ITAC Roundtable - June 2021

The Spectrum of Possibilities

Executive Summary

In June 2021, a multi-stakeholder group representing various communities within the International Alliance of ALS/MND Associations' network gathered to discuss innovation and technologies currently available and existing on the near horizon for persons affected by ALS/MND. Participants reviewed pre-event materials to familiarize themselves with tools and programs from the perspectives of 4 personas that represent points in time along the ALS/MND journey, in light of the Foundational Rights of PALS and CALS and along the continuum of Maslow's Hierarchy of Needs.

Participants joined one of two facilitated discussion groups to review the materials, identify gaps and discuss three questions related to innovation and technology available to help with care of PALS, finding a cure for ALS/MND and the role of the Alliance. The facilitators and Alliance staff reviewed and analyzed the ideas generated by the group discussions. Five initiatives emerged:

1) Global Peer-to-Peer Support
2) Information Aggregator
3) Technology Rating App
4) Open Data Project
5) Artificial Intelligence (AI) Project

The facilitators and Alliance staff evaluated the level of effort and resources required for each initiative against the value to Quality of Life impact and presented this evaluation at the Plenary group discussion to identify opportunities to develop infrastructure support and address barriers. The Innovation and Technology Advisory Council (ITAC) will review these ideas to set priorities, feasibility and realistic delivery from the Alliance as it moves forward with project development.

The Alliance is grateful to all participants in the Roundtable, especially the people living with ALS/MND and their caregivers whose contributions to the entire meeting and its outcomes were instrumental. The Alliance wishes to thank its industry partners for their engagement in the Roundtable program, specifically Amylyx, Biogen, Cytokinentics, Ionis, and Mitsubishi Tanabe Pharma for their sponsorship of the meeting.

Background

Until there is a cure, technology is the cure.
*Steve Gleason to Elon Musk

People living with ALS/MND have the right to the best quality of life possible.
*Alliance Patient Rights

Building on these statements, the International Alliance hosted a 2-day roundtable to discuss innovation and technology available and existing on the near horizon for persons affected by ALS/MND.

Participants prepared for the roundtable by reviewing foundational materials centred around a People Living with ALS/MND (PALS) Needs Matrix. This matrix established a framework to identify various tools and concepts that address the evolving needs of PALS and CALS at different stages of their journey. The Alliance utilized personas created by ALS Canada to depict humanized points along that journey and framed these points using Maslow's hierarchy of needs. Additionally, participants reviewed a video comprising segments that highlight the innovation and technology behind various tools for care and cure.

The framework provided was intentionally not complete, and instead presented a starting point for the roundtable discussion during which the participants were asked to consider existing and emerging innovations and technologies in their jurisdiction from the perspective of the personas to which they were assigned. The discussion focused on uncovering gaps and realizing potential adaptations of existing innovation and technology.

- See Appendix 1 for the Participant Roster
- See Appendix 2 for Pre-viewing Materials: Personas, Explanation of Maslow's Hierarchy of Needs, Statements on the Fundamental Rights of people living with ALS/MND and their caregivers; and the PALS Needs Matrix
- See Appendix 3 for Pre-viewing Materials: Agenda, which includes the Video topics, and Presenters' biographies

Roundtable Outcomes:

On June 23, the Alliance convened two groups for discussion. Participants selected to join one of the groups based on their timezone, schedule and availability. After a brief review of the PALS Needs Matrix, the personas and Maslow's Hierarchy of Needs, the facilitators explained that participants would be assigned randomly to a breakout group based on one of the 4 personas. These breakout groups would review and discuss the PALS Needs Matrix from the perspective of the assigned persona to identify gaps and additional applications of existing innovation and technology.

- See Appendix 4 for Topics List generated by that discussion

After a brief report from each breakout group, the participants again were assigned randomly to a different breakout session to discuss the role of Innovation and technology in improving care, supporting cure, and areas used for care that can be used for research designed to find a cure. The group also discussed the role of the Alliance to ensure advances in innovation and technology deliver the best Quality of Life care and support finding a cure.

- See Appendix 5 for Topics List Generated by that discussion

Plenary Discussions:

On June 29, participants reconvened in a plenary format to review the ideas generated by both groups and all the breakout groups. Facilitators presented a composite list, identifying key themes and important design considerations from the User Experience (UX) perspective as well as identifying technology supports of value to people affected by ALS/MND at different points of disease trajectory.

