Timeline Overview

Personas

Steve
Newly diagnosed (1-4 weeks)

- Access to information
- Personal welfare

Moira
Slow progressing symptoms

- Access to personalized info
- Creativity & expression
- Emerging technologies

Fred
Advanced ALS/MND & changing symptoms

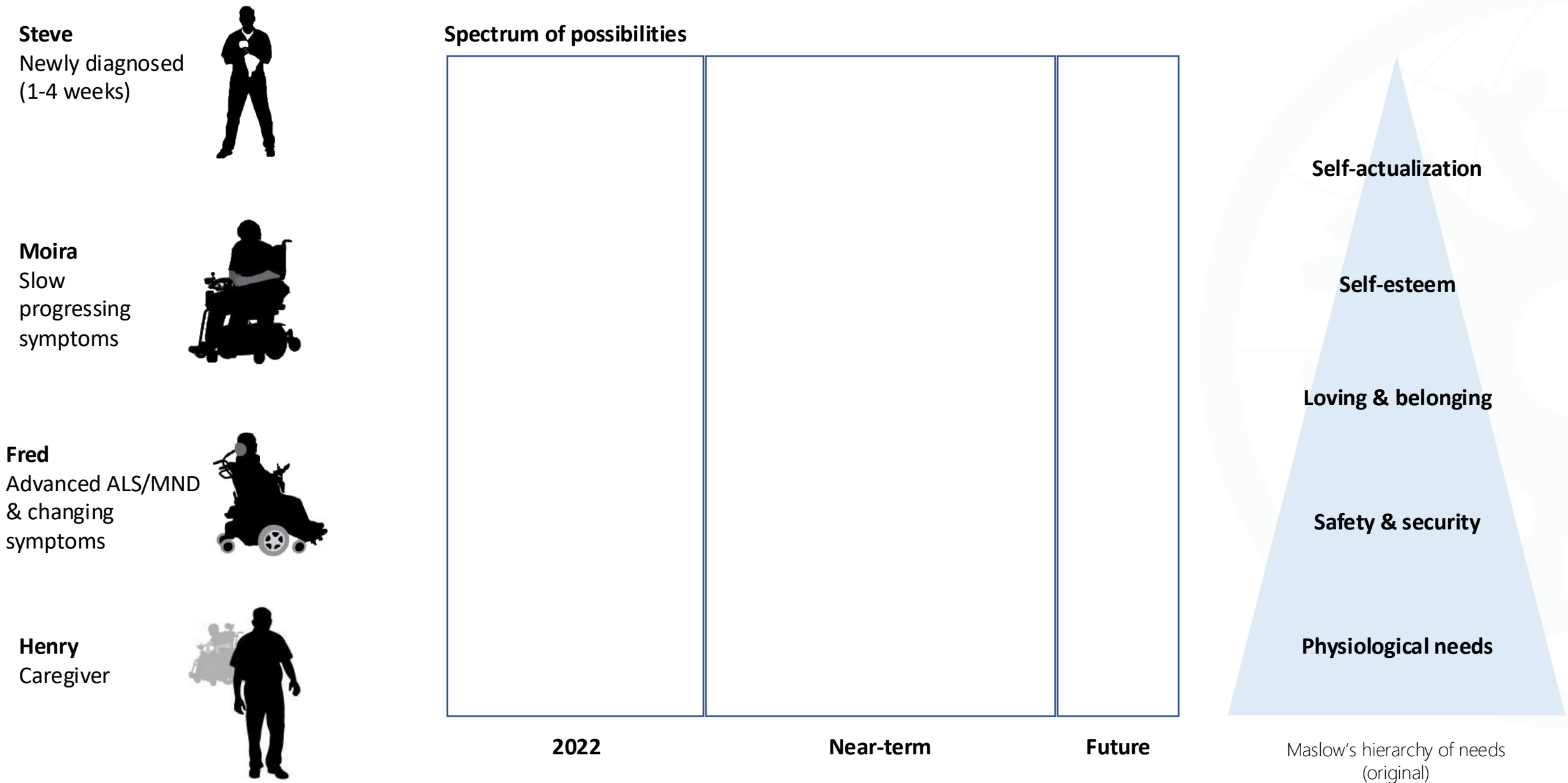- Communication
- Care
- Control
- Contribution

Henry
Caregiver

- Access to information, resources & services
- Technology aids

Framework Integrating QoL & Personas

Steve
Newly diagnosed
(1-4 weeks)

Moira
Slow
progressing
symptoms

Fred
Advanced ALS/MND
& changing
symptoms

Henry
Caregiver

Spectrum of possibilities

2022	Near-term	Future

Self-actualization

Self-esteem

Loving & belonging

Safety & security

Physiological needs

Maslow's hierarchy of needs
(original)

Patient Needs Matrix (2022)

