, Knowledge Sharing, & Resource Management	• Architecture design based on reqts analysis • Design and development of training and support content • Governance and compliance	• Share insights and learnings with relevant communities • Evolve interaction design model • Incorporate with Knowledge management framework	
Enhancing Quality of Life through Personal Insight	• Co-design workshops and reviews • Establish industry and academia partnerships • Develop interaction model		

CONTENT FROM EXPERT PRESENTATIONS

We started with a story about a personal connection with ALS/MND and the collective effort to find solutions for the disease! Technology has a key role to play in that solution set and has been shown to significantly impact the quality of life for PALS; hence, access to technology is not just a luxury but a matter of dignity and human rights. The vision is to provide universal access to the latest technological advancements for PALS and CALS, regardless of their financial status or geography, and we can only accomplish this through collaboration and collective effort.

The International Alliance focuses on equality of access and quality of life for people living with ALS/MND. As an organization comprising 70 members from 40 countries, we enable global collaboration. A key focus of our work in on Fundamental Rights, and a key one is the right to the best quality of life. Our survey indicates that that less than 50% of people with ALS/MND reported having access to the best quality of life, which is both a challenge, and an opportunity.

We have seen how technologies like electric chairs and bath chairs significantly improve quality of life, and how more recently, advances in voice preservation and communication technologies are crucial for maintaining identity. Equally importantly, we have data that clearly establishes that participation in cultural activities significantly impacts the quality of life and strongly believe that technology needs to support this.

Which of the following statements best describes your active involvement in culture, such as making, playing, or enjoying art, music, sports, games, or social events:

I currently enjoy doing cultural activities within my abilities	20%
I would like to carry on doing my cultural activities, but my abilities are limiting me	19%
I can no longer do my cultural activities, due to my limitations	34%
I have found new ways to carry on doing my cultural activities	10%
I avoid voluntarily doing my cultural activities	4%
Does not apply/ No opinion	12%

Next, we turned to the [importance of retaining digital information collected over a lifetime and outlined how it is possible to preserve legacy software to ensure long-term access to data](). It is widely acknowledged that retaining digital information collected in our private lives or through various organizations is a real problem. Traditionally, societies have used formal archives to transfer information from one generation to another, ensuring accessibility and curation; and continuous access to information is crucial, especially for medical treatments and research, which rely on digital data for experimentation and validation. Because digital information often requires specific software to interact with and interpret the data, the longevity of software becomes a significant issue, as it may become incompatible with new operating systems.
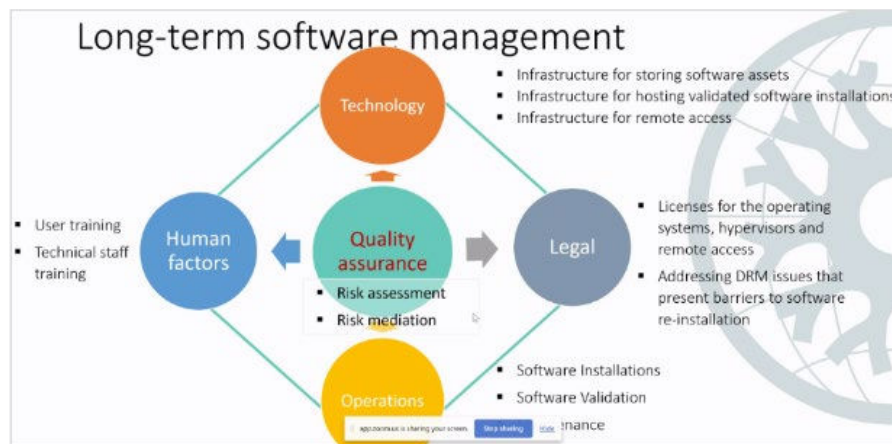
A scalable solution to this is using virtual environments to run old operating systems, allowing access to legacy software and preserving digital art and data. These environments can be viewed through browsers, ensuring the art and data remain accessible and secure without relying on old, unsupported computers.

The Alliance has, over the past few years, been laying more and more emphasis on the importance of cultural activities in improving quality of life for ALS/MND patients and their caregivers. Through adopting a 'design-thinking' approach, the Alliance has sought to bring together tangible examples of how innovation in technology and our understanding of people's stated and unstated needs across both the Global North and the Global South, come together to enhance and enrich

quality of life. Through the shared lens of personal, cultural, and social aspects, the Alliance has developed the Patient Needs Matrix and mapped it against Maslow's Hierarchy of needs (using the later eight level model encompassing the range of needs from physiological, love and belonging, all the way through to aesthetic appreciation and transcendence.)

The real insight came when the model was mapped to personas, reflecting the spectrum of ALS/MND experiences, to indicate how each persona relates to the eight layers at a uniquely deep and personal level.