Additionally, facilitators and Alliance staff presented the findings of their review of the group discussion ideas and revealed five reoccurring themes. The group discussions generated more ideas, some of which were out of scope for the work of the Alliance because of local or national focus. These five themes became the 5 Initiatives. Alliance staff assessed the level of effort and resources of the Alliance against the value to Quality of Life impact of each initiative and slotted these 5 Initiatives on a priority matrix to consider priorities, assess feasibility of the initiative, and evaluate realistic delivery from the Alliance.

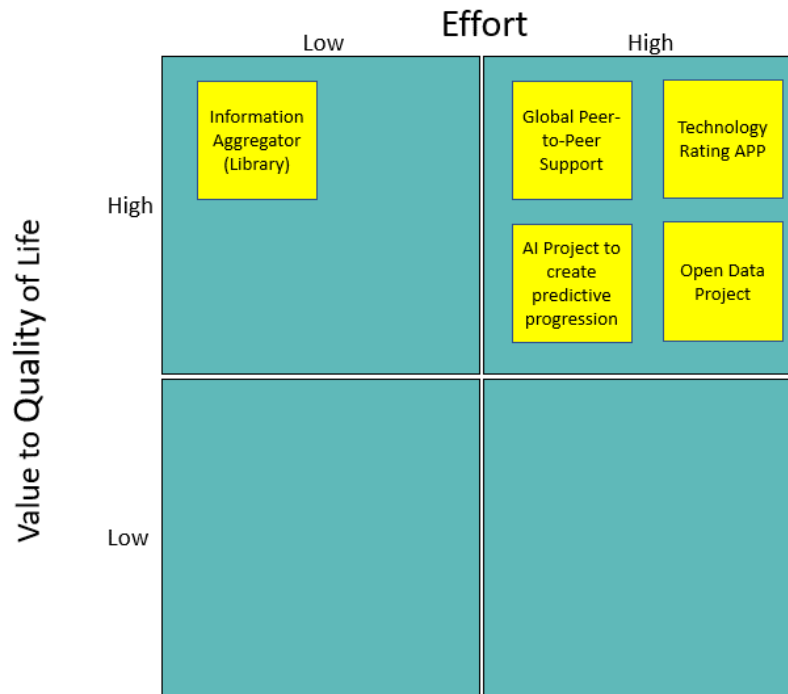## Summary: Personas and UX:

Persona summary of technology needs

Steve
Newly diagnosed
(1-4 weeks)

- **Access to information**
- **Personal welfare**

Guiding UX (User Experience) principles

- Ability to adapt to a person and their environment

Moira
Slow progressing symptoms

- **Access to personalised information**
- **Creativity & expression**
- **Emerging technologies**

- Not increasing burden with plethora of additional technologies

Fred
Advanced ALS & changing symptoms

- **Communication**
- **Care**
- **Control**
- **Contribution**

- Built-in communication channels between PALS/CALS and Clinicians (avoid misunderstandings over interpretation of data)

- Importance of usability of tech (given PALS are usually older)

Henry
Caregiver

- **Access to information, resources, and services**
- **Technology aids**

Presenting the Guiding UX (User Experience) principles:

- Ability to adapt to a person and their environment
- Not increasing burden with plethora of additional technologies
- Built-in communication channels between PALS/CALS and Clinicians (avoid misunderstandings over interpretation of data)
- Importance of usability of tech (given PALS are usually older)

Summary: Five Initiatives

Effort

	Low	High	
High	Information Aggregator (Library)	Global Peer-to-Peer Support	Technology Rating APP
		AI Project to create predictive progression	Open Data Project
Low			

Value to Quality of Life (vertical axis)

Alliance Staff explained the components of each initiative and why the initiative earned its placement on the priority matrix:

1) Global Peer-to-Peer Support
   - Support PALS through progression
   - Support CALS and share information
   - What Now and What Next: new and emerging things
   - Coordination of help with life; surrounding life of family and friends
2) Information Aggregator:
   - Alliance website updated to serve as Global Gateway: member resources
   - More than a library
     - Landscape research conducted on where and what types of research is being conducted
     - More user-focused
   - Categorized as low effort because Alliance is rich in resources based on the strength of members.
3) Technology Rating App
   - Currently focused on voice banking in the UK

- Broaden to world
- Broaden to other technology
- Feedback gets to industry to help drive them to remain current, if not lead in the area

4) Open Data Project
- Governance role; trusted data broker
- Avoid duplication; reduce data silos
- Privacy law issues
- Set expectations and standards; enforcement

5) AI Project
- Increase value of data already collected
  - Better/more care based – "People Like Me" idea
  - Asymptomatic Gene Carriers might belong here
- AI as mining tool

Discussion on 5 Initiatives

After the explanation, facilitators asked participants to consider these 5 Initiatives in the framework of the following questions:
- What do you like as fit for Alliance?
- What don't you like?
- What different things should the ITAC consider for each of these initiatives?