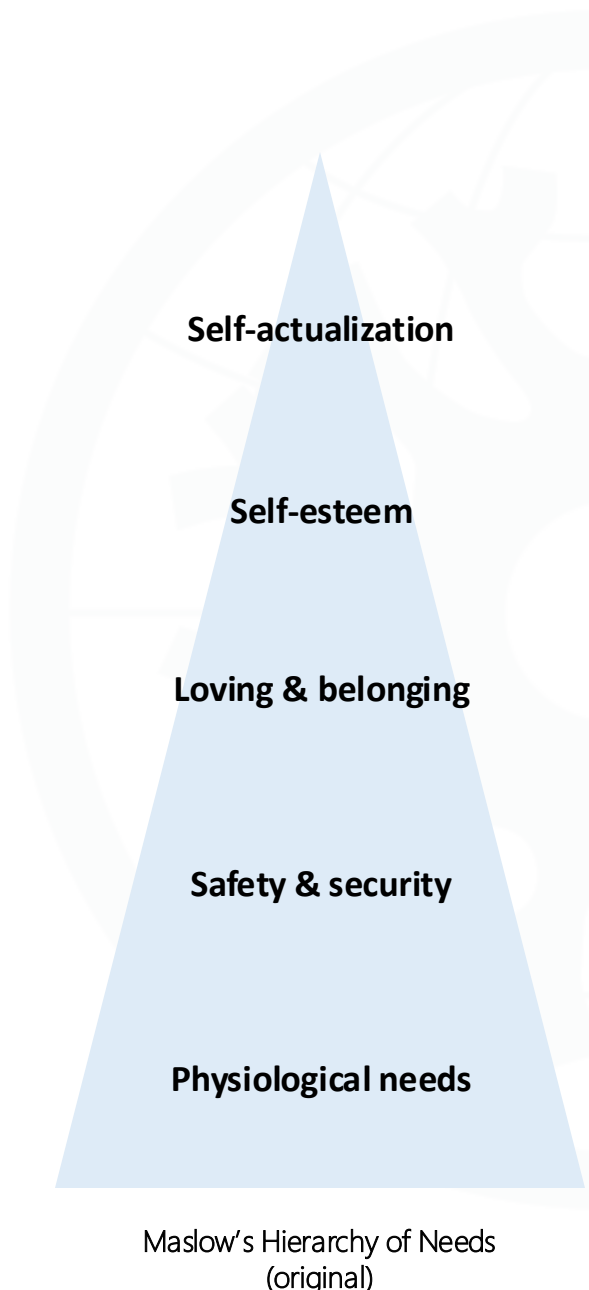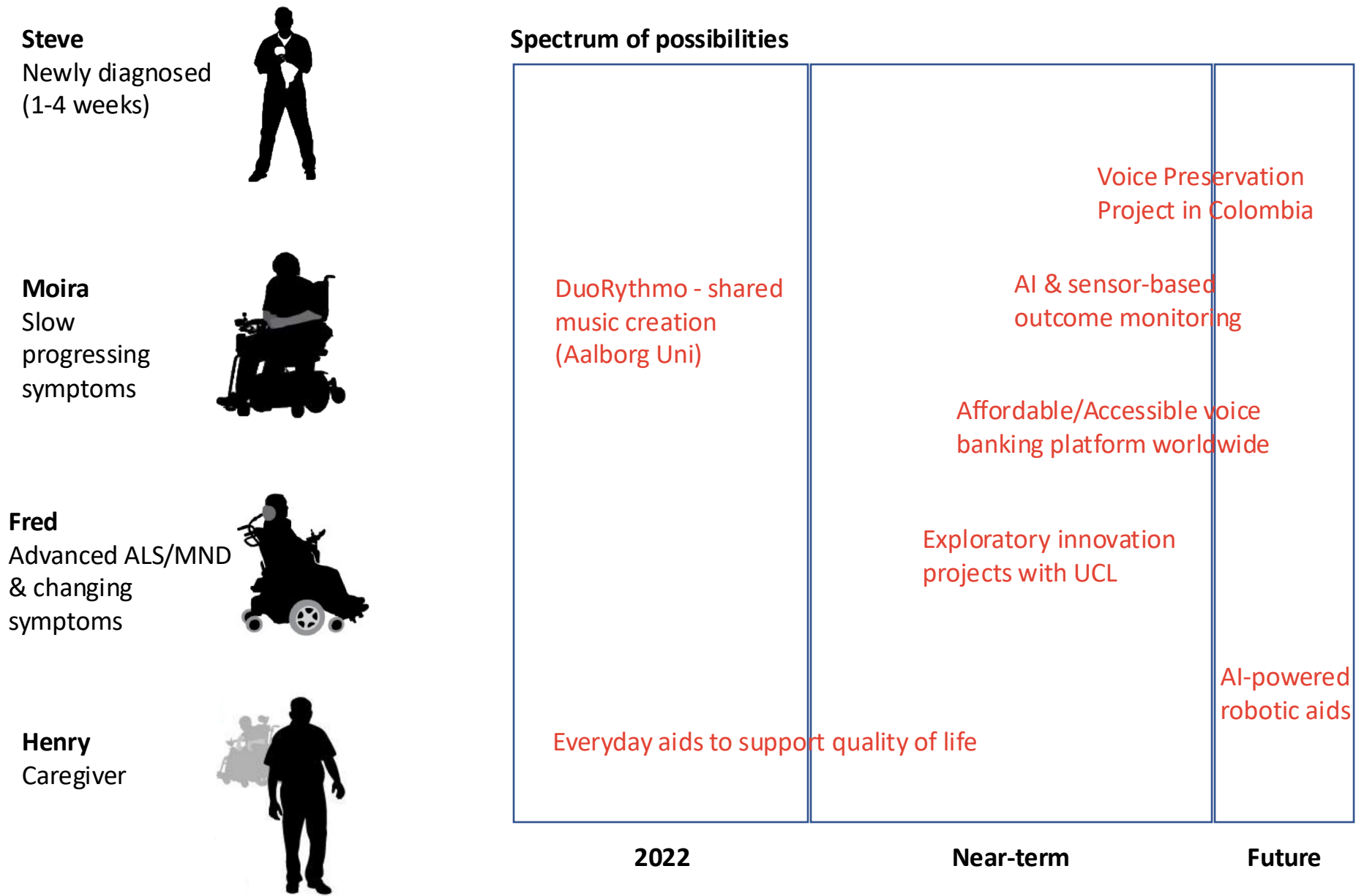|	Physiological Need				Safety and Security					Loving and Belonging		Self-Esteem	Self-Actualization	
	Nutrition Support	Skincare Equipment	Care - Hygiene (Toileting & Bathing)	Respiratory Support	Care - Telehealth	Home Integration & Modifications	Wearables	Access to Information	Mobility	Virtual Support	Genetic Counselling and Testing	Communication	Human Expression Intrinsic	Human Expression Extrinsic
Steve (newly diagnosed)						Environmental Control - Smart Locks			Wheelchair Control: seat elevation and tilt	UCL APP: Sharing Experiences & reviews of Assistive Technology: Jessica Hong		Project Euphonia: Fernando Vieira + Google Research	Gaming	Advancing the State of the Art of the Possible in Technology: Cathy Holloway
Moira (slowing progressing)		Equipment Assistance: Bed Positioning; Wheelchair Interface	Equipment Assistance: Shower Chair; Bidet	Non-Invasive Ventilation (NIV)	e-health APP: Angelique van der Lit	Designing for Inclusive Smart Home Control: Joel Moffatt			Redefining the New Normal: Wheelchairs as Command Centres: Daniel Vance				Concerts, Exhibits	DuoRhythmo: The Joys of Musical Co-Creation: University of Aalborg
Fred (advanced and changing)	Eating Assistance			Thinking Differently Through Integration: Chris O. Brooks	Web-based Home Monitoring for Personalized ALS/MND Care in The Netherlands: Drs. Anita Beelen + Esther Kruitwagen	Environmental Controls: Computer access; TV control; Video monitoring			Leveraging Technology at the MDA ALS Center of Hope: Dr. Terry Heiman-Patterson (Mobility and Accessibility)			Real Time Expression: Ann Paradiso	Virtual Reality Travel	
Henry (caregiver)						Environmental Controls: video monitoring							Spiritual	

From 2022 to 2024

- Significant changes in the technology landscape

- Voice Preservation Project in Colombia

- Supporting partners in LATAM, Africa and India

- The Global South (low- and middle-income countries) is very different to the Global North!

How do we, as the Alliance, respond to this effectively in line with our vision of "A World Free of ALS/MND"?

Framework Integrating QoL & Personas

Steve
Newly diagnosed
(1-4 weeks)

Moira
Slow
progressing
symptoms

Fred
Advanced ALS/MND
& changing
symptoms

Henry
Caregiver

Spectrum of possibilities

DuoRythmo - shared
music creation
(Aalborg Uni)

Voice Preservation
Project in Colombia

AI & sensor-based
outcome monitoring

Affordable/Accessible voice
banking platform worldwide

Exploratory innovation
projects with UCL

AI-powered
robotic aids

Everyday aids to support quality of life

2022   **Near-term**   **Future**

Self-actualization

Self-esteem

Loving & belonging

Safety & security

Physiological needs

Maslow's Hierarchy of Needs
(original)

