**Photovoice impact on communication and social participation for improved
quality of life in Motor Neurone Disease**

Submitted by Nicole Jackson

Bachelor of Applied Science (Speech Pathology), La Trobe University,
Melbourne
Advanced Diploma of Photography, Photography Studies College,
Melbourne

Supervisors: Dr. Bruce Rumbold and Dr. Peter Higgs

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College of Science, Health and Engineering Health Sciences
La Trobe University
Bundoora, Victoria, 3086
Australia

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Declaration

Except where reference is made in the body of the thesis, this submission contains no material published elsewhere. No other person's work has been used without due acknowledgement. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution

All research procedures reported in this thesis were approved by the Research and Ethics Committee at Calvary Health Care Bethlehem and by the Faculty of Health Sciences Ethical Review Committee at La Trobe University.

Signed

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	Acronyms and Abbreviations
CHCB	Calvary Health Care Bethlehem, Melbourne Victoria
PAR	Participatory Action Research
ALS	Amyotrophic Lateral Sclerosis (US term, synonymous with MND)
MND	Motor Neurone Disease
pwMND	Person with Motor Neurone Disease
NDIS	National Disability Insurance Scheme (Federal government funding)
MNDA	Motor Neurone Disease Australia – peak body
QOL	Quality of Life
WHO	World Health Organisation
SDH	Social determinants of health
CALD	Culturally and Linguistically diverse
NICE	National Institute for Health and Care Excellence (UK)
TTS	Text to speech (converting text to voice output on a device)
APP	Application (downloaded by a user to a mobile device)
MMS	Multimedia Messaging Service (mobile device message can include text, photos and videos)
SMS	Short messaging Service (mobile device text based message)

ABSTRACT

Background

Motor Neurone Disease is terminal and causes life-changing speech impairment or complete loss of speech in up to 93% of sufferers. Alternative and augmentative communication methods, including non-verbal methods, use of communication equipment, social media and photo-sharing, are crucial to maintaining social participation and quality of life. Photovoice is a participatory research tool that privileges patient voice for advancing health. An understanding of the lived experience and the impact that photovoice methodology can have on communication and social participation is crucial for preventing social isolation and for providing meaningful patient centred care. Due to the communication impairment itself, the voices of people living with MND are often not heard in the realm of service planning, service delivery or policy change.

Objective

The objective of this research is to investigate how an action research approach using photovoice can improve the quality of life for families living with MND.

Methods

A mixed methods design was employed which was predominantly qualitative in nature using a participatory action research methodology known as photovoice. A quantitative tool measuring of quality of life, WHOQOL- BREF, was also utilised.

Nine people with communication impairment due to MND and their primary caregivers, were recruited from Calvary Health Care Bethlehem. The seventeen participants were assigned to one of three groups involving delivery of a 4-week photovoice communication program, using a protocol previously pilot-tested and evaluated at CHCB. Data collection included photos, written photo narratives and focus group discussions. A thematic analysis was conducted following a framework devised by Braun and Clarke.

Results

Three hundred and twelve photographic outputs were shared, forming the basis of critical discussions surrounding group assets and issues. Five themes were derived including: 1. identity and self-care, 2. communication and connection, 3. networks of support for wellbeing, 4. maintaining social participation and 5. taking action. Participant driven

actions provided evidence of significant individual and collective change. 100% of participants responded that the photovoice process and outcomes improved their quality of life. Results of the WHOQOL-BREF questionnaire were insensitive to the impact on quality of life observed.

Conclusion

Photovoice is a powerful communication tool and change agent for families living with MND. Through the process of sharing photos, discussing assets and issues, reflecting and taking individual or collective action, participant-driven actions resulted in personal and organisational changes that improved the quality of life for people living with MND and their families.

Chapter 1: Introduction

Population under study

Calvary Healthcare Bethlehem (CHCB) is a state-wide provider and national leader in the provision of care for people with progressive neurological diseases (PNDs). CHCB is a Level 5 service under the Victorian Sub-Acute Planning Guidelines, providing specialist inpatient and outpatient assessment, care and management for people with PNDs. The majority of the caseload managed at CHCB has a diagnosis of Motor Neurone Disease (MND), a neurological disease in which the nerve cells (motor neurones) that control voluntary muscle movement progressively weaken and die. With no nerves to activate them, the muscles of speech, swallowing, movement and breathing become paralysed.