Highlights are included below.

- Global Peer-to-Peer Support: regional circumstances contain more commonalities than differences and the Alliance can stand outside the community-based interaction to provide modern and up-to-date information
- Technology Rating App: need to build in initial and progressive feedback system and ensure that technology matches the clinical assessment of rater's need
- AI Project: the Alliance can add value to existing activity by filling role of connector/custodian/developer of partnerships and principles to guide activities
- Information Aggregator: The Alliance's website currently serves this function; Information and Support for PALS/CALS: https://www.als-mnd.org/support-for-pals-cals/
- Open Data Project: big, long-term, slightly daunting project for which the Alliance can build the relationships needed to gather data people as well as scientists to reduce duplication and adapt for disease progress prediction to aid in intervention and decision-making.

- See Appendix 6 for a complete list

Next Steps

Ultimately, the Alliance is a conduit for Associations and members to give voice and experience to technology. In that role, the ITAC will review the 5 Initiatives to set priorities, feasibility and realistic delivery from the Alliance. This review will help define how the Alliance moves forward with project development and implementation.

Appendices

1: Participants Roster
2: Pre-reading Materials: Personas, Matrix, Statement of Rights, Hierarchy of Needs
3: Pre-reading Materials: Agenda; video topics and presenters
4: Group Discussion: Persona Themes
5: Group Discussions: Supporting Care and Cure Themes
6: Plenary Group Discussion: 5 Initiatives

Innovation and Technology Roundtable: *The Spectrum of Possibilities* June 2021: Attendee Roster				
Given Name	Family Name	Affiliation	Country	Group No.
Wendy	Abrams	International Alliance of ALS/MND Association	USA	1
David	Ali	Motor Neurone Disease Australia	Australia	2
Pablo	Aquino	ALS Association Argentina	Argentina	1
Mona	Bahus	Stiftelsen ALS Norge	Norway	1
Calaneet	Balas	International Alliance of ALS/MND Associations; The ALS Association	USA	1
Nancy	Bayerlein	Mitsubishi Tenabe Pharma	USA	1
Erin	Beneteau	University of Washington	USA	2
Gorrit-Jan	Blonk	ALS Netherlands	The Netherlands	1
Chris	Brooks	Presenter	USA	2
Shae	Cameron	International Alliance of ALS/MND Associations	Canada	1,2
Blair	Casey	Team Gleason Foundation	USA	1,2
Richard	Cave	Motor Neurone Disease Association (MNDA UK)	England, Wales, N Ireland	1
Jarnail	Chudge	Microsoft Research	UK	1,2
John	Costello	Boston Children's Hospital	USA	1
Grainne	Crowley	Biogen	USA	1
Cathy	Cummings	International Alliance of ALS/MND Associations	Canada	1,2
Matthew	Davis-Morin	Boston Children's Hospital	USA	1
Emma	Dryden	Drexel University	USA	1
Marcus	Dyrholm	Aalborg University	Denmark	1
Mike	Gardner	International Alliance of ALS/MND Associations	Canada	1

Nick	Goldup	Motor Neurone Disease Association (MNDA UK)	England, Wales, N Ireland	1
Antoinette	Harrison	Mitsubishi Tenabe Pharma	USA	1
AJ	Haskins	Microsoft	USA	2
Dr. Cathy	Holloway	Global Disability Innovation Hub	UK	1
Shauna	Horvath	Amylyx	USA	1
Tracy	Hutchin	Irish Motor Neurone Disease Association (iMNDA)	Ireland	1
Balazs	Ivanyi	Aalborg University	Denmark	1
Dr. Gordon	Jewett	Alberta Health Services	Canada	2
Dr. Alper	Kaya	ALS/MND Association Turkey	Turkey	1
Kellie	Krake	International Alliance of ALS/MND Associations	Canada	1,2
Dr. Esther	Kruitwagen	UMC Utrecht	The Netherlands	1
Jessica	Mabe Bernal	Asociación Colombiana de Esclerosis Lateral Amiotrófica	Colombia	1
Norman	MacIsaac	International Alliance of ALS/MND Associations	Canada	2
Lisa	Marchitto	ALS Society of Canada	Canada	1,2
Tammy	Moore	ALS Society of Canada	Canada	1
Megan	Murphy	Biogen	USA	2
Christopher	O'Dowd	Microsoft	USA	2
Ann	Paradiso	Microsoft Research	USA	1
Andrea	Pauls Backman	Les Turner ALS Foundation	USA	1
Evy	Reviers	ALS Liga België (ALS League of Belgium)	Belgium	1
Dr. Hemangi	Sane	NeuroGen Brain & Spine Institute, StemAsia Hospital & Research Centre	India	1
Marcela	Santos	Asociación Colombiana de Esclerosis Lateral Amiotrófica (ACELA)	Colombia	2
Gudjon	Sigurdsson	MND Association of Iceland	Iceland	1
Valentino	Škiljan	Croatian Muscular Dystrophy Association (SDDH)	Croatia	1
Bugyeong	Son	Korean ALS Association	South Korea	2
Dr. Jamie	Timmons	Amylyx	USA/Canada	1
Truls Bendik	Tjemsland	Aalborg University	Denmark	1
Angelique	Van der LIt	ALS Patients Connected	The Netherlands	1