"Day in the Life" Suite at the APF

Living room area

Toilet area

Wash-basin area
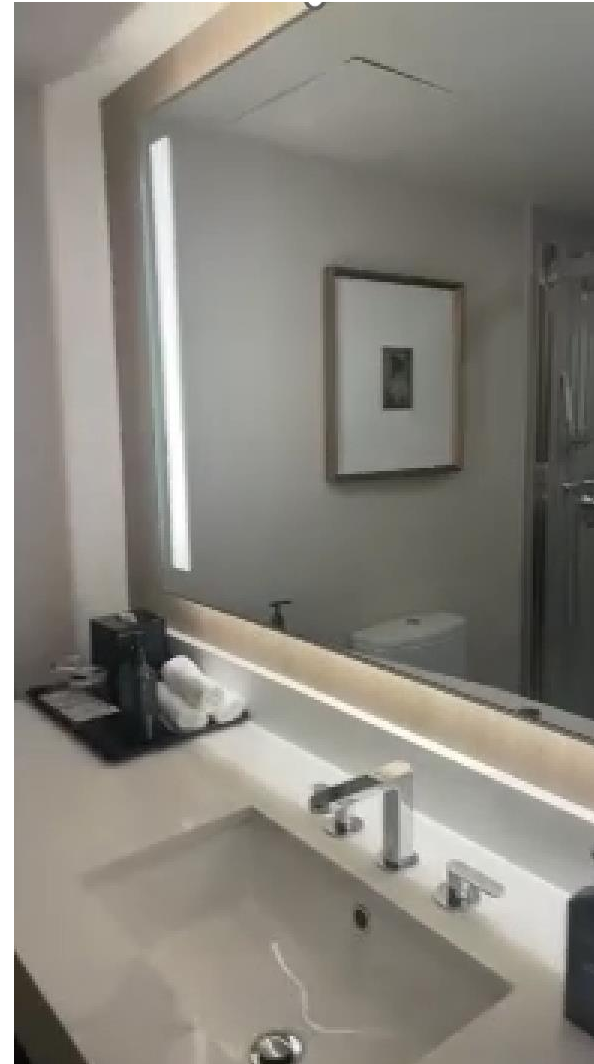
Kitchenette area

"Day in the Life" Showcase

Partner/Supplier	General	Bathroom	Bedroom	Living Room	Kitchen	Dining & table area	Suite entrance area	Outside ballroom	Notes
Colleen O'Connell (and team from Stan Cassidy Centre)	Smart home controls Netgear router Speech bubbles Labels Station 2 - home security Station 4: health reminders	IR bidet Switch adapted toothpaste Toothbrush adapter Hair dryer holder Smart plug Personal alert system Apple watch Switch bot Lamp with dimmer	Strip lighting Remote 3D paddles Alexa dot Smart plug Fan/heater Switchbot curtain	Roku remote Page turner Rocket switch Blue 2 Echo display (drop-in non-verbal) Oculus (x2) - World Tour app Head mounted mouse 3D joystick toppers	Echo display (intercom) Tricella pill Door sensor (doll house) Indoor camera Tablet device Medication reminder		Door lock Video door bell Apple watch Tablet	Custom stylus	
To clarify with Marla & team	Fall alarm OT guide to ALS		Adaptive clothing/make up Aids for dressing Adaptive clothes (dictus)	Breast-feeding pillow Neck collar					
Kate Busch, Leigh Stevens			Bedside table						
Alexandre Campeau-Lecours, Simon Latour						Flexible drink holder Cellphone holder Assistive eating device			
Dr. Deirdre Murray	Hand splint Hand massager							Confirm with Deirdre	
Makers Making Change (Courtney Cameron)								Titch switch	
ALSA - Creative Pursuits Catalog							Art, music, writing, in person tours	2 tables, floor space (for foot gantry), monitors	
Your ALS Guide	Information brochures and leaflets				Suite & ballroom				
Amazon				Fire tablet (with eye-gaze)					
Silverts			Adaptive clothes/apparel						
Tech Owl			Intimacy						
ProBed			Adaptive bed (with eye-gaze)					Adaptive bed (with eye-gaze)	
Kinova						Robotic arm eating aid			

"Day in the Life" Showcase

Partner/Supplier	General	Bathroom	Bedroom	Living Room	Kitchen	D
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Kate Busch, Leigh Stevens			Bedside table			
Alexandre Campeau-Lecours, Simon Latour		F				F C A
Dr. Deirdre Murray	Hand splint					

Personas

Steve
Newly diagnosed (1-4 weeks)

- Access to information
- Personal welfare
- Regulatory
- Cost & infrastructure

Moira
Slow progressing symptoms

- Access to personalized info
- Creativity & expression
- Emerging technologies
- Socio-cultural
- Mobility & independence

Fred
Advanced ALS/MND
& changing symptoms

- Communication (with my voice)
- Care
- Control
- Contribution
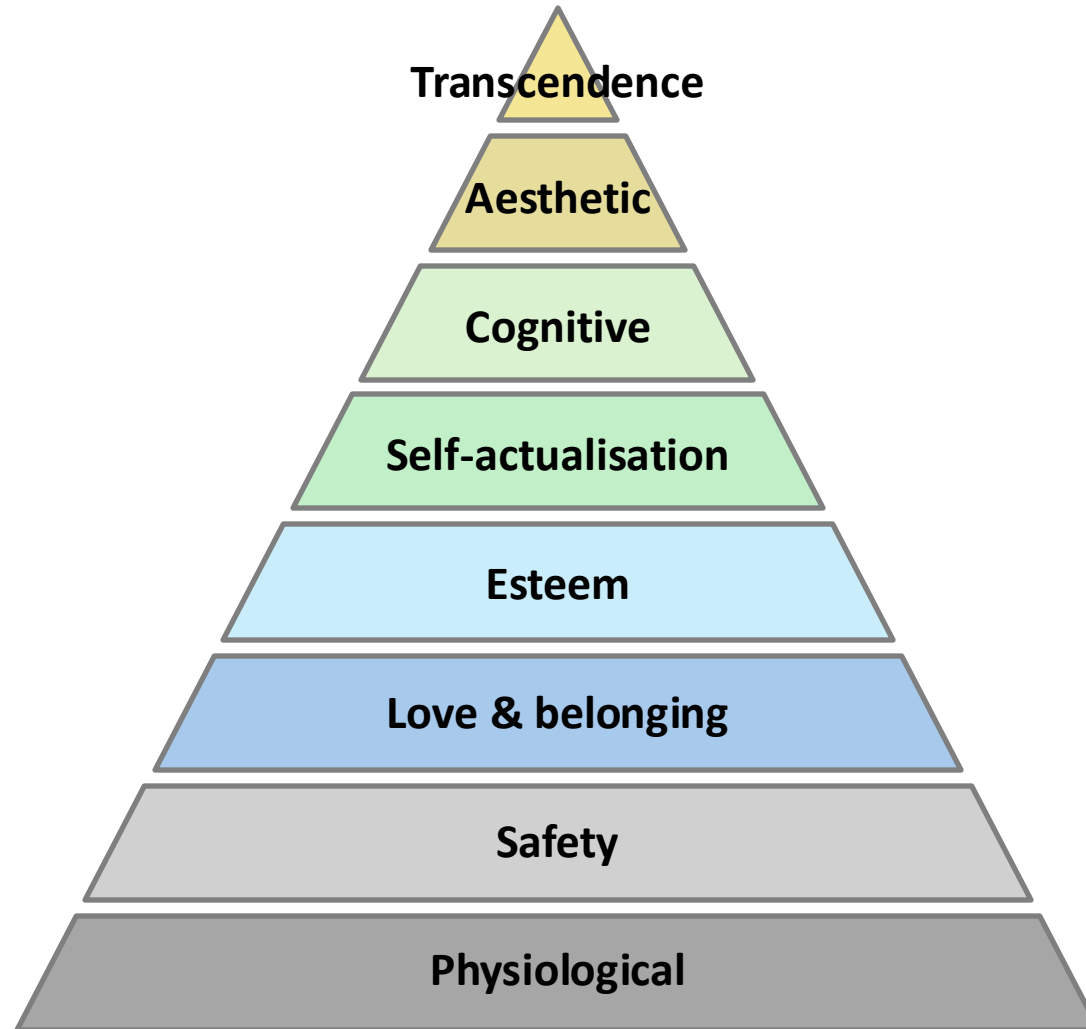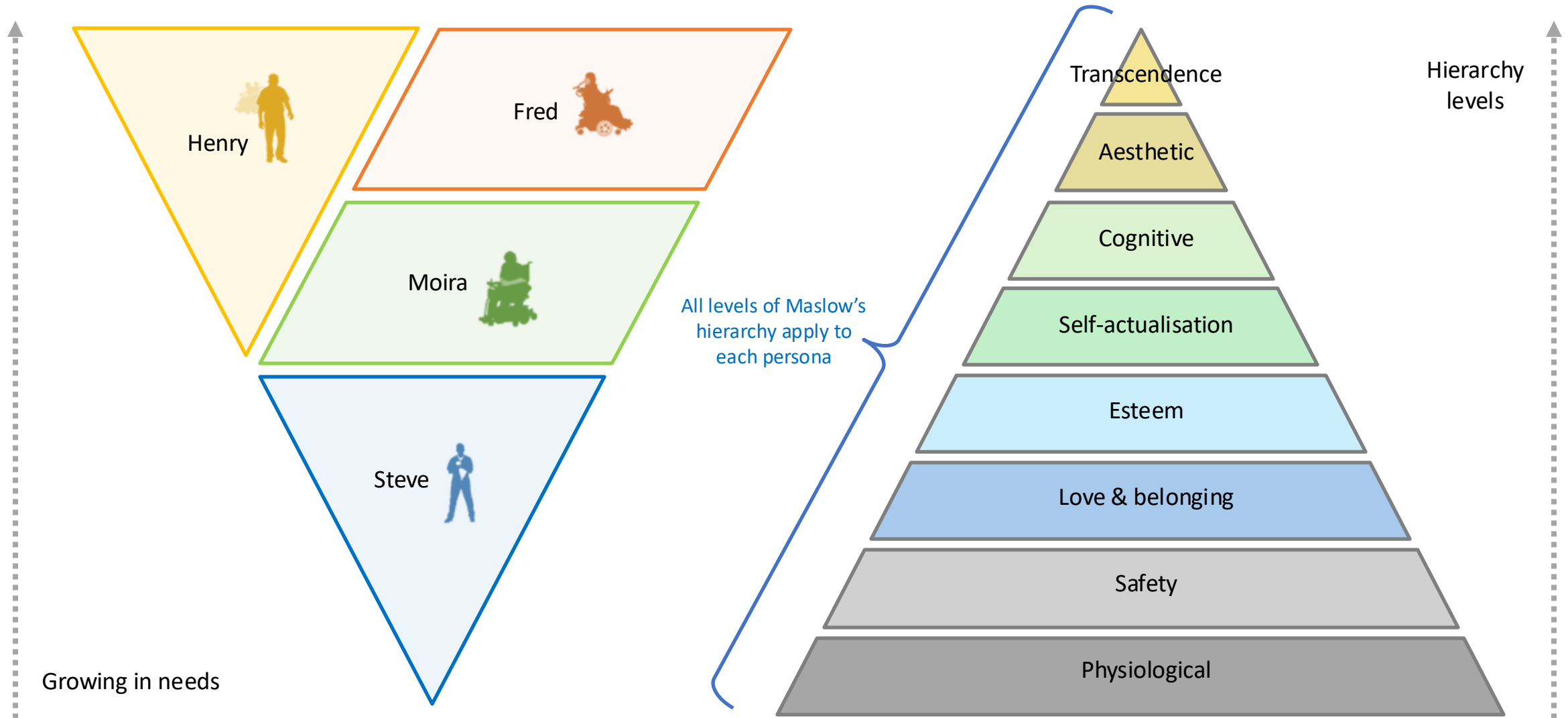- Access to affordable technology