Epidemiology and burden of MND

Of the 2000 Australians living with MND, half of those are aged under 65 with an average life expectancy of 2.5 years (https://www.mndaust.asn.au). There is no cure, no remissions and progression is usually rapid, creating high levels of disability and consequent demand for a wide range of supports and services. A recent systematic review of bulbar-onset MND highlighted the devastating nature of this variant, which is characterised by the fastest decline, the shortest survival (<2 years from diagnosis) and significantly reduced quality of life (Shelilkeri et al. 2017). Speech and swallowing impairment are the most common bulbar symptoms. Dysarthria (impaired motor speech) is commonly reported to occur in more than 80% of people with MND (Tomik and Guiloff, 2010), however the incidence of dysarthria is reported to be as high as 93% (Chen et al. 2005, Kuhlein et al.2008). Anarthria (total speech loss) can occur after only a few months in bulbar-onset MND, causing major disability. In addition to the rapid motor speech decline, a significant proportion of people with MND present with an increased burden of cognitive and/or social language impairment. (Fisher et al. 2016) There is much research that that shows effective communication, having a voice, is one of the key social determinants of health (SDH), a position strongly supported by the World Health Organisation and the International Communication Project (ICP), which states "Communication is the most fundamental of human capacities" (para. 1), highlighting the importance of human communication and how communication disabilities significantly impact every aspect of life including "social, educational, emotional and vocational potential" (https://internationalcommunicationproject.com).

The burden of disease progression and high care needs in MND can result in a loss of communication complexity and richness. This combination of challenges contributes to social isolation with people being marginalised not only within their broader community but also within their friendship and family networks (Chio et al. 2004, Sakellariou, 2013).

The loss of speech and ability to communicate is an enormous barrier to social participation in life, and research highlights that next of kin share the burden of communication impairment (Olsson et al. 2010). Hobson et al. (2017) surveyed people with MND and their family/friends and discovered that provision of alternative and augmentative communication (AAC) equipment does not always reduce the burden of communication impairment as there are many barriers to functional equipment use, including physical access, poor digital literacy, as well as economic and psychosocial barriers.

The exploration of barriers and facilitators to communication as well as the involvement of primary caregivers in this process is therefore a vital step towards improving quality of life, and as such has been prioritised by CHCB and recommended by peak bodies such as MND Australia and in the widely used comprehensive MND guidelines published by the National Institute for Health and Care Excellence (NICE) in 2016.

Research Questions
- How does communication impairment impact on quality of life?
- What are the facilitators and barriers to communication and social participation for families living with MND?
- How does 'photovoice' impact communication to support ongoing social participation and positively impact quality of life?

Research aim
The research aims to improve quality of life for people living with MND, and their carers. This will occur through taking and sharing photos to elicit critical discussion, build individual and community strengths, engage in community capacity building and implement actions for change.

Whose voice?

This research will privilege participant voice, the voice of pwMND and their caregivers. The research is designed to equalise participant-research power relations and ethically advance participant voice beyond awareness raising in order to achieve concrete change.

The impact of the research

Action research is a process that can shape individual as well as organisational change, which is critical for marginalised or vulnerable groups.

This research will raise awareness and impact on healthcare practice due to improved understanding of the lived experience and the MND population's assets and issues.

- Personal/individual change –individual empowerment and capacity building to improve communication skills promoting improved quality of life through expanded social networks, development of new peer networks and ongoing social participation in life.

- Community change – Building social capital and improving the health of the MND community through enhanced community involvement in action and advocacy.

- Organisational change – Provides rich and meaningful data for quality improvement and service development such as building a model of care focused on person-centred healthcare.

This research project is aligned with:

- CHCB Strategic Plan
- CHCB Consumer Engagement Framework (2018 – 2021)
- The International Communication Project
- Motor Neurone Disease Australia, Action Framework 2018
- Victorian Public Health and Wellbeing plan 2019-2023 (https://www2.health.vic.gov.au/about/health-strategies/public-health-wellbeing-plan)

Chapter 2: Literature Review

There is a continued focus on biomedical and clinical research which aim to develop new pharmacological treatments, characterise genomic structures or measure physical deficits, however the evidence about how people live well with health limiting diseases, which are often chronic in nature and an economic burden to the modern day health system, is poorly publicised and poorly understood (Davies 2016, Fancourt & Finn, 2019).

Trends in healthcare have seen the emergence of creative participatory approaches to improving health, coinciding with a global shift to patient centred healthcare (Papoulias, 2017). 'Arts in Health' refers "to the practice of applying creative, participatory or receptive art interventions to health problems and health promotion settings to create health and wellbeing across the spectrum of health practice from primary prevention through to tertiary treatment" (National Arts and Health Framework, 2013, p. 6). There is a wealth of literature summarising evidence for use of the arts in health, which has been utilised to inform policy development and attract funding support (Fenner et al. 2012).