While this model is still in development, the Alliance believes that this ground-breaking approach will provide access to each person on where they are on their personal journey and what matters to them now, and in the future.
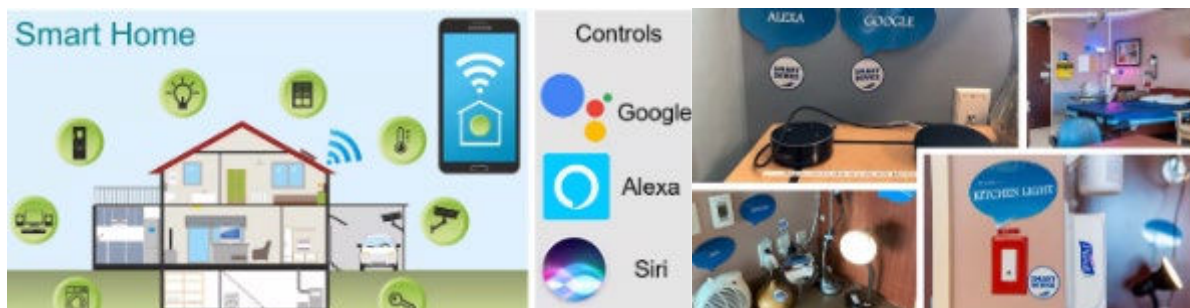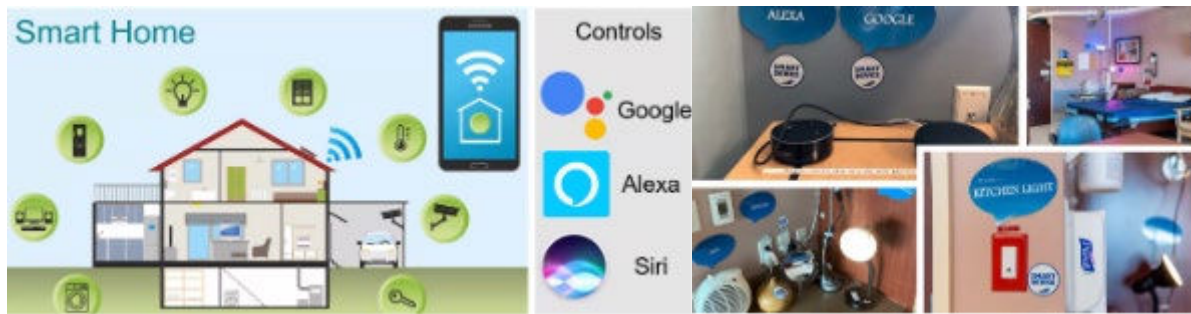
Next, we turned towards getting the Allied Health Professional's perspective from two very different vantage points. Firstly, in the Global North, we looked at best practices in how technology can enhance the lives of PALS through a range of devices and digital content. We learnt that Occupational Therapists help individuals obtain cost-effective options to maximize safety and independence, using readily available mainstream technology where possible, such as smart home automation, which supports both daily tasks and helps enhance social connections through video calls, texting, and speech-generating devices. We also learnt that collaborations with rehab engineers and organizations in the open-source community, like Makers Making Change, enable the creation and distribution of custom devices at low-cost and scale.

Secondly, we had the opportunity to learn from a Speech and Language Therapist who shared her experience with voice banking technology for augmentative and alternative communication (AAC), and the impact it had on her patients. From not being familiar with the technology at the outset, it provided a great opportunity to learn about it, how it worked, and how she would incorporate it into her role, the most important insight was how the voice preservation helped to preserve the vocal identity of individuals, allowing them to communicate with their own voice and vocal quality.

Continuing in this vein, we transitioned to a personal perspective of the situation and experience in Kenya. Kenya, like much of Africa, faces significant challenges in accessing essentials such as clean water and reliable electricity and the knock-on effects they have on healthcare when, for example, frequent outages disrupt the user of essential medical and assistive technologies. Many families struggle with the costs of assistive devices and innovative solutions for those living with ALS/MND. The diagnosis of ALS/MND is delayed and costly, putting a financial strain on families. To improve the situation, it is recognised that education and awareness

will have a key role to play, as will policy advocacy, and access to affordable assistive devices; and, underpinning all this, the criticality of global collaboration and how it will help improve the quality of life for PALS and CALS and the broader community.

Diving deeper into the different areas which play such a key role in quality of life, we heard from a scientist and educator, and his wife and caregiver, that following his diagnosis of a slowly progressive form of MND, he found purpose, and success, through computer-generated art. Marrying the use of traditional graphics applications, the use of AI has helped him create digital paintings in his own unique style and expression, and enabled him to find a way to express beauty, joy, and hope. He believes AI can empower others who feel trapped, helping them rediscover creativity, positivity, and purpose. Together, they believe it has helped him retain his positivity and creativity, and has improved his mood and wellbeing. The meaning to his life it has provided he described as being in a position where he sees what he does as "a gift to the people you love".
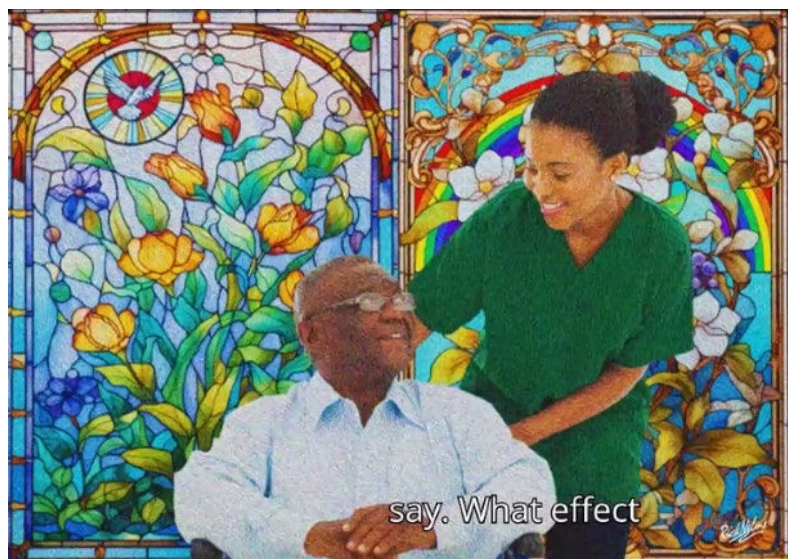
Turning next to the perspective of a big technology company, we heard about the development and challenges of AI and assistive technologies, particularly in the context of helping individuals with ALS. Attention was drawn to the difference between general-purpose tools and bespoke solutions, and the barriers these technologies face in terms of cost, discoverability, and platform availability. For example, AI tools can be categorized into general-purpose tools designed for mainstream users and bespoke solutions tailored for smaller communities like

PALS/CALS. An example was provided of modifying speech recognition systems to better understand individuals with ALS/MND which in turn would improve overall speech recognition and text-to-speech technologies. It was encouraging to hear the emphasis placed on the need for collaboration centres to map out user needs and technology capabilities, ensuring solutions are discoverable and effective for everyone.

We then shifted focus towards innovations taking place in academia and how the use of open-source could present a path forward to affordable access and scale. Using the Tech for Good AI Lab at University College London as an example, we heard how it focuses on offline AI and has been developing AI prototypes in areas like touchless computing and voice banking through collaboration with real-world partners as part of the Industry Exchange Network (IXN) where students are provided with the opportunity to work on 'real-world' projects in small teams. The lab's largest project, the Motion Input Project which detects a broad range of user motions and gestures and has involved over 300 students and developed applications in gaming and accessibility for various disabilities.