Henry
Caregiver

- Access to information, resources & services
- Technology aids
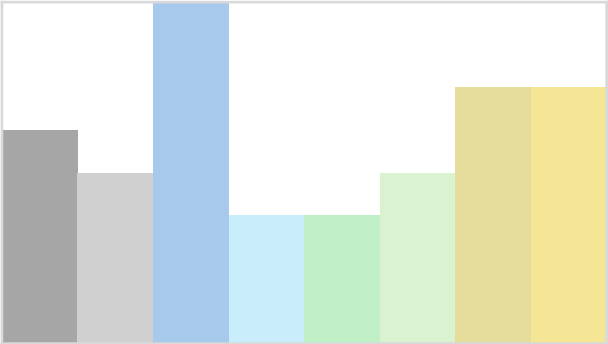- Family/friends network (community)

Maslow's Hierarchy: Expanded

Mapping to Personas: Key Finding

Each layer of Maslow's hierarchy applies to each of the personas in a unique and personal way!
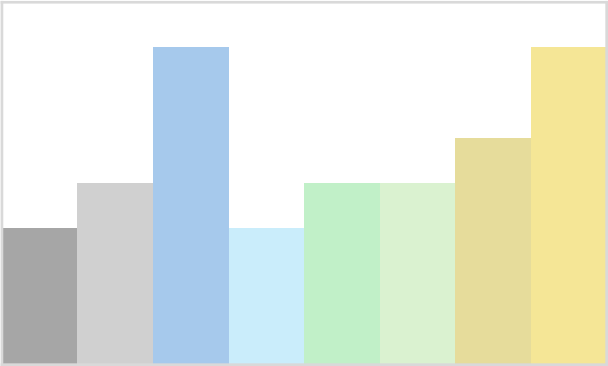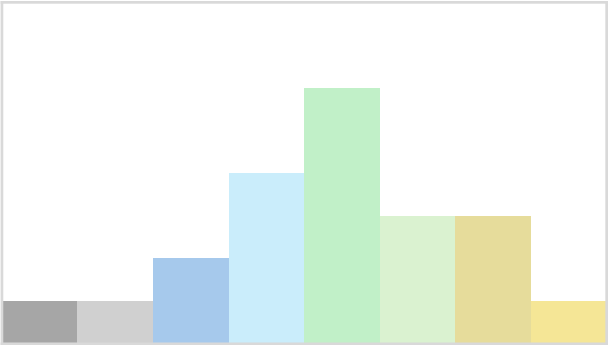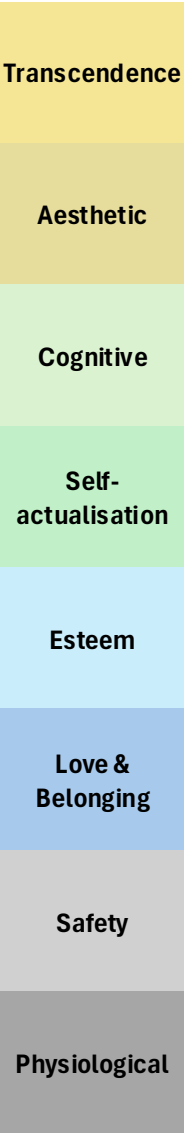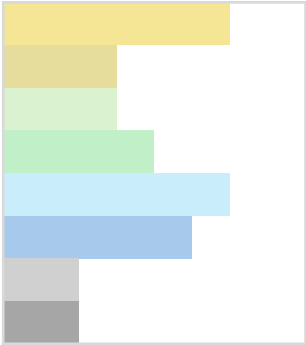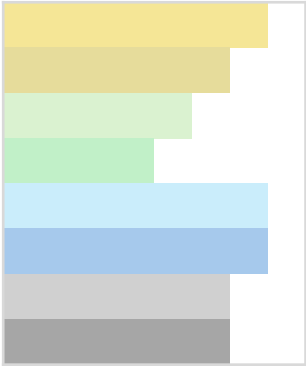
Mapping to Personas