The real impetus for change however, came from a large scale Arts, Health and Wellbeing Inquiry, commenced in 2014 by United Kingdom's All Party Parliamentary Group (APPG), culminating in the release of the 2017 report, Creative Health: Arts for Health and Wellbeing, which comprehensively summarises two years of research and evidence gathering. The report outlines a series of suggestions aimed at improving practice, research and funding, and has been a catalyst for the potential of the arts in health to be realised with policy recommendations targeted to all levels of government, health and wellbeing boards, healthcare services, arts organisations and the voluntary and community sector in health and social care (APPG, 2017).

Once criticised as lacking academic rigour and visibility (Raw et al. 2012), the arts in health field has since gained momentum. Davies (2016) describes how standardised terminology has been adopted, national frameworks developed, and objectives and practices aligned with international health policies surrounding person-centred care with consideration to holistic health, quality of life and the social determinants of health. "There is clear empirical evidence that arts and health is a health-promoting endeavour for all members of society" (National Arts and Health Framework, 2013, pg. 2). Arts in

Health based approaches have consequently become more accepted in the health sector as evidence-based practice. More rigorous research methods are also being utilised, along with the more recent emergence of qualitative studies sitting alongside randomised controlled trials (RCT's), a practice which can assist the process of "changing professional practice or the organisation of care" (Lewin et al. 2009). In response, government initiatives such as the National Alliance for arts health and wellbeing in the UK, and the Australian National Arts and Health framework have bought about policy change and opportunity for healthcare transformation. Large scale health promotion practice at a national level such as UK's NHS 'arts on prescription' programs are further fuelling the uptake of arts in health approaches (Chatterje et al. 2018).

Photovoice is a descriptive qualitative methodology that uses photographs to give voice to people, who often feel unheard and unseen in society and by healthcare providers (Wang et al. 1998). By privileging these voices, photovoice seeks to investigate, disrupt, and ultimately improve structures and practices that often fail to fulfil the needs of diverse populations (Call-Cummings et al. 2018, Latz, 2018). As a research tool, the method fits within the Participatory Action Research (PAR) model with its emphasis on empowerment, participant–researcher collaboration, community capacity building and a focus on action (Catalani & Minkler, 2010, Sitter, 2017).

First described in the mid 1990s the photovoice methodology (Wang and Burris, 1997) was used for sociological purposes. The method is systematic, easily replicable and routinely employed and advocated within the health and psychology fields as its application is well suited to a psychological qualitative method (Brunsden and Goatcher, 2007). The last decade has seen a significant expansion in use and application. It is flexible, economical and has a broad reach and scope, its use ranging from health prevention to health promotion, with application across the lifespan from children to the elderly (Teti et al. 2009). Whilst many visual tools exist, photovoice has particular benefits in enabling communication as it can overcome challenges related to language, literacy and communication impairment (Glegg, 2019).

Hergenrather et al. (2009) and Catalini and Minkler (2010) published comprehensive, well cited evidence reviews outlining the use of Wang and colleagues photovoice methodology in healthcare settings and for public health purposes, concluding that

photovoice is a useful and flexible tool that can empower individuals as well as provide rich qualitative data to improve community health and enhance community engagement in action and advocacy for health promotion. Numerous reviews and applications of photovoice to more specific health fields or disciplines have since been published, including reviews related to nutrition and dietetics research, occupational therapy research (Lal et al. 2012), health and homelessness (Seitz & Strack, 2016), health and physical disability (Dassah et al. 2017), and health and wellness in schools (Overby et al. 2018).

There is also much literature showing evidence of photovoice being used effectively in health prevention (Bisung et al. 2015, Ardrey et al. 2016), and in recent years there is a definite move towards photovoice being used as an intervention, in health and healthcare quality improvement (Balbale et al. 2016), and in the education sectors for addressing social determinants of health in early intervention approaches for marginalised or at risk youth (Call-Cummings et al. 2018).

Methods

Description of type of meta-synthesis undertaken

A descriptive metasynthesis was undertaken to extend knowledge about how photovoice methodology is currently being used in qualitative healthcare research, the nature of health outcomes being realised, the limitations of the methodology and the building of new interpretations. Given the proliferation of arts in health approaches such as photovoice, the metasynthesis will also allow theory building, showing arts in health and associated qualitative research as a turning point contributing to patient centred care.

Criteria for including studies in the review

The retrieved titles and abstracts, and full text if required, were screened to select studies on the basis of meeting the following criteria:

- Studies published in peer-reviewed journals in the English language.
- Studies conducted in the last 5 years (2013 – present).
- The study involved the active participation of adult subjects
- The studies targeted patient centred care with aims focused on health promotion: improving functional health outcomes for individuals, groups of individuals collectively or improvement of healthcare service delivery.

