

INTRODUCTION: ALS/MND HEALTH LITERACY MAP

A framework for health literacy and improving quality of life for people living with ALS/MND (PALS) and their communities (CALs)

This ALS/MND health literacy map covers the many topics that an individual and their loved ones need to know when they are faced with an ALS/MND diagnosis. This community is at the centre of our initiatives, and we aim to empower them to make informed decisions that impact their health and quality of life. The framework covers the continuum of subject areas that are important for understanding the disease, living with it, treating it, and taking action. It is a broad yet inclusive initiative which showcases the inter-dependence of the players in our ecosystem including PALS and CALs, Alliance members, health care professionals, researchers, industry, and all the various other collaborators we work with.

Health literacy refers to the ability to obtain, understand, and use health information and services to make informed decisions about one's health and well-being. It helps individuals and their loved ones to manage their health, participate in healthcare decisions, and advocate for their needs. The Alliance plans to take steps to ensure information is accessible, easy to consume and understand, and can be available in various languages for any stage of the disease. This project will inform the Alliance's operations, website, educational delivery, and it will be a guide for us to understand where the opportunity gaps exist so that we strive to provide necessary resources to people globally.

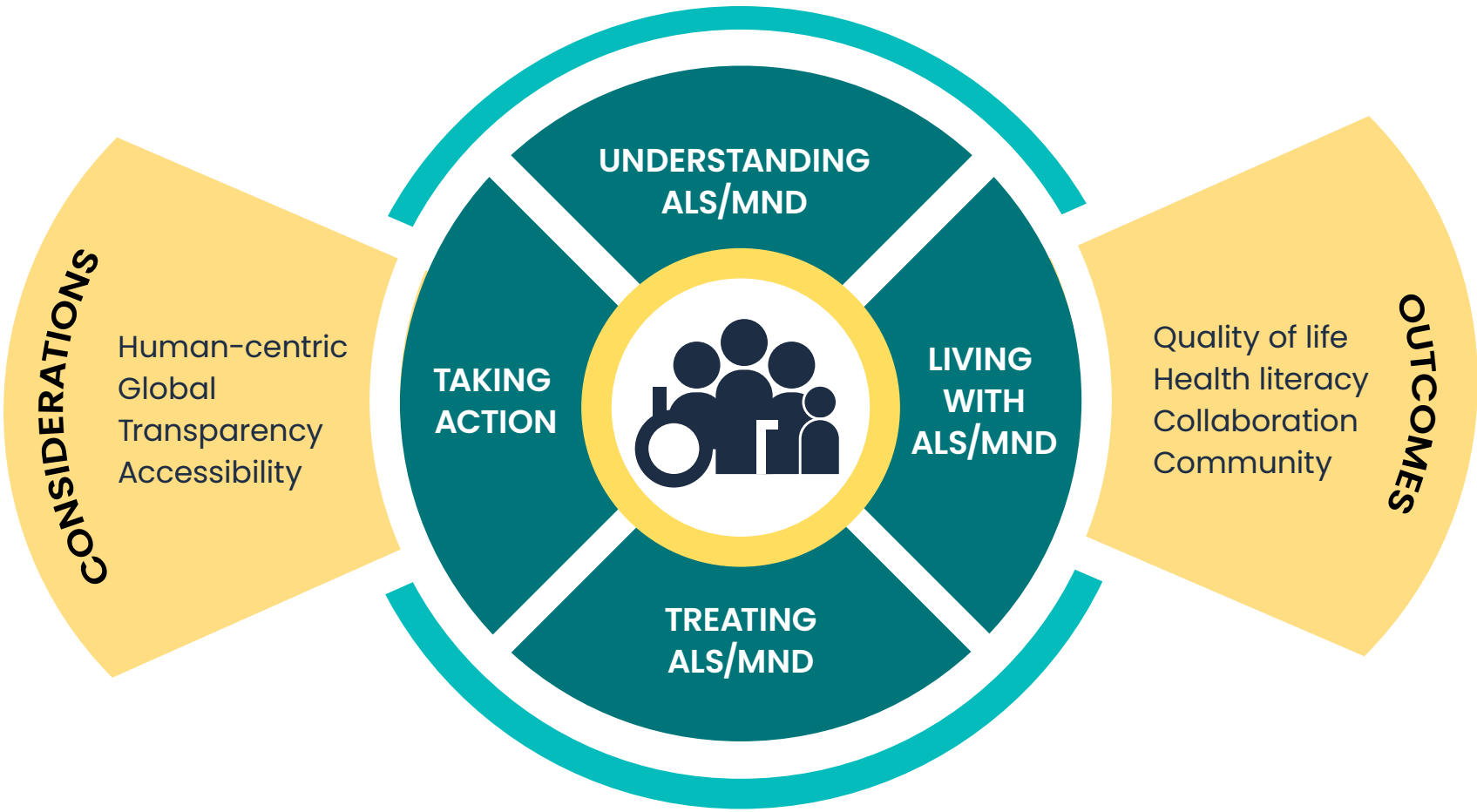
We hope this will be a useful tool for all in our community, and we look forward to updating the framework as we work toward a world free of ALS/MND.