V2 Patient Needs Matrix: Mapping *(work in progress)*

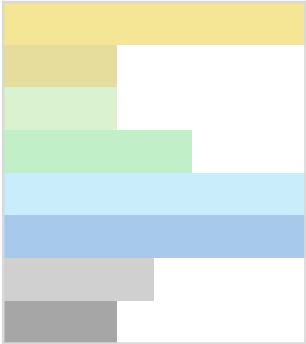| PATIENT NEEDS MATRIX	Sub-categories	Steve (newly diagnosed)	Moira (slow progression)	Fred (advanced & changing)	Henry (caregiver)
Physiological	Nutrition	Diet	Adjustable height table	Eating assistance Soft food/water thickener Flexible drink holder Eating utensils/devices	
	Skincare		Adaptive make-up aids	Adaptive clothing	
	Hygiene		Equipment - shower chair, bidet	Toilet support rails	
	Rest		Automated recliner	Adaptive bed mattress (positioning)	
	Respiratory	Fan	Non-invasive ventilation		
Safety	Telehealth	Video calls	E-health apps	Web-based home monitoring	
	Smart-home	Smart locks Thermostat Plug (lights, curtains, doors etc)	Command centre/console e.g. on wheelchair, device		
	Wearables	Smartwatch		Fall alarm	
	Info access	Research on trials	Mobility Bathroom & hygiene Dressing	Travelling guidance	
	Support (physical)		Ankle support brace	Pneumatic glove Hand splint Cordless hand massager	
	Mobility		Wheelchair (seat elevation, tilt)	Eye-gaze control	
Love & Belonging	Virtual support	Online webinars	Community	Video monitoring	Sharing experiences and reviews of assistive tech
	Genetic counselling	Research			
	Intimacy	Information guides	Devices	Positioning aids	
Esteem	Communication	Voice banking/preservation	AAC devices	BCI	
	Control	Voice activated interaction			
	Leisure	Gaming	Head mounted mice Joystick (adaptive)	Eye-gaze Switch controls	
	Entertainment	TV/radio remote control			
Self-Actualisation	Personal growth		VR app		Self-care
	Hobbies/interests	Learning	Online	Community (sharing)	
Cognitive	Learning	Generative AI			
	Virtual reality	Augmented reality travel and exploration			
Aesthetic	Expression (intrinsic)	Creative (music, art, writing, crafts etc)			
	Expression (extrinsic)	Concerts			
Self-Transcendence	Spiritual	Meditation			

V2 Patient Needs Matrix: Mapping *(work in progress!)*

PATIENT NEEDS MATRIX	Sub-categories	Steve (newly diagnosed)	Moira (slow progression)	Fred (advanced &
Physiological	Nutrition	Diet	Adjustable height table	Eating assistance Soft food/water thick Flexible drink holder Eating utensils/devic
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	Genetic counselling	Research		
	Intimacy	Information guides	Devices	Positioning aids
Esteem	Communication	Voice banking/preservation	AAC devices	BCI
	Control	Voice activated interaction		

Approach to Analysis

What we have so far:

- Growing number of lo- and hi-tech technology solutions

- Deeper understanding of PALS/CALS diversity of experiences

Translate into actionable insights

- Highlight gaps and opportunities through:

  - **G**lobal access

  - **I**ndustry

  - **A**cademica

- Subjective rating of "Good" ■ and "Poor" ■ to **promote constructive discussion**

View through Lens of Access, Industry Investment & Academic Research

PATIENT NEEDS MATRIX	Sub-categories	Steve (newly diagnosed)	G	I	A	Moira (slow progression)	G	I	A	Fred (advanced & changing)	G	I	A	Henry (caregiver)
Phsiological	Nutrition	Diet				Adjustable height table				Eating assistance				
										Soft food/water thickener				
										Flexible drink holder				
										Eating utensils/devices				
	Skincare					Adaptive make-up aids				Adaptive clothing				
	Hygiene					Equipment - shower chair, bidet				Toilet support rails				
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	Respiratory	Fan				Non-invasive ventilation								
Safety	Telehealth	Video calls				E-health apps				Web-based home monitoring				
	Smart-home	Smart locks				Command centre/console e.g. on wheelchair, device								
		Thermostat												
		Plug (lights, curtains, doors etc)												
	Wearables					Smartwatch				Fall alarm				
	Info access	Research on trials				Mobility				Travelling guidance				
						Bathroom & hygiene								
						Dressing								
	Support (physical)					Ankle support brace				Pneumatic glove				
										Hand splint				
										Cordless hand massager				
	Mobility					Wheelchair (seat elevation, tilt)				Eye-gaze control				
Love & Belonging	Virtual support	Online webinars				Community				Video monitoring				Sharing reviews of assistive tech
	Genetic counselling	Research												
	Intimacy	Information guides				Devices				Positioning aids				
Esteem	Communication	Voice banking/preservation				AAC devices				BCI				
	Control	Voice activated interaction												
	Leisure	Gaming				Head mounted mice				Eye-gaze				
						Joystick (adaptive)				Switch controls				
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Self-Actualisation	Personal growth					VR app								Self-care
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Self-Transcendence	Spiritual	Meditation												

View through Lens of Access, Industry Investment & Academic Research

PATIENT NEEDS MATRIX	Sub-categories	Steve (newly diagnosed)	G	I	A	Moira (slow progression)	G	I	A	Fred (advanced & changing)	G	I	A
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	Hygiene					Equipment - shower chair, bidet				Toilet support rails			
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		Thermostat											
		Plug (lights, curtains, doors etc)											
	Wearables					Smartwatch				Fall alarm			
	Info access	Research on trials				Mobility				Travelling guidance			
						Bathroom & hygiene							
						Dressing							
	Support (physical)					Ankle support brace				Pneumatic glove			
										Hand splint			
										Cordless hand massager			
	Mobility					Wheelchair (seat elevation, tilt)				Eye-gaze control			
Love & Belonging	Virtual support	Online webinars				Community				Video monitoring			
	Genetic counselling	Research											
	Intimacy	Information guides				Devices				Positioning aids			
Esteem	Communication	Voice banking/preservation				AAC devices				BCI			
						Closed captions (speech to text)							
	Control	Voice activated interaction											
	Leisure	Gaming				Head mounted mice				Eye-gaze			
						Joystick (adaptive)				Switch controls			
	Entertainment	TV/radio remote control											
Self-Actualisation	Personal growth					VR app							
	Hobbies/interests	Learning				Online				Community (sharing)			
Cognitive	Learning	Generative AI											
	Virtual reality									Augmented reality travel and exploration			
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	Skincare					Adaptive make-up aids				Adaptive clothing
	Hygiene					Equipment - shower chair, bidet				Toilet support rails
	Rest					Automated recliner				Adaptive bed mattress (positionin...
	Respiratory	Fan				Non-invasive ventilation				
Safety	Telehealth	Video calls				E-health apps				Web-based home monitoring
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		Thermostat								
		Plug (lights, curtains, doors etc)								
	Wearables					Smartwatch				Fall alarm
	Info access	Research on trials				Mobility				Travelling guidance
						Bathroom & hygiene				
						Dressing				
	Support (physical)					Ankle support brace				Pneumatic glove
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	Genetic counselling	Research								
	Intimacy	Information guides				Devices				Positioning aids
Esteem	Communication	Voice banking/preservation				AAC devices				BCI
	Control	Voice activated interaction								
	Leisure	Gaming				Head mounted mice				Eye-gaze

Summary & Next Steps

Goal

- Shape our vision and strategy to support PALS & CALS, and our broader community

Learnings

- Human-driven design approach in the context of an ecosystem

- Value of diverse and global perspectives

Call to Action

- Participate in member's RoundTable (February 2025)

- Familiarise yourselves with the pre-read content!