- Subjects under study formed a homogenous group with a defined health disorder or condition.
- The study applied photovoice as a research methodology or used photovoice methodology alongside a randomised control trial to explore deliverer or recipient responses to a photovoice intervention.
- The study utilised photovoice methodology as outlined by Wang and Burris (1997) in its original form or in a modified form.
- Photovoice methodology was a significant part of the study.

Exclusion criteria included:
- Studies not yet published.
- Studies focused on Public health prevention.
- Studies involving participation of children.
- Population health studies involving heterogeneous communities such as the study by Annang et al. (2016) assessing the long-term impact of a disaster on a community's quality of life.
- Studies in which the photovoice methodology was not adequately described or played a minor role in the study.

Search methods and Study selection

The following databases were searched for peer-reviewed health and public health literature: PubMed, Embase, CINAHL, ProQuest and PsycINFO. Initially a broad search was undertaken using the terms photovoice AND health which yielded n=346 (CINAHL), n= 301 (PsycINFO), n=478 PubMed and n=462 (Embase). Search terms were then refined and included photovoice, health, healthcare, public health, health promotion, quality of life, health impact, health behaviour, health outcomes, participatory action research, qualitative and qualitative research. The most relevant research was revealed with the search terms Photovoice, health and quality of life.

The broad search also graphed timelines of study publications, with an exponential rise in photovoice publications over the last 10 years. Search filters were then applied to only include peer-reviewed journals published in the last 5 years, from 2013 – present, to examine current methodology and outcomes.

This narrowed studies to a total of 81: n=17 (CINAHL), n=11 (PsycINFO), n=26 (PubMed) and n=27 (Embase). After removing duplicates, the total was 53 and 9 of these met the inclusion criteria.

Sage and Taylor and Francis online databases were then searched as well as the specific journals of Qualitative Health Research and Health Promotion Practice using the terms Photovoice and health, which revealed a special Photovoice issue in the Journal of Qualitative Health Research (Vol 26, July 2016). These searches provided several relevant commentary and methodological articles and a further 7 relevant qualitative research studies for inclusion.

The Cochrane Library (https://www.cochranelibrary.com) and the US National Library of Medicine Clinical Trials (https://clinicaltrials.gov) databases were also searched specifically for RCT interventions utilising photovoice methodology as part of the study design. Search terms Photovoice AND healthcare revealed only 2 studies, but photovoice AND health yielded 21 studies employing photovoice methodology currently listed on the Cochrane Register of Controlled trials. 12 studies were listed on the Clinical Trials database. After removing duplicated studies, there were a total of 24 studies in various stages of completion. 3 of the studies were completed, published and met the inclusion criteria, and were therefore included in the selected studies, under the category Photovoice interventions.

A total of 19 studies met the inclusion criteria.

A number of relevant photovoice literature reviews (n=7) and doctoral dissertations (n=3) were also discovered through the search process.

Assessment of study quality

As suggested by Meyrick (2006), the two core indicators of quality research are transparency and systemacity. Accordingly, the 19 included studies were assessed in terms of the conceptual approaches embedded and the sampling and methodology described which is vital to consider given its impact on resultant evidence/outcomes.

The studies were grouped into 4 categories with a breakdown of stated purposes, participants, methodology and study outcomes, including whether an action component was involved or not.

1. Health promotion – Exploratory research to improve health / quality of life (n=8)
2. Health promotion - Therapeutic intervention to improve health (n=2)
3. Intervention – Mixed method. Randomised controlled trial (RCT) + Qualitative Analysis of health improvement (n=3)
4. Health services Quality Improvement (QI) (n = 6)

Sampling

Participant groups were predominantly homogeneous (n=16), for example, adult women with polyscystic ovary syndrome (Williams, 2016). Three of the four studies in the Health services QI category were heterogeneous groups, including adults in low SES families, consumers/providers in Veterans Affairs health services and the elderly. Sample size ranged from 10 – 82, with 2 studies forming part of a larger cohort study.

Participants recruited were predominantly patients, but one study recruited patients and caregivers (Wong, 2019) and another patients and health care workers (Balbale, 2016). Flanagan (2016) was the only study to focus solely on primary care providers. Sampling techniques were predominantly purposive quota samples (n=10) although only two studies related sample number to data saturation (Wong 2019, Chew, 2018). Data trustworthiness is considered low for Maratos (2016) and Genoe (2013) as the sample sizes of n= 5 and n= 4 for the more common stroke and dementia populations may be too low to reach data saturation. Most studies achieved equal quotas of male/female although some samples were notably gender specific health conditions (Williams, 2016, Thomas, 2013). Two studies used convenience sampling (Balbale, 2016, Thomas, 2013) which is of a lower quality because of increased risk of bias. Increased risk of sample bias was also evident in the unevenly distributed purposive samples of Beaupin (2018) and Prevo (2018) with 83% and 80% females respectively.