Conny	van der Meijden	ALS Patients Connected	The Netherlands	1
Daniel	Vance	Team Gleason Foundation	USA	1
Bruce	Virgo	International Alliance of ALS/MND Associations	Scotland	1
Fran	Vuljanic	Croatian Muscular Dystrophy Association (SDDH)	Croatia	1
Dr. Jill	Yersak	The ALS Association	USA	1
Bernice	You	Microsoft Research	USA	2

Steve:

Access to information (trusted, reliable, current, consumable)
- Relevant resources and data…in one place!
- Emphasis on the importance of nutrition and maintaining weight
- Ensuring that one's financial affairs are in order
    - Including rights of access to social care and public health coverage
    - (Notwithstanding variations worldwide)
- Cultural and regional differences and variations in prevailing medical care approach
    - Value of occupational therapy
    - Voice-banking (preparedness for the future)

Personal welfare (communal, supportive, purposeful)
- Support and guidance in establishing positive routines and habits
    - Prepare for the future (e.g., setting up controls & assistance)
- Opportunity to connect with mentors in the community
- Resilience re: dealing with the overwhelming nature of the diagnosis
    - Impact on, and role of, family
- Maintaining sense of independence

Moira:

Access to personalised information
- A "PALS Google" with all the relevant resources and data…in one place!
- Link to relevant clinical trials
- Guidance on connecting to relevant support groups
- Issue of 'interpreting' a person's real needs
- A simple guide to explain *her* progression

Creativity & expression
- Recreational needs (hobbies, games, art, music…with additional devices!)
- Access to well-being content e.g., meditation, mindfulness
- Range of activities, choice – result in increased self-esteem
- Platform for advocacy for other PALS via peer-to-peer network or virtual forums

Emerging
- Increasing value of data e.g., wearables sensor data looping back to clinical systems
    - Opportunity for more personalised care based on 'people like me'
- Telehealth = high-value interactions with relevant insights

Fred:

Communication
- Early voice and message banking (through high and low-tech systems) to preserve voice
- Express assistance needs through communications technology
  - Importance of early introduction of assistive technology needs (to account for potential changes down the line and need for different technology based on progression)

Care
- Innovation in adaptive care needs to address complications (being too long on a toilet, pressure release, skin care etc.)
- Counselling – for self, and family

Control
- Independent breathing
- Environmental control technology

Contribution
- Ability to use his skills for financial planning for not only himself, but potentially help others with ALS with those needs
- He needs to feel like he is supporting his family members as well as the wider community
- Potentially support others who are earlier in their diagnosis

Henry

Access to information, resources, and services (with positive net-effect!)
- Virtual and mental health support e.g., self-identity, caregiver support group, connecting with peers through a virtual platform, online mentorship etc.
- Genetic counselling and testing regarding other family members
- Health diet & nutrition; optimised sleep/rest/recovery (for self and family care!)
- Financial and legal administration and planning e.g., wills, legacies, etc.
- Equipment to assist caregivers (e.g., hoist), through to services provided by local health provider and associated qualifying criteria
- Remote monitoring (by exception) e.g., intelligent alerting through currently available technology (Apple watch, Alexa, Nest video camera etc.)
- Respite carers (in person and/or remote assistance)
- App to co-ordinate family and friends

Technology aids
- Support aids (lifting, feeding)
- App for managing care, routines, visits, activities (including access to family & friends)
- Platform for advocacy for other CALS via peer-to-peer network or virtual forums