- Contribute to shaping our collective future…

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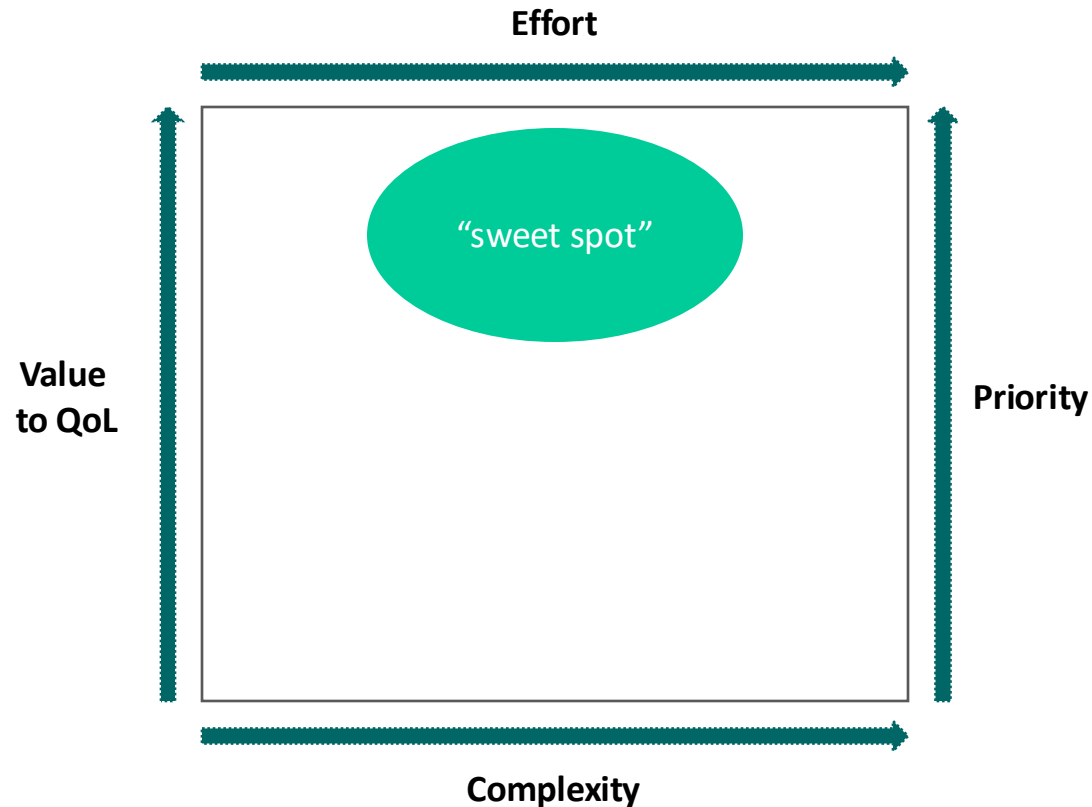
The following criteria have been applied to determine the areas of focus for the Alliance regarding its innovation and technology strategy:

- It must reflect the unique position the Alliance has as an organisation 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.

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
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	• Build new capabilities • Share and disseminate to other domains and sectors
Enhancing Quality of Life through Personal Insight	• Co-design workshops and reviews • Establish industry and academia partnerships • Develop interaction model		