Random sampling was used in the three RCT studies and in Wallace's (2014) study exploring living with chronic pain.

Conceptual frameworks

Excluding the three RCT studies, the qualitative designs described, are predominantly based in grounded theory (Charmaz, 2006), including the constant comparative method, which is highly systematic in its stepped approach to codifying, categorising and identifying themes. Phenomenological studies were also employed, both designs embodying the journey of discovery relating to the lived experience (Smith, 2015). Other studies described content analysis, narrative research design and empowerment theories.

All espoused the principles of patient- centred care.

Methodology

The photovoice methodology referred to in all studies is related to the methodology described by Wang and Burris (1997) which utilises a combination of qualitative methods. The method is grounded in the belief that participants living with an illness or disability are "experts" in their lives and therefore most well positioned to explore and prioritise issues that impact their health and quality of life (Hergenrather et al, 2009). Participants are given cameras to take photos of their lived experience which form the basis of discussion in one on one structured or semi-structured interviews and one or more focus groups to provide rich data. Data collection tools therefore include visual data (photos), written data (photo captions or narration) and verbal data (critical dialogue) which is transcribed verbatim and used for thematic analysis. Different thematic analysis approaches are used, with or without the addition of software designed to assist organisation of the data. An action and advocacy component is the final component of the methodology which includes some type of output designed to influence decision-makers. As Wang and Burris describe, the element of "voice" represents the "**V**oice of **I**ndividual and **C**ommunity **E**xperience", which has the power to achieve social change (Wang & Burris, 1997).

Results

Study characteristics:

All identified articles were published in the last 5 years. Most studies were conducted in the United States (n=12), followed by Canada (n=3), and 1 in each of United Kingdom, Africa, Singapore and Netherlands.

The populations under study are generally marginalised and/or stigmatised groups with health issues that are often chronic in nature and at times 'invisible' such as HIV/AIDS, cancer or mental illness. The impact of these health conditions on quality of life is often poorly understood by health professionals and the wider community and as such are well suited to qualitative research methods such as photovoice to extract rich qualitative data which can address self-identified health needs and foster the conditions in which under-represented or marginalised groups can advocate for themselves (Lal et al. 2016, Kabel et al. 2016). Bates (2018) and Wong (2019) also involved caregivers in the data collection process whilst Flanagan, 2016 employed a photovoice intervention aimed at changing the behaviour of healthcare providers. Study purposes were well defined in all studies and a clear rationale evident.

Study quality - Data Collection and Analysis

The three RCT studies were included as they used photovoice as a data collection tool in their quantitative research, transforming the rich qualitative data into quantitative data which is useful for examining the efficacy of photovoice interventions. As such the data collection related to outcome measures of interest eg. quality of life or stigma scales. Notably many of these are self-report instruments which are acknowledged by the authors as having inherent limitations (Russinova et al. 2014). All other included studies reported data collection use of the photovoice methodology as outlined by Wang and Burris (1997) but many described a modified version (n=8), with variations in frequency and style of sessions. Modifications to data collection are described in Table 1 and included: focus group alternatives – 1:1 interview, reduced face to face contact, use of technology such as email, skype or social media and use of accompanying audio narrative as well as written. In regard to implementing Wang and Burris's advocacy objective, only 47% (n=9) of included studies reported an action component to advocate or promote social change. This is a reduction compared to the finding reported by Catalani and Minkler (2010), who stated "the majority (60%) of projects culminated in action to address issues identified through community documentation and participation" (p. 444).

Thematic analysis was the main analytic method to identify, analyse and report patterns within the data. It is a widely used, flexible tool in qualitative data analysis that establishes systemacity through the use of an explicit framework such as that of Braun and Clarke (2006) or Strauss and Corbin (2008), the latter referring to the process of

analysing data as 'coding'. Data analysis impacts the trustworthiness of findings therefore it is important that the thematic analysis technique employs a series of systematic steps, involving multiple "coders" to reliably identify themes with high levels of agreement. Ideally these themes are cross validated with other professionals to ensure inter-rater reliability, enhance internal validity and reduce potential bias in coding. Use of software to organise and collate thematic data (NVivo and Atlas.ti) was also described in six of the included studies, creating a transparent audit trail.