Appendix 5: Group Discussions: Supporting Care and Cure Themes

Question 1: How can innovation & technology support CARE?
- Information overload
- Self-monitoring (pros and cons)
- Environmental control
- Wearables to gather information/data on changes in speech and gait
- Telehealth for PALS
    - Lack of access to many, challenges with equipment e.g., viewing apparatus
    - Loss of interpersonal communication/relationship
    - Assist with functional assessments
    - Privacy related concerns (being under constant 'observation' may take away autonomy)
- Avoid duplication of efforts worldwide
- Alliance to help steer funding towards better NIV (Non-Invasive Ventilation), means of swallowing, etc.
    - Research of investments in this area is critical
- Importance of the role of education for the Alliance
- Greater autonomy and independence reduce economic burden on govt and other support organisations e.g., loaning equipment
- The world has changed in the last 18 months, what can we tap into re: new ways of working, sharing data e.g., self-monitoring, tele-health, virtual care
- Tech that brings independence is most exciting e.g., wearables, BCI (Brain Computer Interaction), voice, video, sensors, monitors, potential of VR (Virtual Reality) related experiences & technologies

Question 2: What innovation & technology can we look at to support CURE?

- Exploiting data from everyday activities [utilisation of information/data for more than one purpose]
    - Value of data & AI i.e., exploiting data from everyday activities [utilisation of information/data for more than one purpose e.g., self-monitoring data feeding insights and research, identify patterns based on analysis)
    - Speech data supporting research to monitor progression drawn from voice banking, talking to devices (e.g., draw on data from Amazon, Google, Apple from voice interactions with agents)
    - Sensors and wearables for movement tracking for insights on motor-control function
        - Provenance of the data… (commercial orgs v personal collection)
    - Leverage existing tech e.g., patient facing app to collect data
    - Build predictive models for care and cure… (leading to better PALS stratification)
    - Importance of open data standards (technology version of a bio-bank?)
    - Organisational
    - Alliance forming consortia to bring together global resources, expertise (based on observation that the ALS community is generally very co-operative, and the opportunity to serve underserved areas like Africa, South America…)

- Governance role re: platform for sharing best practices worldwide as a trusted data broker & co-ordinate information to avoid duplication of efforts and creation of data silos E.g., bring key stakeholders together (including those outside the ALS community; address the gap between what is happening in the lab vs what is happening in the real world; unified incentive model for researchers, commercial orgs etc.)
- Is there an opportunity for the Alliance to create a set of expectations/standards of clinical trials E.g., for a study to be registered it must use certain templates and adhere to defined standards?
- UNESCO – top 100 challenges for AI. Programme brings consortia together to solve problems…opportunity for the Alliance identifying problems to be solved which gives students/researchers opportunity to respond to identified challenges
- Guidelines on privacy (addressing data sharing for general use while ensuring independence, autonomy re: what is shared by PALS)

Appendix 6: Plenary Group Discussion: 5 Initiatives

1) Global Peer-to-Peer Support
- Issues around regional differences re: resources, privileged information, cultural competence
  - But these issues are not big enough barriers – there are enough universal likes vs unlikes; even if resources may not be available or available at the same level, you can relate to the situation
  - Can spur local innovation
  - Create education/awareness, which is the power to advocate for change
- Alliance to help with more systematic country capacity
  - Strengthen
  - Create product narrative (about and around innovation and/or technology)
    - Advocacy tool to explain
    - Human rights and well-being as well as economics
  - Global mapping
  - Helps with considering developing countries
- Alliance to stand above community-based interaction to provide modern and up-to-date information
  - Alliance as moderator, not direct resource
  - Develop a list of reliable PALS
  - Non-ALS patients can guide PALS, as well
- Issues: language barrier; tech-savviness of aging population.

2) Technology Rating App
- Need to build in initial feedback as well as progressive feedback
  - How does tech holdup overtime
- Need to be cautious of marketing influences
- Need to ensure the tech rated is matched by clinical trial/assessment of individual needs – ground truth in clinical use (cf: WHO assistive technology product recommended use)

3) AI Project
- Can the Alliance add to the already existing work done by for-profit and/or academics?
  - Landscape analysis –
  - Connect up existing organizations and entities – connecting and informing
- Alliance filling role as developer and custodian of partnerships
  - Setting agenda
  - Forming partnership to develop diverse, inclusive community
  - Creating Principles for sharing data and defining what is common and central data
  - Facilitate data and protocol sharing

4) Information Aggregator
- Set aside for today because International Alliance website will include this idea

5) Open Data
- Described as a 5-year project
- Big project, not easy to get outcomes
- Foundational Efforts
  - Need to develop relationships, gain trust
  - Get data people together, not just scientists

- Global data = global solutions
- Open data reduces duplication
  - Need to establish data structure standards
  - Any new system needs to plug into existing system (compatibility)
- Can be used for progress prediction for intervention and decision-making