CONSIDERATIONS

Human-centric
Global
Transparency
Accessibility

UNDERSTANDING ALS/MND

MEMBER ORGANIZATIONS

COLLABORATORS

GETTING INVOLVED

LIVING WITH ALS/MND

RESEARCHERS

HEALTHCARE PROFESSIONALS

TREATING ALS/MND

OUTCOMES

Quality of life
Health literacy
Collaboration
Community
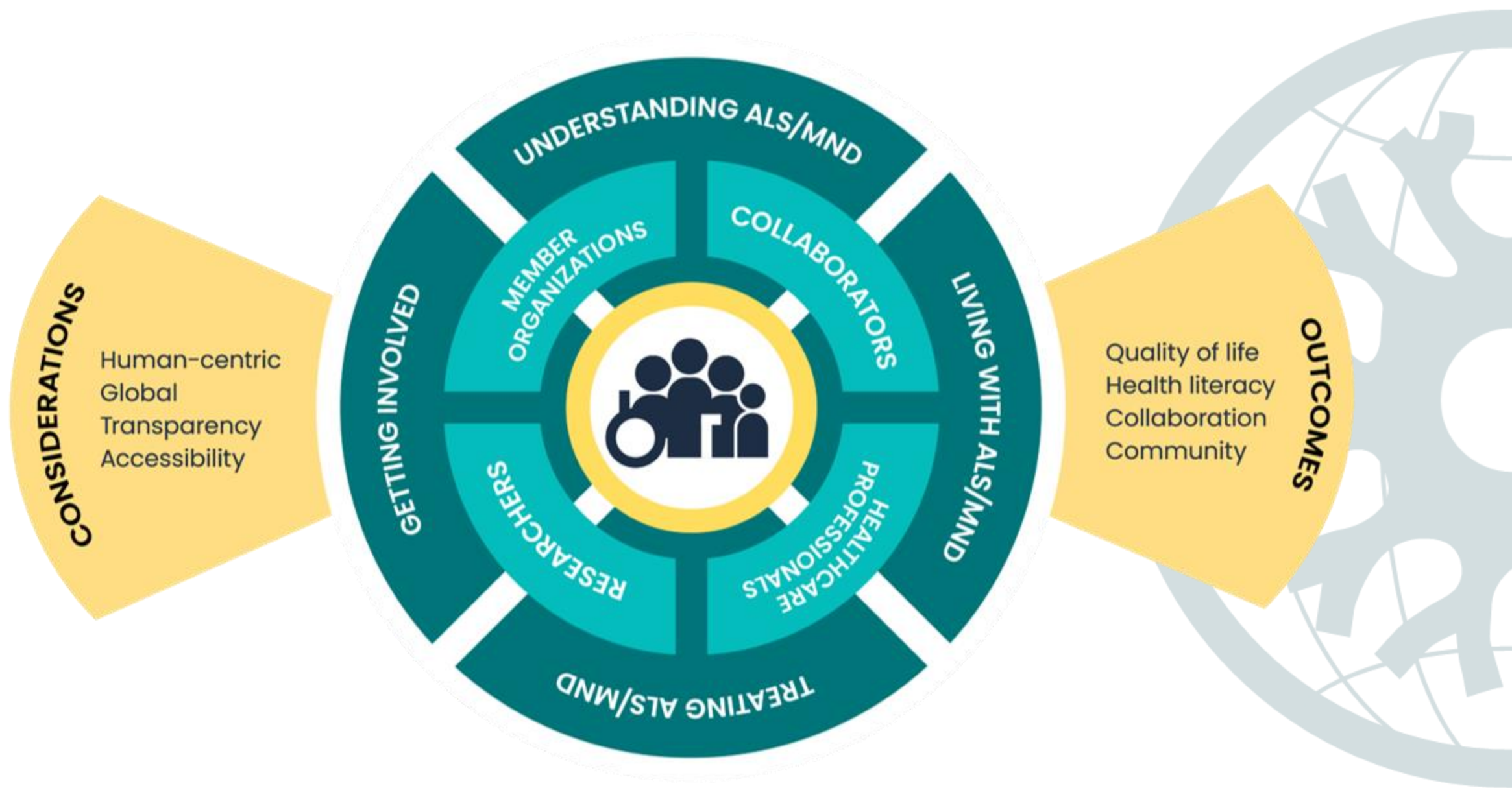
Mapping PNM to the Knowledge Map
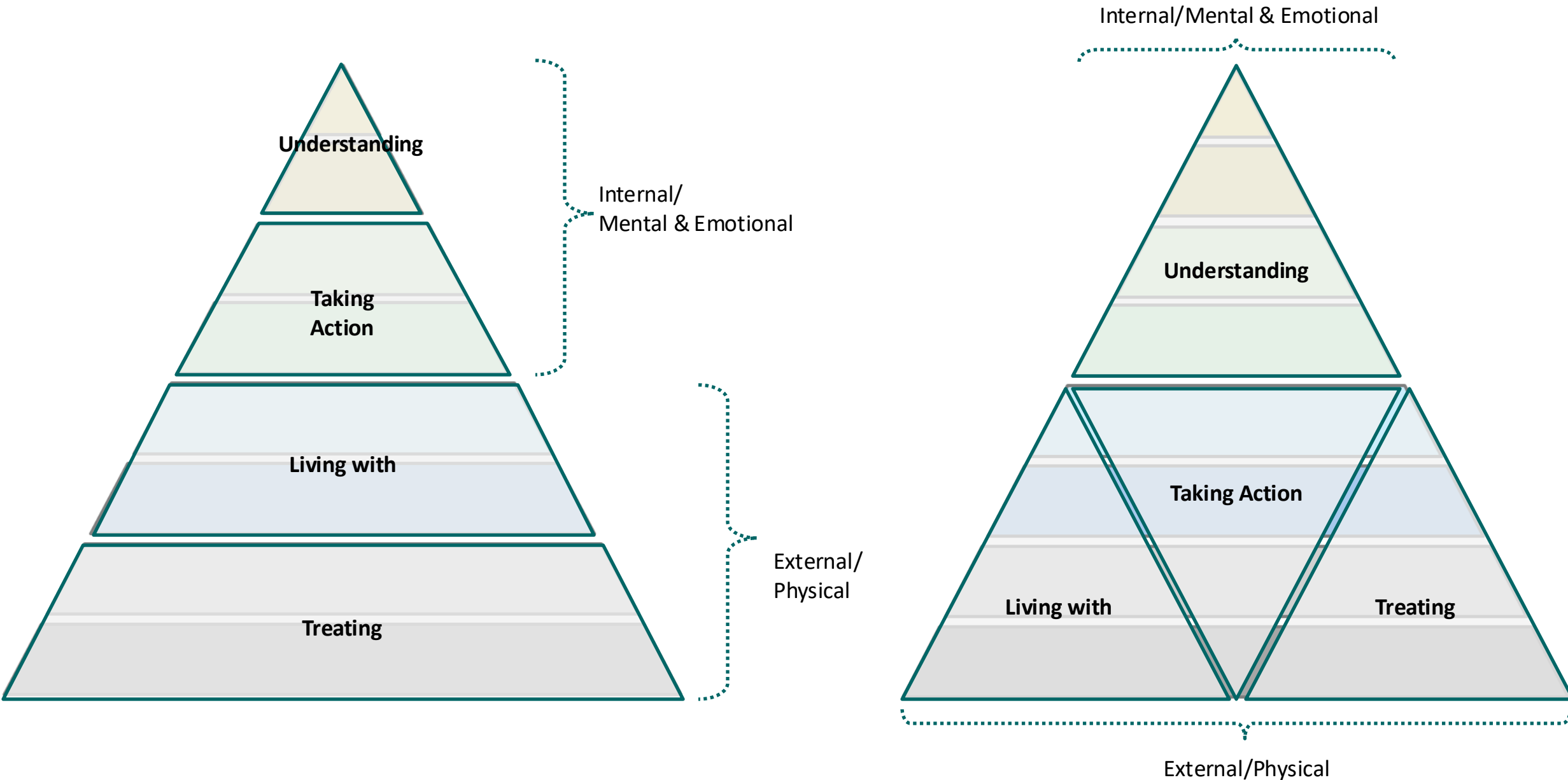
Mapping PNM to the Knowledge Map
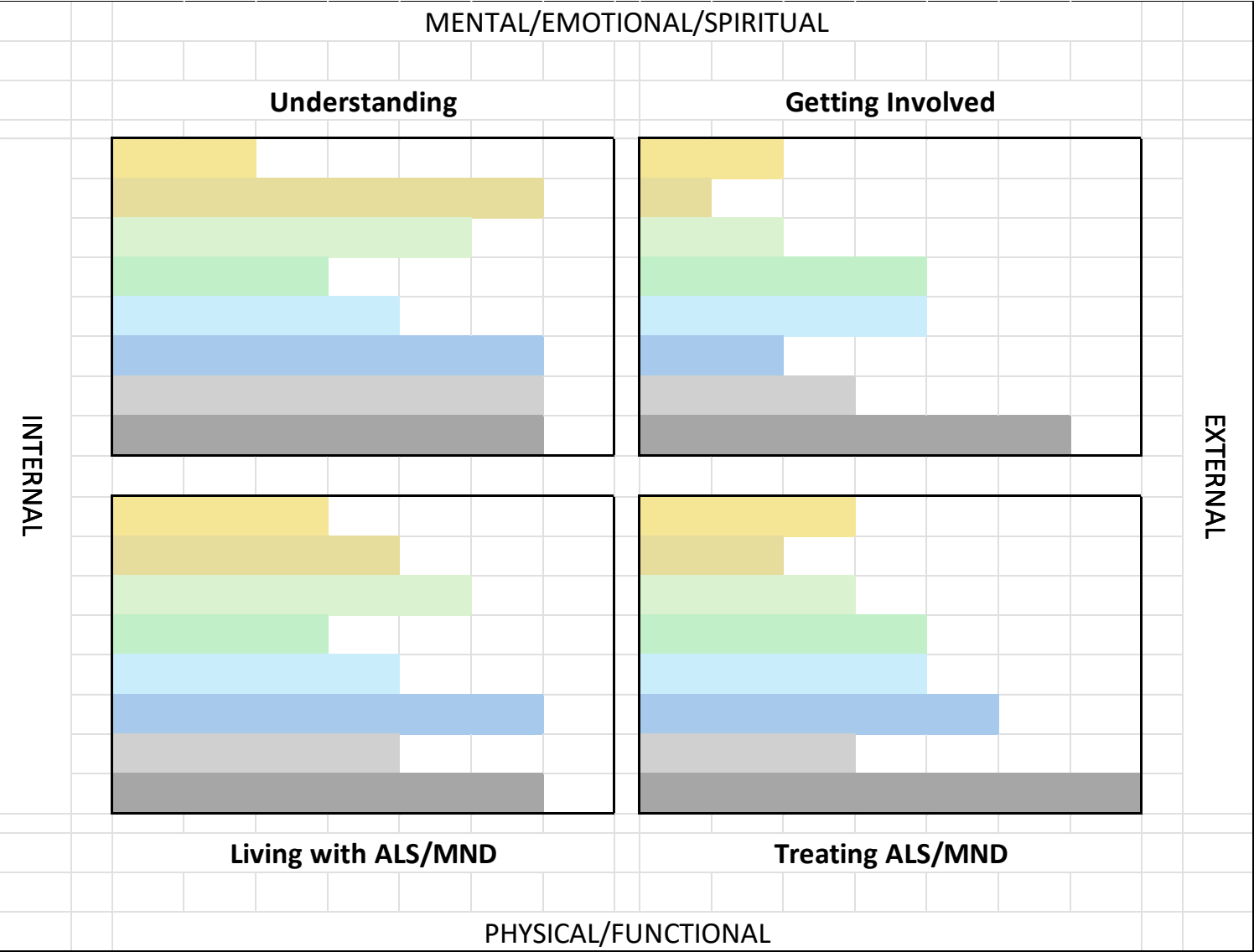
Process for Enhancing QoL through Personal Insight