Of the 16 studies that utilised thematic analysis, 44% (n=7) were transparent in describing their methodology as shown in Table 1. The remaining 56% (n=9) did not adequately describe their methodology, deeming them lower quality as the studies are not replicable and the results not as trustworthy. In true participatory action research, the participants should also be involved in all stages of the research, including thematic analysis. 13 of the studies used three or more people to code themes. Three of the studies reported involvement of the participants in the cross-validation of themes however methods were poorly described, reducing the study quality.

The highest quality studies included Chew & Lopez (2017), whose dual thematic analysis enhanced trustworthiness of findings and LaDonna &Venance (2015) study exploring the experiences of patients living with myotonic dystrophy and also displayed a rigorous, transparent, systematic and replicable methodology. Their detailed descriptions of sampling, recruitment, data collection and analysis allow researchers to assess transferability of study findings and service providers to assess potential for clinical application or service delivery change.

Synthesis of findings

Each thematic analysis yielded a range of 4-7 themes. Many recurring themes were identified from participant photos and narratives. A synthesis of the themes and subthemes from the included studies are listed.

1. Striving for health and wellness – maintain social relationships, diet, physical activity, nature, self-worth, doing chores/work, active learning, accepting life, striving for meaning, spirituality, accepting unpredictability, adapting to change – the "new" normal

2. Health assets – family, social relationships, work, belonging, inclusion, control and choice, self-reliance (family = strongest indicator)

3. Barriers to health – everyday challenges - physical, emotional, attitudes, social exclusion, lack of social connection

4. Emotions– distress, happiness, shock, pain, frustration, fear of the future

5. Dependence / independence – medications, changes in roles, caregiver guilt, burden, feeling useful, empowerment to self-care

6. Supports – family, caregivers, ("courage givers"), pets, online support groups, social exercise, patient centred health care, timely access,

7. Needs – Support people, sense of belonging, resources, tangible results

8. Social determinants of health – social connections, lifestyle factors, feeling safe, accessibility, financial security, physical resources

9. Frustrations – health services, health workers, discrimination, stigmatised, poor communication

10. Preferences – social element, peer-based approaches, active learning, inclusion, being heard.

Discussion

1. **Photovoice and technology**

Unsurprisingly, with the omnipresence of computers/tablets and smartphones, technology played more of a role in photovoice methodology than noted in the earlier reviews by Catalani and Minkler (2010). Photovoice methodology has been modified more readily with younger populations, with some innovative ideas published regarding use of Smartphone technology and digital diaries (Volpe, 2018) and social media platforms such as Instagram (Yi-Frazier et al. 2015). Communication platforms have become more multi-modal through use of photos written and spoken dialogue, both face to face and using technology such as smartphones, skype, email and social media, however, the selected studies, despite their recency, are failing to make use of available technology that adults nowadays are also familiar with, which is perhaps a failure to enhance participation, which has been recognised to be highly influenced by different approaches to taking pictures (Bendell & Sylvestre, 2017). So we know that the arts can help keep us well, aid our recovery from illness and support longer lives better lived however there are gaps in the evidence base. An exploration of photovoice methodology that includes social media

use to increase communication, social connectedness and empowerment for improved quality of life for people living with significant illness or disease is needed.

2. Agency and capacity

Findings highlighted that participant agency is critical. High level of engagement across all studies and the sharing of mutual experiences allows participants to become agents of change within their community (Catalani & Minkler, 2010). The capacity of individuals to act independently and make their own free choices is critical to health. Recognition of the powerful influence of the social determinants of health also has implications for public health in recognising the need for upstream interventions (Lal et al. 2012, Prevo, 2018).

3. Empowerment

Family and social support consistently had the strongest link with feeling empowered. Empowerment enables people to develop capacity to self-care and drive social change. Maintaining social connections with family and support networks is therefore critical to improving health outcomes. The theory of psychological empowerment discussed by Chew et al. (2018) and the notion of empowerment as "a culturally driven concept", influenced by philosophical, religious and cultural norms highlights potential limitations of the use of photovoice methodology which the authors described as a concept of "nonaction" in which participants may withhold information for fear of judgment by others. This impacted on the style of data elicitation and the necessity to modify the photovoice methodology. Whilst all of the studies outlined ethics and consent procedures, the nature of photovoice does impose some limitations on its ethical use in empowering communities, particularly when vulnerable populations are involved such as those with mental illness (Creighton et al. 2018, Harley, 2012).