Transitioning next to the Global Disability Innovation Hub (GDI Hub) at University College London with its focus on disability innovation, social justice, and policy development, in regions like India and Africa, and how those regions seek to tackle the complex issues related to disability. People in low-income regions often depend on government-subsidized products or create their own solutions using available resources; a particularly memorable example of this "frugal innovation" included using a potato with a pen inserted through it as a writing tool to help people with

hand related mobility issues. The GDI Hub promotes co-designing with users to create bespoke solutions, involving students in the design process, and seek to encourage and support startup solutions for people with ALS/MND in low-income regions, by drawing on and sharing the demonstrated ingenuity of frugal innovation.

Tying the previous two sessions together, next was an opportunity to learn about an [open-source, student collaboration project aimed at improving accessibility tools for speech](#). The voice project is open-source, with all code and research being shared publicly to facilitate innovation and collaboration and inspire others by illustrating how different technologies can be integrated to enhance accessibility. The technology is designed to help people speak quickly and with minimal interaction, by using AI to predict responses based on context. The AI has been built to generate relevant responses with minimal input, enhancing real-time communication; it allows users to select keywords to generate custom sentences, providing more personalized communication options.

We closed the plenary by tying together all the previous sessions [by positioning technology and the roles it plays in addressing various challenges through the lens of social, political, and economic structures](#). The disparity between the Global North and South is all too readily apparent in terms of access, inclusion, availability of resources and supporting infrastructure, but at the point of the lived experience, the importance of affordable technologies for those who need them most is at the heart of improving quality of life across the world.

The need to share, exchange ideas, and learn from each other is pivotal to this and recognising that creativity is, at its core, the art of making the obvious obvious, before it is obvious(!), and recognising that sometimes the most impactful solutions come from the most unexpected places. Some practical examples of this were provided, such as the formation of "Renaissance teams" which are diverse and inclusive by design and bring together individuals and organizations with specific areas of expertise which, when combined with the others, lead to greater likelihood of having tangible impact because potential ideas and solutions are reviewed and validated against a broader and more representative set of criteria. This was further reinforced by the need to ensure there is sufficient structural support to build platforms that can extend and enrich the experience of individuals with ALS/MND, through technology adaptation, for example (i.e., the ability to adapt existing

technology to meet the needs of PALS, including using older technologies that might be more accessible in developing countries).

GROUP DISCUSSIONS

Two discussion groups were held, and the following summarizes the key points raised.

- Parallels regarding lack of awareness in both Kenya and the US. The needs and the gaps in Kenya resonated with some of those gaps evident in the US. For example, the lack of awareness of the technology, education about what it is and how it works, the support of it, etc. are just as relevant to New York City.

- For PALS, communication really is the main issue e.g., being able to call a caregiver at night, and, if this is not happening the huge stress it causes PALS and caregivers alike.

- The importance of establishing guard-rails about how a particular technology will work and the value and impact it could provide. This is important to avoid mis-setting of expectations and end-user disappointment. The technology that is off-the-shelf may have accessibility features built in, but for equipment and services which are bespoke, there has to be great care taken in understanding how it will work for PALS/CALS. Making sure that caregivers get training in the use of the technology that's helping support the PALS in their life.

- The importance of considering any technology design or solution in the broader context which includes political, economic, and social dimensions too. E.g., when thinking about potential solutions, it is not just about how it is made, but just as importantly, what is the cost, how will it be distributed, etc.?

- One of the less-discussed aspects of ALS/MND is how isolation creeps in. Even when assistive technology is available, if it takes too long to type a sentence or too much effort to engage in a conversation, people may simply withdraw.

- Recognizing that insight, innovation, knowledge transfer goes both ways between the Global North and South! The innovation ideas that come from places of constraint, whether economic or political or otherwise in the Global South, may be just as impactful for the Global North! What role might the Alliance play in supporting this resource and knowledge sharing?

- The importance of awareness and education, and how it applies to implementation of ideas and to support better collaboration (to avoid

duplication of effort and dilution of focus!) The need to better understand the implications of privacy and security, and what they mean for the healthcare system. Where do we start!?

- Map all the resources we have for different types of technologies, right! If the problem is related to money or finance, then these are the resources you can look at. If your problem is that it is not in the language you need, then these are resources that you can use. Have the Alliance be that one stop place where you can go and check and learn about what your options are ("…we really feel like the Alliance is a place to share…"). E.g., with technology…what am I able to access, what requires payment, what is free, etc. The Alliance as the place to learn about what people are doing out there. Being the connector between PALS/CALS and allied health professionals to help bridge the gap in knowing what assistive technology is available out there.

- Understanding the devices in uses and testing them - both from an infrastructure but also support standpoint, what language services are provided? Are there local support systems? Does the local infrastructure, be it broadband or actual devices themself, support the testing that needs to happen, who is able to access these not just from a recruitment standpoint, but from an actual infrastructure standpoint.

- Importance of policy wins and sharing them via a database for the community to access. E.g., in France, assistive technology is now provided for 60+ and the rationale or 'case' behind it is important to document…so we have a database of policy wins across different countries that might have governments and policy and healthcare policy similar to France…this could then be useful in making that case locally.

- Recognition that many people are currently lacking access to basic equipment and ensuring it is going to be sustained in the long term.

- Focus on families and caregivers for full wraparound support to also include mental health support.

- Importance of meeting unmet needs! Collaboration between the supply side and the demand side, e.g., academia and startups as a different way of addressing the supply and demand equation.

- Discoverability is a big challenge, when there is so much content out there! And how to get the technology from the developer to the final user. We talked a lot about compiling a living database resource at the global level, not specific to any jurisdiction, in terms of what's available to fulfill the needs on the patient needs framework.

- Creation of a global ALS/MND experience network for everyone, so whether you're a healthcare provider or someone with lived experience, or an organizational person, a regulator, etc., it is open to all to be part of the experience network. Allow each person to interact with the broader community, whether it's about assistive devices, solutions for better sleep, advocacy and so on.