For more information about the Alliance, please visit: als-mnd.org.

THE MAP



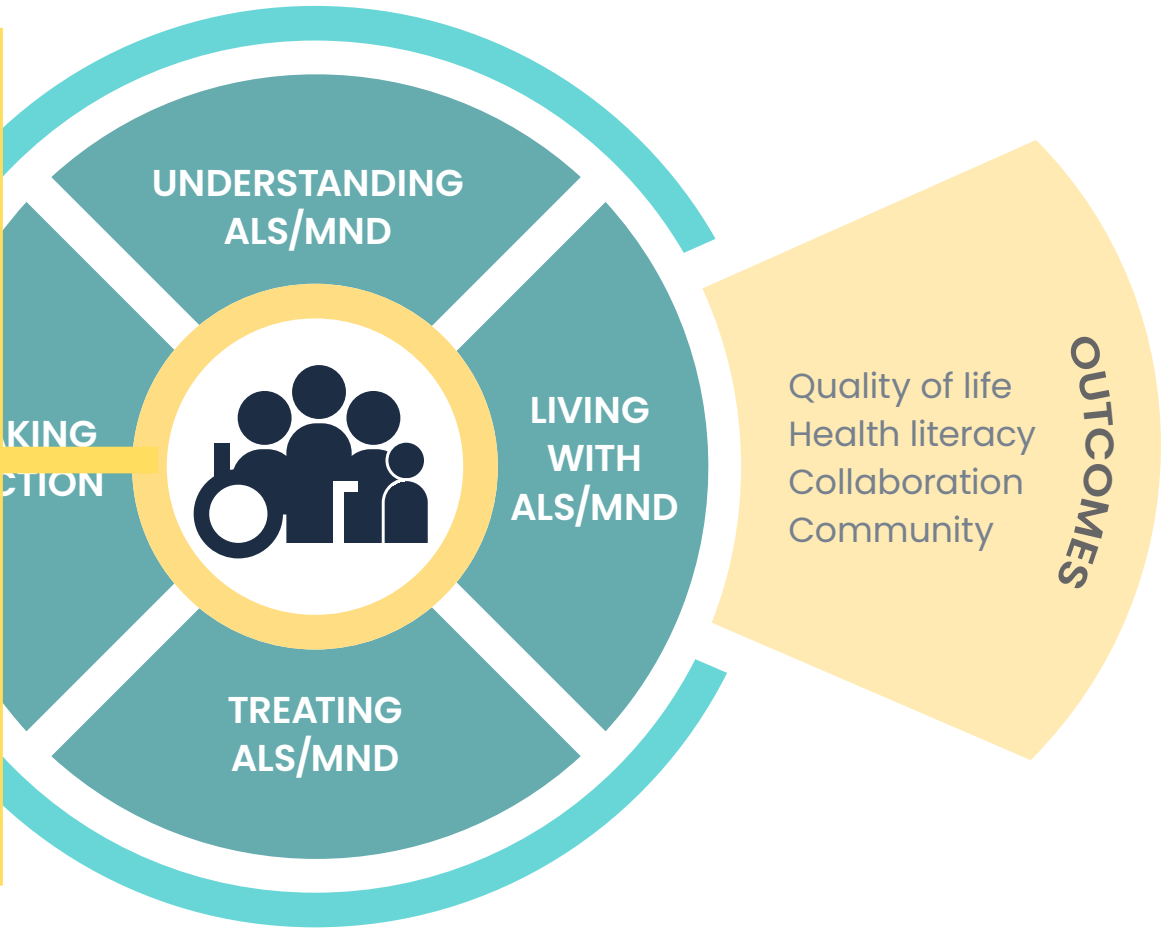
ALS/MND HEALTH LITERACY MAP



ALS/MND HEALTH LITERACY MAP: PALS/CALS

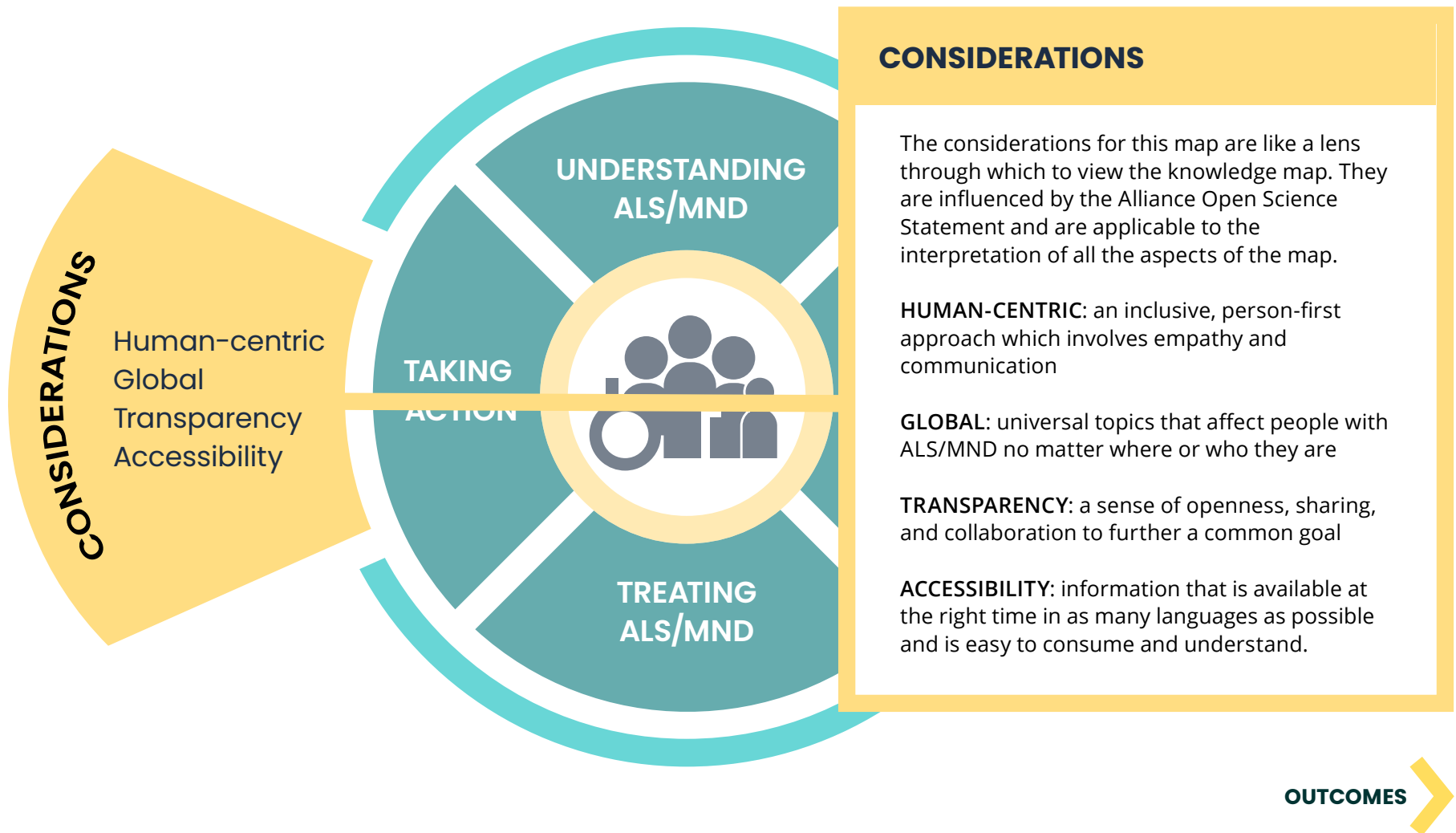
PALS/CALS

People living with ALS/MND (PALS) and the communities of people living with ALS/MND (CALS) are intentionally mentioned together and at the centre of all