4. Transfomation to patient-centred care

Photovoice can seek to bring about positive social change in marginalised groups so that they can advocate and improve the quality of their lives (Wang & Burris, 1997, Sitter, 2017). Evans-Agnew & Rosemberg (2016) commented there is little evidence in the literature that participant voice has effected policy change, however that idea is strongly refuted in the Creative Health Report (APPG, 2017) and in the statistically significant outcomes being realised with the advent of randomised controlled studies using photovoice interventions. Integral to healthcare service transformation however is

building capacity to provide patient centred health care. Program developers' lack of penetration into the communities of service users has been a major barrier to the success of health promotion initiatives therefore including target groups in the planning phase will likely reduce mismatch failures (Prevo, 2018). Investment in resources and implementation of training for staff in arts and health practices is critical for changing stereotypes, reducing stigma of people, of services and of primary health care providers. Recognition of the powerful influence of the SDH is critical and training of health care providers is needed (Balbale, 2015), but not provided in arts in health (Dewey Lambert & Sonke, 2018). *Talking about Arts in Health* is a white paper recently released by the University of Florida (2017) which outlines steps taken towards improving this situation: developing a unified taxonomy, defining the scope of practice, addressing ethical issues in educating the workforce and developing recommendation or higher education programs internationally. The Creative Health Report (APPG, 2017), makes clear its recommendations on this front, advising changes to undergraduate, postgraduate and professional development modules for practicing clinicians, public health professionals and other staff involved in the delivery of healthcare. Wider initiatives focusing on organisational level change and models of care that are sustainable and patient-centred are also recommended and being implemented.

Conclusion of meta-synthesis

Most studies focused on reporting themes relating to quality of life however 21% of studies (n=4) reported intervention evaluation findings and outcomes. Photovoice is therefore useful for exploring lived experience, identifying needs but also for providing data for quality improvement and service change. The findings highlight that photovoice allows partnership building and community participation as a highly engaging research tool with results consistently conveying that participants are more concerned with health and quality of life than disease and deficits, which has enormous implications for public health, and the nature of health promotion in achieving patient-centred health outcomes.

THE PRESENT STUDY

The need for this study arises from identified needs based on clinical experience working as a Speech Pathologist, and as a Manager in a public health service servicing the MND population. The devastation, frustration, grief and disempowerment of communication impairment or loss of speech presents many challenges to both pwMND and their

families. Where we live, work and play matters! Being a parent, a partner, a lover, a worker, a sister, a friend and an active member of your community requires communication. The ability to communicate and socially connect are recognised as social determinants of health (SDH) and have an enormous impact on quality of life.

The advent and support for patient-centred models of care have opened a policy window; an opportunity to address social determinants of health and lead change. In a recent white paper, *Shifting Gears*, examining the consumer-led transformation of health, The Consumers Health Forum states clearly "there is clear and growing value placed on consumer insights, advice and lived experience in policy making, program and service development" (Consumers Health Forum, 2018 p. 3).

Arts in health approaches are also experiencing strong support with clear evidence for their role in improving health and wellbeing. The Health Evidence Network synthesis report on arts and health, launched by WHO in November 2019, presents the most comprehensive and compelling review of arts and health evidence to date, referencing over three thousand studies (Fancourt & Finn, 2019).

Finally, the metasynthesis conducted highlighted the need for exploration of photovoice methodology that includes social media use to increase communication, social connectedness and empowerment for improved quality of life for people living with significant illness or disease. Visual evidence, such as photos, is a powerful tool for those who have lost the power of speech. A pilot photovoice intervention (n=46 patients and carers), was previously designed, piloted and evaluated at CHCB and shown to be highly effective in advancing participant voice to achieve concrete and sustainable changes that improve the quality of life for individuals and the MND community at large (Australian Centre for Arts and Health, 2018, p. 44).

This current research project is thus a logical follow-on from an established intervention and aims to build evidence demonstrating the significant impact of photovoice on communication and social participation for improved QOL in MND. Whilst the value of patient narratives is acknowledged in the literature, this information is not commonly used by health services in any systematic way to drive better health outcomes. (Consumers Health Forum, 2014). Qualitative research such as this is vital as the outcomes have enormous potential to develop the knowledge required to inform patient centred care

using patient driven priorities and actions rather than the tokenism exhibited in many traditional health care institutions, "so that health professionals, pwMND and their carers understand each other's standpoint when they talk about decisions that are good, about care or about improving quality of life" (Sakellariou, 2017, p. 1773).

Chapter 3: Research Methods

Research Design and Epistemology

A mixed methods design was undertaken with the emphasis on a qualitative participatory research approach within an "arts in health" framework. Aligned with the philosophy of humanism, which firmly believes in the value of the human experience and the agency of human beings, both individually and collectively, an action research approach was employed - A naturalistic enquiry collecting evidence relating to the issues and assets that impact on the QOL of people living with MND by stimulating social change. Accordingly, action research should be judged on the outcomes achieved and whether or not change occurs (Newby, 2014).