- It doesn't have to be a progression such that you don't have to satisfy all the physiological needs first and then move to the higher end needs. How do we create that living database so that you can, no matter where you are in the world, see what people are using for everything, whether it's physiological or, related to transcendence, spirituality, creativity, etc. It doesn't have to be a progression.

- Important for companies to come up with solutions that are already inclusive in their way of being used e.g., providing direct contact with our users, their caregivers and everyone else involved (generalising a more humane approach to solution design and delivery.)

- Technology transfer from one domain to another e.g., robotic vacuum cleaners which use sensors to map out a place. That approach can be transferred to steer a wheelchair around a mapped space to remove a lot of friction in the current experience.

- Alliance could play a role in training people on the use of technologies, in a consistent manner around the globe, perhaps by working with technology companies – but there are issues of funding, sharing resources, etc.

- Important to consider the downstream impact of a technology e.g., a situation where a person has the technology in their home, and it gives them a quality of life that is, that is great for them, but over time it may actually make them socially isolated! A person may be able to continue to work and be productive

from that perspective, but the social isolation it creates may diminish their quality of life.

- Managing expectations around the value and use of technology and avoiding the tendency we often have of falling into trusting technology in a way that detracts from our own capabilities. Instead, technology should augment and enhance our natural capabilities and not detract from them. Importance of upholding those values of improving, enhancing, enriching quality of life. And in many ways, AI is a great litmus test for us.

- The importance of building greater capacity so that, for example, including developing countries more in research, clinical trials, etc., to have a more representative group of participants will help improve the quality and efficacy of drug treatments.

- Perhaps in some places, the high-level technology is less of a concern, and more important is to get the standards of care in place regarding quality of life.

- Observation that it was in Africa where micro payments first originated through cell phone infrastructure, and now they're common place around the world.

APPENDIX

1. **Biographies: Speakers and Facilitator**

2. **Attendees**

3. **Pre-read Materials**

4. **Approach to Group Discussions**

BIOGRAPHIES: SPEAKERS AND FACILITATOR

SPEAKERS:

Calaneet Balas

Calaneet Balas became CEO and President of The ALS Association in December 2017. She joined the organization in June 2016 as the Executive Vice President of Strategy, leading all three mission areas, including global research, public policy and care services, which work in an integrated fashion to find a cure, advance treatments and enhance the quality of life for people living with ALS/MND.

Calaneet joined the Board of Directors of the International Alliance of ALS/MND Associations in December 2017. She was elected Chair in December 2018.

Blair Casey

Blair Casey is one of the original members of Team Gleason, starting as Steve Gleason's caretaker after his diagnosis of ALS/MND in 2011. After three years of caretaking, Blair's hands-on knowledge was needed to help others living with ALS/MND live more productive and purposeful lives. As Team Gleason's Executive Director, Blair Casey provides executive oversight to partnerships, innovation, finance, and operations. Casey also chairs Team Gleason's Technology Advisory Committee and has spearheaded partnerships with technology companies like Apple, Comcast, Google, Microsoft, Synchron, Neuralink, and more. These relationships have allowed Team Gleason to continue innovating technology that provides people with ALS/MND the latest in accessibility functions.

Blair was named on Gambit's 2022 40 Under 40 list for his work and dedication to advocating for the ALS/MND community through technological innovations.

Dr Natasa Milic-Frayling

Dr. Natasa Milic-Frayling is a Founder and CEO of Intact Digital Ltd, a digital continuity company that enables long term use of digital data and software, and Research Director at the Qatar Computing Research Institute, leading Arablic Language Technologies team that focuses on advanced methods in NLP and AI. She is Professor Emerita at the School of Computer Science at the University of Nottingham where she served as Chair of Data Science.

Natasa has 25+ years of experience in computer science research and innovation, including 17 years at Microsoft Research (MSR) in Cambridge UK. She authored over 100 research publications and has a dozen of patents to her name. She has been involved in initiatives that promote collaboration on strategic ICT industry challenges including digital preservation (PLANETS and SCAPE EU projects), and responsible innovation in computing, including policies on generative AI technologies (ACM Technology Policy Committee).

Natasa is actively engaged with a broader professional community. She is a member of the Preservation Sub-Committee within the UNESCO Memory of the World Programme and serves as Chair of the Research and Technology Working group for the UNESCO PERSIST project. Natasa is an active member of the Association for Computing Machinery (ACM) and served on the ACM Europe Council and as Chair of the ACM Women Europe Executive Committee.

Marla Calder

Marla Calder has been a practicing occupational therapist for the past 24 years who has worked in the field of Assistive Technology for more than 18 years at the Stan Cassidy Centre for Rehabilitation in Fredericton, New Brunswick Canada. She assists clients with home environmental controls in the Smart Home Suite, ensuring access to digital content, wheelchair integration, research, and adapted video gaming.
Most recently, she worked with an interdisciplinary team to launch the first accessible video gaming clinic in Canada, Game Changers, who are now collaborating on the national GAME Checkpoint program.

Haide Jineth Briceño Suarez

Haide Jineth Briceño Suarez is a speech language therapist from the National University Hospital of Colombia (HUN), with experience in the clinical area of outpatient consultation in the diagnosis and treatment of myofunctional, voice, swallowing and human communication disorders, as well as experience in research with eye tracking technology and subtitle reading, perception and comprehension of audiovisual content.

Haide is currently supporting the Alliance´s pilot on Voice Banking for People Living with ALS/MND, in partnership with Asociación Colombiana de Esclerosis Lateral Amiotrófica (ACELA.)

Philip Kipngeno Langat

Philip Langat is a seasoned livestock development specialist with over thirty years of experience in the industry. He holds a Master of Science in Environmental Management with a Sustainable Development option from the University of Queensland, Australia. Philip's journey into ALS/MND advocacy is deeply personal. Having lost two brothers, two uncles, and potentially his father to ALS/MND-related complications, he has dedicated himself to raising awareness and advocating for improved care for those affected by the disease. He believes MND is not a curse, as many in the Global South may perceive it to be. Though devastating, individuals with ALS/MND can live qualitatively with the right support, innovation, and technology.