Alliance initiatives, including this knowledge map, as they inform us with the unique perspective of lived experience. We are purposely expanding the CALS terminology, from caregivers of people living with ALS/MND to communities of people living with ALS/MND, to include a broader array of impacted friends and family members who may or may not be caregivers. When a person is diagnosed with ALS/MND, their whole community is unequivocally impacted as well.



CONSIDERATIONS

ALS/MND HEALTH LITERACY MAP: CONSIDERATIONS



ALS/MND HEALTH LITERACY MAP: OUTCOMES

OUTCOMES

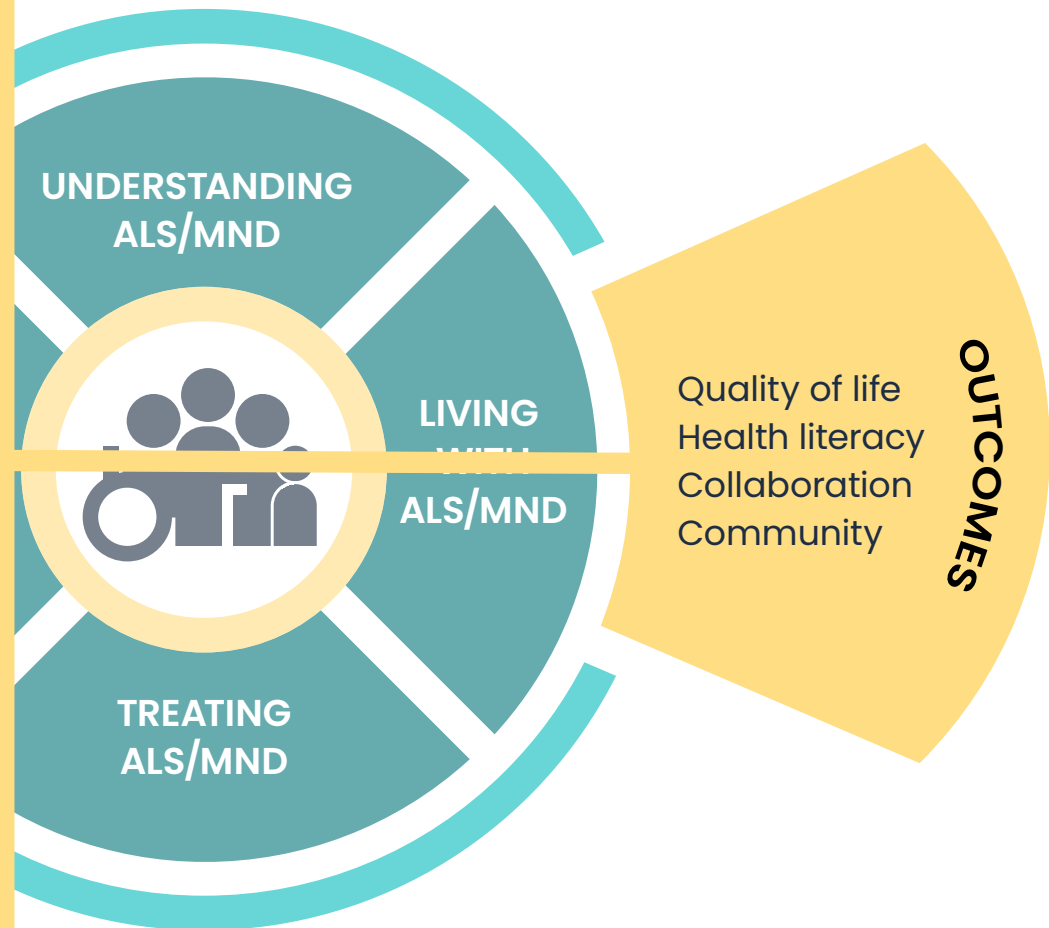
The outcomes of the knowledge map include the consequences that our ecosystem will gain from access to information, resources, education, services, legacies, events on the various map topics.