PALS/CALS			NEEDS MATRIX LENS	MASLOW'S MODEL
Understanding ALS/MND				
What is ALS/MND?	Characteristics of the disease	Types	Access to information and ability to locate it quickly and easily	Transcendence
		Symptoms	via a range of modes e.g. type, voice, eye-gaze, switch etc.	Aesthetic
		Statistics	across a range of devices	Cognitive
		Risk factors	regardless of infrastructure	Self-actualisation
		Cognitive and behavioural changes		Esteem
				Love & Belonging
	Genetics	Hereditary ALS/MND	Make available the list of actions possible	Safety
		Genetic causes and risks of ALS/MND	Point to resources at 'right time' for each person	Physiological
	Glossary	Key terms and acronyms in ALS/MND		
Diagnosis	What to expect	Diagnosis	Clearly set expectations re what happens next and when…	
		Prognosis		
		Progression		
Navigating the community	Find a…	Association/organization	Avoid overwhelm by too much information	
		Clinic	Global clinic locator	
		Clinical trial	Scope, availability, eligibility, stipulations	
		Support Group	Local, regional	
		ALS/MND Event	Information, awareness, registration, subscriptions	
Living with ALS/MND				
Planning	Legal	Advance care directives	Ensure 'wishes' documentation is in place	
			Process of engaging with identified persons	
		End of life considerations	Expand to include where, how, environment, who else is present	
		Estates	Services will vary from country to country	
		Wills	Provide relevant checklist	
		Power of attorney		
		Confidentiality & privacy		
	Financial	Employment	Services will vary from country to country	
			Provide relevant checklist	
		Finances	Tools, hints, tips to complete	
			Community - learning from others	
		Insurance		
		Benefits		
	Life	Care	Relationship, role they play, access they have…	
			Role they play, access they have	
			Info on what is available, and eligibility	
			Role they play, access they have	
			Location (home, care-home, care facility, hospice…)	
		Caregivers	Access to information, resources, and support	
			Balancing with other commitments e.g., work	
			Emotional and physical impact assessment	
		Emergency preparedness	Access to information and resources kit	
		Getting around	Guidelines for travel mode	
			Physical mobility needs	
			Based on individual mobility	
		Equipment and technology	Digital and analog	
			Management and maintenance	
			Medical devices and COTS products, e.g., fall monitors	
			Hardware, software, services	
		Communicating about ALS/MND	Community - levels of access and trust ('different circles')	
			Guidance	
			Shared stories	
	Genetic counselling and testing	Why/why not get genetic testing	Family history, availability	
		Diagnostic testing		
		Predictive testing		
		Accessibility		
Physical Health	Physiological functions	Muscles, mobility, and exercise	Off the shelf braces, splints, massagers	
			Wearables (smartwatch)	

1. Each of the 4 main themes of the Knowledge Map and its subsequent breakdown into categories and specific items within them presented the opportunity to review each line item against where it belonged in Maslow's model
2. The colour-coding provides an at-a-glance view of which category or categories are represented in the map
3. This helps identify the prevalent areas of concern from a patient perspective and what care and services are important from a provider perspective
4. It also helps identify gaps in the map e.g., travelling with ALS
5. Significantly, each of the singular items and their categorisation with the Needs Matrix, can be queried at an individual item to help establish where each person is according to the map, but also where they are on their individual journey…
6. …opening up the opportunity to the different ways and areas where QoL can be improved or enhanced…

Mapping Knowledge Map to the patient journey *(life-course)*
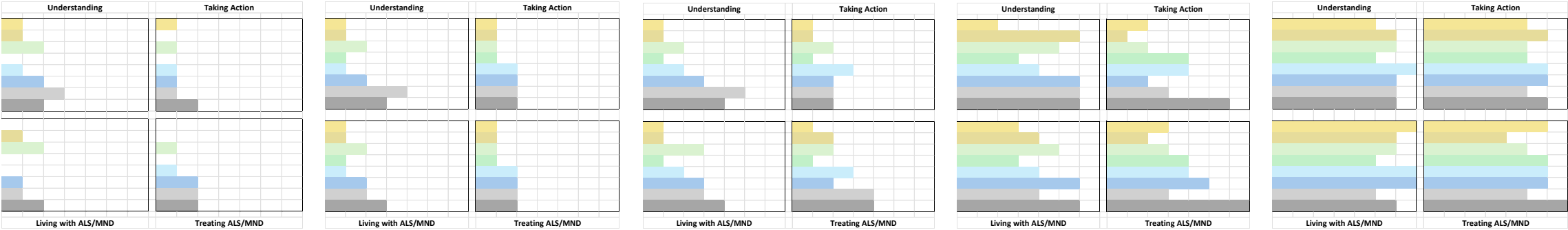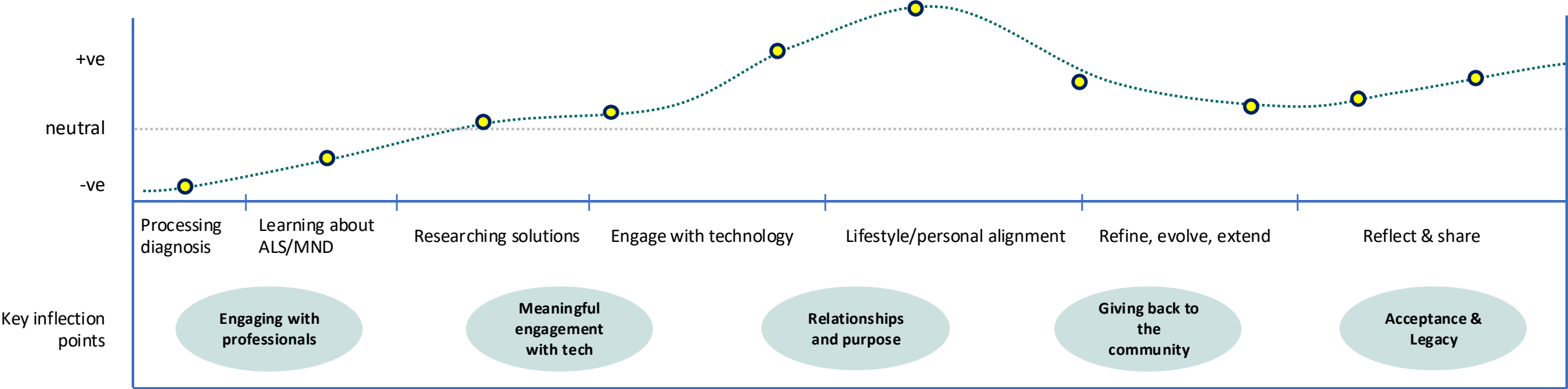
Process flow for system design

Premise

The relevant themes of the Health Literacy Map (HLM) and its breakdown into categories and specific items present the opportunity to review each line item against where it belongs in Maslow's framework.

The colour-coding provides a view of which category an item belongs to and an at-a-glance view of a whole area in the HLM.

Each of the single items and their categorisation with the Patient Needs Matrix, can be queried at an individual level to help establish where each person is on their individual journey…

Opening up the opportunity, through the AI assistant, to explore the different ways that particular areas can be improved to enhance Quality of Life

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Develop a prompt catalogue using an LLM for rows 25-63 (as a starting point) based on the
information in the HLM
          ↓
List out the questions that are generated from the individual prompts for each row
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Use the data to collect data from the ALS/MND community (survey, form)
          ↓
This will help establish a base dataset (which can be used to create synthetic data) and
against which we can develop appropriate Machine Learning models to design the 'AI
Assistant' to make suggestions etc, based on the unique profile of each user
          ↓
For refining the AI Assistant, in an iterative manner, incorporate Reinforcement Learning
(RL) and Retrieval Augmented Generation (RAG) approaches to improve and train the AI
Assistant's interactions
          ↓
From the generated data and insights, produce personalised dashboards visualising the
'life course' for each person (helping identify the prevalent areas of concern from a
PALS/CALS perspective and what care and services are important from a provider
perspective)
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