As the founder and chairperson of the Motor Neuron Disease Association of Kenya (MNDAK), Philip is committed to ensuring that ALS/MND is recognized as a critical health issue in Kenya and by extension Africa. His advocacy efforts focus on securing access to innovative assistive technology such as motorized wheelchairs, beds, and communication devices. He is also pushing for affordable care, genetic testing, and policy inclusion of ALS/ MND within Kenya's national non-communicable disease strategy.

Guided by the International Alliance of ALS/MND Associations, Philip is working to bring tangible support and hope to people living with ALS/MND in Kenya and beyond. He actively seeks partnerships and support to bridge the overwhelming gaps in care, technology, and awareness in the Global South. ***And there is HOPE.***

Dr. Rick Nelms

Dr. Rick Nelms, biologist, educator, innovator, advocate, writer and artist living with ALS/MND, painting without brushes, painting hope.

'"Painting Without Brushes' because I can't control a brush now. I use an adapted PC to paint at home and a smartphone and tablet on our travels. '"Painting Hope' because I am incurably positive, and because ongoing research is getting ever closer to effective treatments for neurodegenerative diseases. 'Painting Hope' also refers to my Christian faith. My blog https://drrickblog.wordpress.com/ has, in the most recent post, a complete set of links to the three pages at "Under The Thinking Tree", flickr, DeNPRU and readable research."

Sue Nelms

Having enjoyed former careers in advertising and working with formerly homeless people, Sue Nelms is now full-time career for her husband Rick, who lives with primary ALS/MND, a Licensed Lay Minister in the Church of England and Disability Advisor to the Bishop of Ely. By nature, Sue is a problem solver, which comes in pretty handy these days as she deals with the challenges that arise out of Rick's illness. She is a passionate believer in using the knowledge and experience she has gained, caring for Rick to help others when the opportunity arises and is a firm believer in the use of humour to get through those tricky little situations that tend to try and get you down.

Dr. Robert (Bob) MacDonald

Dr. Robert (Bob) MacDonald works at Google on AI applications for speech, accessibility and health applications. He previously led teams developing mapping and GIS systems at Google, including technical leadership for key areas of the next generation StreetView system. Prior to joining Google, he was CTO, CEO of Skyline Solar, a technology start-up that developed a low-cost Solar PV system, whose technology was ultimately sold to First Solar. Before founding Skyline Solar, Dr. MacDonald led marketing at concentrating PV pioneer SolFocus. In 2000 he co-founded and served as VP of Sales and Marketing for Onetta, the leading optical amplifier company funded by Sequoia Capital and Matrix Partners. He previously started the telecom components division of New Focus, Inc. This business provided the platform for the company's successful IPO and secondary offerings with proceeds totaling $539 million. Dr. MacDonald received his BS degree in Electrical Engineering from Brown University, graduating magna cum laude. He earned an MS degree in Electrical Engineering from Stanford University, and MS and PhD degrees in Physics from Brown University.

Professor Dean Mohamedally

Professor Dean Mohamedally is a Professor in Computer Science at University College London's Department of Computer Science and a member of the UCL AI Centre. He is the Director for the UCL Industry Exchange Network, which looks after 300+ undergraduate and postgraduate Computer Science students. The students in this network work with charities and companies every year on Tech for Good projects as part of their Computer Science degrees. Dean leads the Tech for Good labs at UCL Computer Science, focusing on first generation proof of concept projects with a focus on healthcare, education and accessibility. He has worked previously on several projects for the ALS/MND community, some of which is now available to all users.

Tigmanshu Bhatnagar

Tigmanshu Bhatnagar is a lecturer in the Department of Computer Science at UCL, specializing in disability innovation and human-computer interaction. His research encompasses the development of new assistive technologies, including Tacilia, an affordable tactile display technology that received the Engineering Talent Award for Innovation of the Year in 2023.

Tigmanshu also leads projects such as the GDI Accelerate initiative and a study on AI in humanitarian settings. Additionally, he directs the Attvaran Startup Accelerator in India, which supports assistive technology startups in collaboration with IIT Delhi and IIT Madras, with a focus on identifying ways to scale assistive technologies and promote inclusive innovation.

James Arney

James Arney is the founder of the AI Accessibility company behind "Ossia Voice". Ossia is an open source and freely available tool helping those whose communication is limited to slow and outdated keyboard input find a completely novel way to speak. James has a deep experience with software and AI across the Manufacturing, Healthcare and Aerospace industries and his expertise here is shaping the adoption of AI beyond research and into the hands of real AAC users. In addition to his role at Ossia Voice, James is a core research engineer at the BioTech startup "BioCorteX." He and the team are developing the world's largest emulation engine for clinical research and innovative treatments of severe diseases. James is involved in research that it is hoped will lead to life-changing advancements in disease treatment, including treatment of Cancer and neurodegenerative conditions such as ALS/MND.

Bill Buxton

Bill Buxton has had a 50+ year romance with human aspects of technology, interaction design, telepresence, multi-modal adaptive designs, access, and the nature of innovation. Morphing from musician to designer/researcher he has practiced his craft at the University of Toronto, Xerox PARC, Alias Research, SGI and Microsoft Research. Awards include four honourary doctorates, co-recipient of an Academy Award for scientific and technical achievement, ACM/SIGCHI Lifetime Achievement Award, and Fellow of the ACM. In December 2023, Bill was appointed Officer of the Order of Canada. Writer, speaker and consultant, he is also an Adjunct Professor, University of Toronto, and Distinguished Professor of Industrial Design, TU/Eindhoven. He is currently largely occupied curating his collection of over 900 artifacts documenting the history of interactive technologies. Outside of work, he has a passion for his family, books and the outdoors. www.billbuxton.com

Catherine Cummings, CAE, MBA

Cathy Cummings has an eclectic mix of work experiences in the Canadian not-for-profit sector including the National Payroll Institute, the Canadian Bar Association, the Canadian Corporate Counsel Association, and now as the Executive Director of the International Alliance of ALS/MND Associations. Cathy has also volunteered extensively with United Way, the Canadian Society of Association Executives and many charities, including ALS Ontario, ALS Canada and Ceridian Cares. She holds an MBA from Athabasca University and is a Certified Association Executive (CAE) designation.

On a personal note, Cathy is married to her wonderful husband Marty, has three awesome children and has a mission nicknamed the "bouquet project" that is trying to reverse the statistic that people are ten times more likely to complain than praise.