Health literacy: empowering PALS and CALS so they can learn and make health-related decisions to optimize their quality of life.

Quality of life: creating and maintaining the highest standard possible of a broad number of areas that enrich the human experience for PALS and CALS while living with ALS/MND.

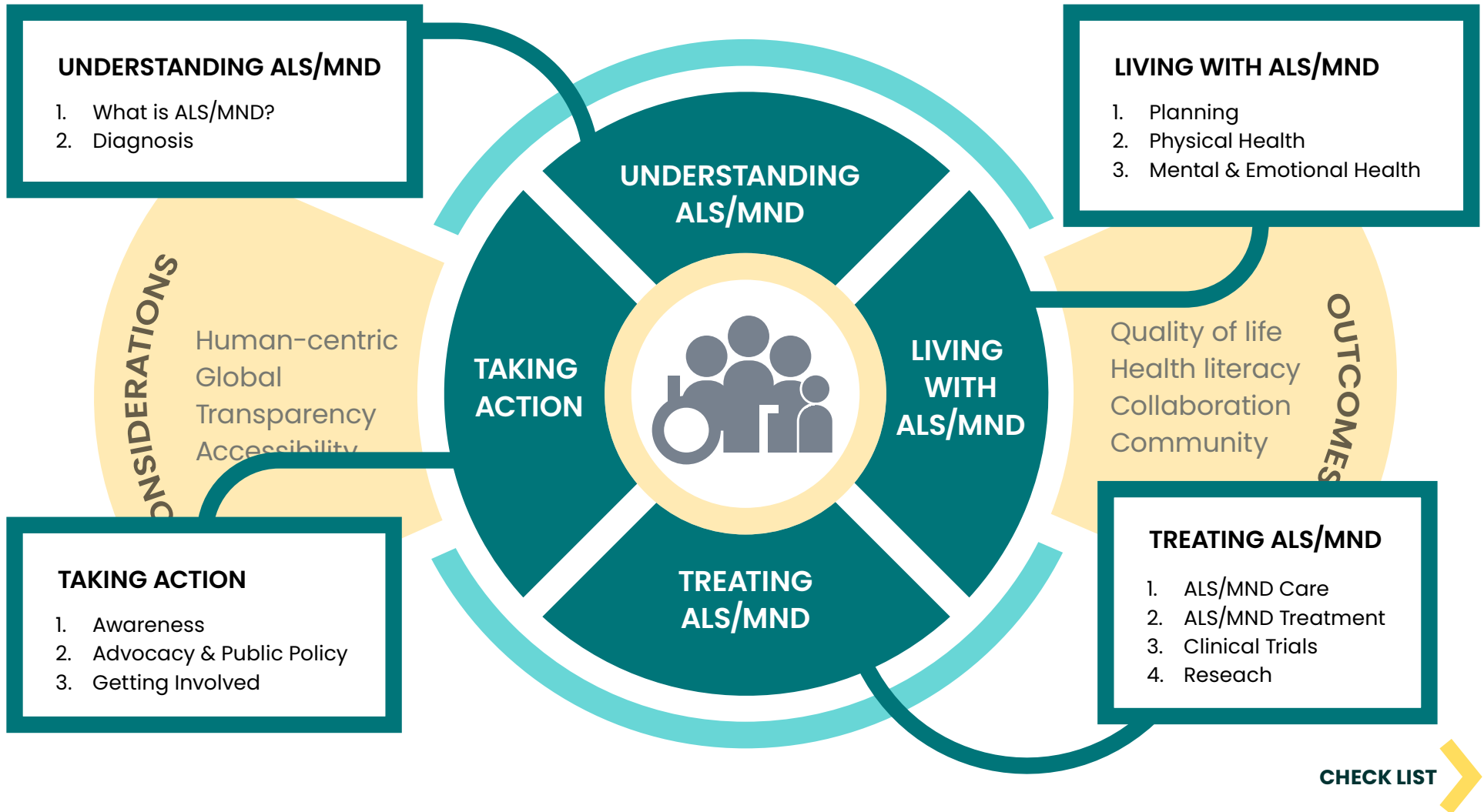
Collaboration: sharing of information, resources, and education materials to increase access to help one another and avoid duplication.