FACILITATOR:

Jarnail Chudge

Jarnail Chudge is an accomplished designer, creative technologist and storyteller with a deep background in purposeful design across diverse industry sectors, cultures, and geographies. He has a proven track record of delivering compelling user experiences and impactful business solutions that address both stated and unstated customer and market needs. Jarnail's career began in academia, where he integrated business, user, and technology needs in the burgeoning field of socio-technical systems; and has always been driven by the motivation to use technology to design and develop innovative, intuitive, and inclusive products and experiences that bring new insights and perspectives. His goal is to drive positive, life-enhancing changes for people, organizations, society, and the environment.

Currently, Jarnail provides strategic guidance on innovation and technology to the International Alliance of ALS/MND Associations and serves as the Executive Director of Soundscape Community. He co-founded Microsoft Soundscape, focusing on inclusive design principles to create empowering audio augmented reality navigation and wayfinding experiences for the blind and low vision community, but which are equally applicable as a general use technology by everyone.

ATTENDEES

Attendee Roster - Discussion Group 1			
Last Name	**First Name**	**Affiliation**	**Country**
Anyim	Martin	LifeArc	United Kingdom
Arney	James	Ossia Voice	United Kingdom
Balas	Calaneet	ALS Association	United States
busch	kate	ALS Québec	Canada
Calder	Marla	Stan Cassidy Centre for Rehabilitation	Canada
Chandler	Linda	Independent	United Kingdom
Chudge	Jarnail	The International Alliance of ALS/MND Associations	United Kingdom
Conte	Silverio	Associazione conSLAncio Onlus	Italy
Cummings	Catherine	The International Alliance of ALS/MND Associations	Canada
de Majo	Martina	The International Alliance of ALS/MND Associations	Italy
Dekeyser	Michiel	ALS Liga België VZW	Belgium
E Jones	Sarah	Canada's Drug Agency	Canada
Feldman	Sara	ALS Hope Foundation	United States
Gierula	Weronika	Acapela Group	France
González Olcoz	Susana	Fundación Francisco Luzón	Spain
Gregory	Wanda	University of Washington	United States
Hockensmith	Tanner	ALS Association	United States
Joe	Phillip	Consultant	United Kingdom
Kaya	Alper	ALS/MND Association Türkiye	Turkey
Langat	Philip	MNDAK	Kenya
Mabe	Jessica	The International Alliance of ALS/MND Associations	Colombia
Marinković	Slobodan	Savez društava distrofičara Hrvatske - SDDH	Croatia
Merry	Scout	MO ASSISTIVE TECHNOLOGY	United States
Milic-Frayling	Natasa	Intact Digital Ltd	United Kingdom
Mohamedally	Dean	University College London	United Kingdom
Mougharbel	Sarah	Wyes	France
Nagin	Karina	Bridging Voice	United States
Nelms	Rick	Person with lived experience	United Kingdom

Nelms	Sue	Person with lived experience - Caregiver	United Kingdom
Parvanta	Sarah	The ALS Association	United States
Pheiffer	Elize	MNDA South Africa	South Africa
Puig	Sandra	Acapela Group	Sweden
Sane	Hemangi	Asha Ek Hope Foundation for ALS/MND	India
Schaeffer	Melody	ALS Association	United States
Schmitz	Robert	Motor Neurone Disease Association of Singapore	Singapore
Stanley	Liz	ALS Association	United States
Stephens	Leigh	ALS Society of Quebec	Canada
Tharmananthar	Giri	Microsoft	United Kingdom
Toledo	Arturo	Pixelspace	United States
Trucco	Ana Paula	FUNDELA	Spain
Virgo	Bruce	PCAC - PALS and CALS Advisory Council	United Kingdom

Attendee Roster – Discussion Group 2			
Last Name	**First Name**	**Affiliation**	**Country**
Ali	David	International Alliance of ALS/MND Associations	Australia
Chapeskie	Robert	Sakura International	Japan
Chudge	Jarnail	The International Alliance of ALS/MND Associations	United Kingdom
Doto	Jennifer	Temple MDA/ALS Center of Hope	United States
Kawaguchi	Yumiko	Sakura International	Japan
Langat	Philip	Motor Neuron Disease Association of Kenya (MNDAK)	Kenya
Lewin Farber	Stacy	PCAC - PALS and CALS Advisory Council	United States
Lieman	Ben	ALS United Greater New York	United States
Lim	Roscoe	University of Toronto	Canada
Mabe	Jessica	The International Alliance of ALS/MND Associations	
MacMillan	Krista	Stan Cassidy Centre for Rehabilitation	Canada

Simon	Julia	The International Alliance of ALS/MND Associations	Canada
Thomas	Gethin	MND Australia	Australia
Thomas	Paul	Health Strategist - Retired	United Kingdom
Trefiak	Paula	International Alliance of ALS/MND Associations	Canada
Yap	Min	FightMND	Australia

PRE-READ MATERIALS

Roundtable on "Fundamental Rights: (e)Quality of Life"

Description
Since our June 2021 roundtable, "The Spectrum of Possibilities," the technology landscape has re have been significant changes in the technology landscape. Artificial Intelligence (AI), robotics and autonomous devices, Brain-Computer Interaction (BCI) are rarely out of the news. Advances in the capability and use of Augmented Reality (AR) and Virtual Reality (VR), and home automation systems, along with investments in communication and voice-preservation technologies, and the growing familiarity of using personal and home devices for tele-health consultations, represent new opportunities to improve the quality of life for PALS and CALS. However, they also bring challenges and raise questions about fair use, ethical handling of data, security and privacy, equitable access at a global level, and the impact they may have on our "humanness."

Join us for what is sure to be a challenging and stimulating discussion as we explore the topics above, with the goal of arriving at a clear set of priorities and outcomes for the Alliance and our global community. These will shape our innovation and technology strategy and help identify key projects to implement with our broad ecosystem of members and the people they serve, as well as with partners and collaborators in technology, research, academia, and other relevant areas to help make change happen.

Central to the discussion will be the updated Patient Needs Framework, which will be cross-referenced to the Fundamental Rights to ensure that it is aligned with the Alliance's overall mission and goals.

1. **Link**: Fundamental Rights Survey 2023: Quality of Life

2. **Video Link**: Patient Needs Framework
   https://youtu.be/3-N60HuIatE

Overview of the Ecosystem
Collaboration is key to making positive and lasting change to the broader ALS/MND community, and diverse perspectives and experiences enable us to design and develop models, frameworks, and solutions that are sustainable and deliver impact

at a global level. Therefore, we are adopting an "ecosystem"-based view that recognizes the inter-dependency of relationships and connections between individuals, groups, organizations, systems (social, cultural, economic), and technologies.

This section provides an overview of several key aspects of the ecosystem, including collaboration models, measures of value exchange, technology, etc. It is designed to provide some groundwork for providing a values-based approach to the plenary session and the subsequent discussion groups.

"You never change things by fighting the existing reality. To change something, build a new model that makes the existing model obsolete."
Buckminster Fuller

Open Source
The open-source model is a collaborative approach to creating, sharing, and improving software, hardware, and even cultural works. At its core, it emphasizes transparency, accessibility, and community-driven development. Instead of restricting access to a product's design or code, the open-source model allows anyone to view, modify, and distribute the material, fostering an environment of collective innovation.

For example, source code or design schematics are made publicly available, typically under open-source licenses that define how the material can be used, modified, and shared. Developers, designers, and users from around the world contribute to projects by fixing bugs, adding features, or enhancing performance. This global teamwork accelerates development and encourages diverse input. Contributions are reviewed by maintainers or the broader community to ensure quality and security. The open-source model thrives on iterative enhancements so that as more people use and refine the product, it evolves to better meet users' needs.

By pooling resources and knowledge, open-source projects often innovate faster than proprietary counterparts, leading to cutting-edge solutions and technologies. In addition, thanks to reduced or no-cost licensing, the technology is more accessible to individuals, businesses, and governments, especially in resource-constrained communities worldwide. However, as with any model, or technology, there are risks to consider, such as malicious actors. Without timely updates and community vigilance, these can pose security threats.

The open-source model embodies the spirit of collective effort and shared progress. In the case of ALS/MND, people living the disease, caregivers, and developers can collaborate directly, ensuring that tools are user-centred and effectively address real-world challenges, allowing the broader community to share experiences, tips, and improvements, creating a support network that extends beyond technology.

https://en.wikipedia.org/wiki/Open_source

Circular Economy
The circular economy model is a sustainable economic system aimed at minimizing waste and making the most of resources. Unlike the traditional linear economy (take, make, dispose), the circular economy follows a closed-loop system where resources are reused, recycled, and regenerated. This model emphasizes the importance of designing products and systems that can be reused, repaired, and recycled, thereby reducing the need for new raw materials and minimizing environmental impact.
Some of the key features of this model include:
- Designing for longevity, i.e., products are designed to last longer, with durability, reparability, and upgradability in mind.
- Efficient use of resources is prioritized, and waste is minimized throughout the production process.
- Materials and products are reused, refurbished, and recycled to create new products, reducing the demand for new raw materials.
- Environmental benefits through reduced waste and pollution

However, while the circular economy model offers these benefits, there are important concerns to address such as transitioning from a linear to a circular economy requires significant changes in infrastructure, business practices, and consumer behaviour; developing and enforcing regulations and standards for circular practices can be complex; and transitioning requires investment in educating consumers about the benefits and practices for widespread adoption.

"Ultimately, we are deluding ourselves if we think that the products that we design are the "things" that we sell, rather than the individual, social and cultural experience that they engender, and the values and impact that they instil. Design that ignores this is not worthy of the name."
Bill Buxton

Artificial Intelligence (AI)

Artificial intelligence (AI) refers to the simulation of human intelligence in machines that are programmed to think, learn, and solve problems like humans. These systems operate based on algorithms and data, and can perform tasks that typically require human intelligence, such as visual perception, speech recognition, decision-making, and language translation. Some of the key components are:

- Machine Learning (ML): A subset of AI where systems learn from data. Algorithms are trained on large datasets to identify patterns and make decisions.
- Neural Networks: Modelled after the human brain, these are interconnected layers of nodes (neurons) that process data inputs to generate outputs.
- Natural Language Processing (NLP): Enables machines to process and respond to human language.
- Computer Vision: Allows machines to interpret and make decisions based on visual data.

AI has the potential to bring significant benefits in healthcare. For example, it can assist in diagnosing diseases, personalizing treatment plans, predicting patient outcomes, and accelerating drug discovery and development.

However, there are important concerns to address:

- Bias and Fairness: AI systems can perpetuate biases present in training data, leading to unfair outcomes.
- Privacy: The vast amounts of data required for AI raise concerns about data security and privacy.
- Job Displacement: Automation may lead to job losses in certain industries, necessitating workforce retraining and education.
- Accountability: Determining responsibility for AI decisions, especially in healthcare is crucial.
- Ethical Use: Ensuring that AI is used ethically, transparently, and for the greater good.

https://en.wikipedia.org/wiki/Artificial_intelligence

Robotics and Autonomous Devices

Autonomous robots are intelligent machines capable of performing tasks without human intervention. They use sensors, algorithms, and actuators to perceive their environment, make decisions, and execute actions. Through incorporating AI, autonomous robots learn from the data, can recognize objects, detect patterns, and improve their performance over time through adapting to changing conditions and being able to operate independently in various settings.

Robots have been used for some time in healthcare; assisting in surgeries, patient care, and rehabilitation, and have been shown to improve some outcomes and reduce human error.

As with AI, there are concerns and ethical considerations to consider, such as job displacement; safety and reliability, especially in critical applications like healthcare; the use of sensors and data collection, which raises issues about data privacy and security; and the need to establish guidelines for ethical use in healthcare.

https://en.wikipedia.org/wiki/Autonomous_robot

Brain-Computer Interface (BCI)

A Brain-Computer Interface (BCI) is a direct communication pathway between the brain's electrical activity and an external device, such as a computer or robotic limb. BCIs decode neural signals and translate them into commands that control external devices, effectively allowing thoughts to be turned into actions. The technology ranges from non-invasive methods like EEG (electroencephalography) to invasive methods involving implanted electrodes directly in the brain. In general, it is believed the closer the sensors are to the brain's neural network, the clearer and more precise the signal interpretation.