Community: fostering the sense of belonging that comes with being part of a group, support, and benevolence that tie us together.



OVERVIEW 

ALS/MND HEALTH LITERACY MAP: TOPIC OVERVIEW



ALS/MND HEALTH LITERACY MAP: AT A GLANCE

UNDERSTANDING ALS/MND

WHAT IS ALS/MND?

Characteristics of the disease

- Types
- Symptoms
- Statistics
- Risk factors
- Cognitive and behavioural changes

Genetics

- Hereditary ALS/MND
- Genetic causes and risks of ALS/MND

Glossary

- Key terms and acronyms in ALS/MND

DIAGNOSIS

What to expect

- Diagnosis
- Prognosis
- Progression

Navigating the community

- Association/organization
- Clinic
- Clinical trial
- Support Group
- ALS/MND Event

LIVING WITH ALS/MND

PLANNING

Legal

- Advance care directives
- End of life considerations
- Estates
- Wills
- Power of attorney
- Confidentiality & privacy

Financial

- Employment
- Insurance
- Finances
- Benefits

Life

- Care
- Caregivers
- Emergency preparedness
- Getting around
- Equipment and technology
- Communicating about ALS/MND

Genetic counselling and testing

- Why/why not get genetic testing
- Diagnostic testing
- Predictive testing
- Accessibility

PHYSICAL HEALTH

Physiological functions

- Muscles, mobility, and exercise
- Nutrition
- Saliva and swallowing
- Breathing
- Fatigue and sleep

Speech and communication

- Voice preservation
- Augmentative Alternative Communication
- Low-tech communication tools

Daily Living

- Hygiene
- Activities

MENTAL & EMOTIONAL HEALTH

Counselling

- Family and relationships counselling
- Mental health counselling

Support

- Social support
- Bereavement support
- Peer support
- Cognition

Quality of life

- Entertainment
- Intimacy
- Spirituality
- Self-care



TREATING ALS/MND

ALS/MND CARE

Multidisciplinary care

- Clinicians and allied health professionals
- Telemedicine
- Symptom management
- Palliative care
- Hospice care

ALS/MND TREATMENT

Drugs and pharmacology

- Approved medication/drugs
- Drugs in development
- Symptom treatments

Complementary treatments

- Wholistic therapies
- Unproven/off label treatments

CLINICAL TRIALS

Interventional trials

- Safety and tolerability
- Efficacy

Observational trials

- Longitudinal/cohort studies

RESEARCH

Clinical management of ALS/MND

- Innovation in ALS/MND management

Clinical understanding of ALS/MND

- Patient registries

Laboratory research and pre-clinical studies

- Genetics and genomics
- Biomarkers
- Pre-clinical research
- Technology
- Epidemiology

Social sciences

- Human behaviour, relationships, and interaction within ALS/MND

TAKING ACTION

AWARENESS

Global recognition of ALS/MND

- Global strategies
- Regional health systems
- National health systems
- Neurology community

ADVOCACY & PUBLIC POLICY

Equitable access

- PALS/CALS fundamental rights
- Blood relatives
- Inclusion of under-represented

GETTING INVOLVED

Fundraising

Governance

Campaign

Events



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