It is felt that BCIs have the potential to revolutionize various fields, such as healthcare, rehabilitation, prosthetic limbs, and so on. Work already underway has demonstrated how it can be used to help restore mobility and communication (by translating brain signals into speech or text) for people with paralysis, ALS/MND, and other neurological conditions. Recent advances using AI have shown BCIs achieving up to 97% accuracy in translating brain signals into speech.

Despite the promising potential, there are several concerns associated with BCIs. In particular, privacy and security are major issues, as the technology involves accessing and interpreting brain activity. There are also ethical considerations regarding the extent to which BCIs should be integrated into daily life and the

potential for misuse. In addition, the long-term effects of implanting devices in the brain are still not fully understood.

https://en.wikipedia.org/wiki/Brain%E2%80%93computer_interface

"AI is neither artificial nor intelligent. Rather, artificial intelligence is both embodied and material, made from natural resources, fuel, human labor, infrastructures, logistics, histories, and classifications. AI systems are not autonomous, rational, or able to discern anything without extensive, computationally intensive training with large datasets or predefined rules and rewards. In fact, artificial intelligence as we know it depends entirely on a much wider set of political and social structures. And due to the capital required to build AI at scale and the ways of seeing that it optimizes AI systems are ultimately designed to serve existing dominant interests. In this sense, artificial intelligence is a registry of power."
Atlas of AI, by Kate Crawford (https://katecrawford.net/atlas)

Augmented Reality (AR) and Virtual Reality (VR)
Let's start with a simple overview of Augmented Reality (AR), Virtual Reality (VR), and Mixed Reality (MR) technologies to help avoid confusion or misunderstandings between them.

- AR overlays digital information, such as images, videos, or data, onto the real-world environment and extends the user's perception of reality by adding virtual elements to their physical surroundings.
- VR immerses users in a completely virtual environment, shutting out the physical world. VR requires the user to wear a headset through which they can explore and interact with simulated 3D worlds, experiencing sights and sounds that create the illusion of being somewhere else.
- MR blends both AR and VR, allowing real and virtual elements to interact in real-time such that users see and interact with both physical and virtual objects (where the virtual elements are anchored to the real world, allowing a more seamless integration between the two).

These technologies have been used in healthcare, particularly in rehabilitation (where VR can assist in physical therapy by making exercises engaging and monitoring progress); and in support of mental health to help treat phobias, anxiety, and PTSD by controlling exposure to triggering stimuli. Built-in eye-tracking

sensors utilize eye movements enabling those with limited mobility to control apps and devices, for instance. Other common examples include virtual exploration, which provides a way to experience environments and activities that physical limitations might restrict; and controlling home devices through their interfaces. However, there are a number of concerns and ethical considerations to take into account. For example, prolonged use can lead to eyestrain, dizziness, or motion sickness. Further, given that AR and VR devices often collect sensitive data, including surroundings and user behaviour, there are real concerns around privacy and data security. Currently, the high costs of devices limit access for lower-income individuals or communities.

https://en.wikipedia.org/wiki/Mixed_reality

Augmentative and Alternative Communication (AAC) Systems
Augmentative and Alternative Communication (AAC) systems refers to methods used to help people with speech or language impairments communicate. These methods can be used to supplement or replace speech, enabling effective communication.

Typically, AAC systems are categorized into two main types: unaided communication and aided communication. Unaided communication involves methods that do not require additional tools, such as gestures, facial expressions, and body language. Aided communication involves the use of tools or devices, ranging from low-tech (e.g., picture boards, communication books) through to high-tech (e.g., speech-generating devices, eye-gaze systems).

AAC systems are commonly regarded as being essential in significantly enhancing the quality of life for people with communication impairments. They enable people to express their needs, participate in social interactions, and maintain independence. AAC systems promote inclusivity and ensure that everyone has a voice, regardless of their ability to speak.

For ALS/MND, AAC devices, such as speech-generating devices and eye-gaze systems, allow people to communicate more effectively, maintain social connections, and enjoy a real sense of autonomy and agency. However, despite these benefits, there are concerns about the high cost of devices and the need for training and support.

https://en.wikipedia.org/wiki/Augmentative_and_alternative_communication

Never doubt that a small group of thoughtful, committed citizens can change the world;
indeed, it's the only thing that ever has.
Margaret Mead

APPROACH TO GROUP DISCUSSIONS

Timeline
- 10 minutes: Debrief from the Plenary and introduction to the Discussion Group and logistics and housekeeping
- 30 minutes: Discussion in breakout groups
- 30 minutes: Summary from breakout groups and general discussion
- 5 minutes: Wrap up and close

Debrief from Plenary

The purpose of the plenary was to provide a diverse and varied set of views and experiences from different disciplines in technology, design, healthcare, human expression, innovation, access, affordability, etc. from a global perspective, with the intention of teeing up interesting, provocative, and illuminating discussions in the subsequent 2 group session. Its goal was to promote a stimulating discussion which will help identify and prioritise areas of involvement, and investment for the Alliance in support of our mission and purpose.

The following questions were provided to each breakout group, in support of going deeper into specific items or topics which came up in discussion of the overarching themes and considerations.

1. Which 3-5 areas do you believe the Alliance should focus on, and why?

2. What criteria did you use to determine priority (e.g., value and impact on quality of life, achievability, resources, constraints)?

3. Are there any key groups, communities, or stakeholders missing from this conversation?
    a) What steps would we need to take to engage them effectively?
    b) What barriers might exist, and how could we overcome them?

4. What would you propose as the next steps to ensure that projects are impactful, scalable, and sustainable?
    a) What specific actions should each key stakeholder take?

5. What role could you or your organization play in contributing to the goals of the focus areas?
    a) What resources, expertise, or support could you contribute?
    b) What would motivate or enable greater participation from your sector or community?

6. What would an effective model or approach for collaboration and co-creation look like and how would we ensure shared ownership and accountability in this effort?

7. What challenges or risks would we need to address to make this work?