Figure one demonstrates how action research can be used to achieve two key changes: 1. Individual change – development and improvement of the individual's own practice, 2. Organisational change – may require changes in goals, practices or procedures, which in turn can necessitate "deeper change in outlooks, aspirations and attitudes" (Newby, 2014, p. 64).
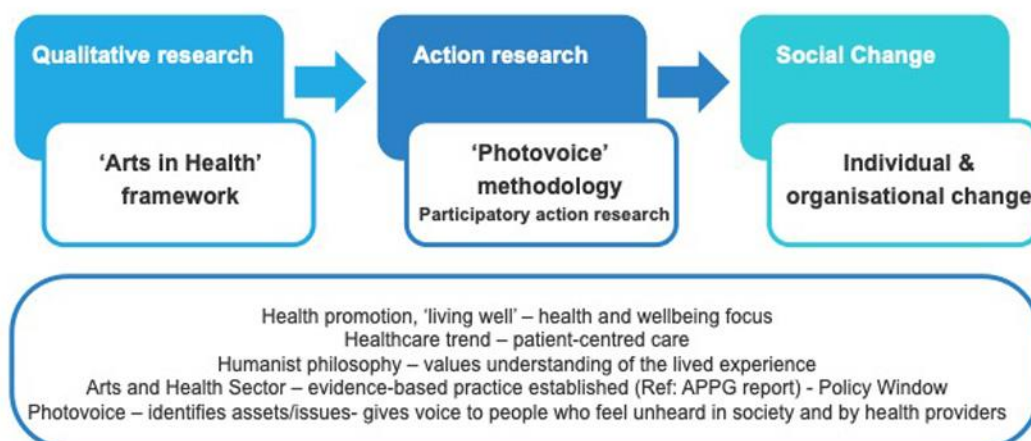

Figure 1. Action research for participant driven healthcare

Methodological approach

A participatory action research (PAR) methodology known as photovoice was employed. Photovoice is a descriptive methodology that uses narrative tools to give voice to people, who often feel unheard and unseen in society, and by healthcare providers.

Photovoice refers to the methodology described by Wang and Burris (1997), which has been comprehensively described in Chapter 2. Data collection tools include visual data (photos), written data (photo captions or narration) and verbal data (critical dialogue), which is triangulated and used for thematic analysis.

Sample size and method

Target sample size n=12 pwMND, with n=12 matched carers.

A large sample size is not necessarily required for a qualitative study. Based on the pilot program conducted (n=46) and the metasynthesis of 19 photovoice studies described in Chapter 2, data saturation can be reached with a sample of 10-20. Data saturation refers to the point at which no new themes are apparent (Braun and Clarke, 2006).

Quota sampling was utilised. Recruitment ceased when the desired quota was reached. The final sample size for data analysis was n= 17 participants (n= 9 households).

Participant criteria

Inclusion criteria:
- A diagnosis of Motor Neurone Disease, any phenotype. (NICE guidelines, 2016)
- Seen by Speech Pathologist because of speech/communication change due to MND. Acceptable range: mild impairment to anarthric (non-verbal)
- Living at home and available for group dates.
- Able to participate with support from a primary carer (partner preferred but alternative carer acceptable if single status or partner working.)
- Prior consent to be contacted for research purposes as per CHCB database.

Exclusion criteria:

- A diagnosis of Motor Neurone Disease with accompanying diagnosed Fronto-temporal dementia (FTD). Cognitive change is common in MND and is not an exclusion criterion.

- Significant psychiatric disorder

Participant recruitment strategies

Recruitment occurred via the CHCB State-wide Progressive Neurological Disease Service (SPNDS). At the time of recruitment in June 2019, there were 335 active patients with MND within this service. PwMND are divided into 10 metropolitan and regional, as well as a small proportion of interstate NSW/TAS n=13) for purposes of assigning each family an MND advisor through Motor Neurone Disease Victoria, a key stakeholder in MND care.

The following Victorian subsets were screened by the Speech Pathology Department to check inclusion criteria.

- Eastern metropolitan n=73
- Northern and western metropolitan n = 66
- Southern metropolitan n =120

77 potential participant dyads (n=154) were identified and mailed a participant information sheet and consent form (See Appendix 1), complying with the CHCB research and ethics committee. Participants were offered the choice of two study sites (MND Victoria- Eastern metro/Canterbury and CHCB - Southern metro/Parkdale) to reduce sample bias.

Fifteen participants were successfully recruited following the mailout (8 pwMND and 7 partners of pwMND) representing a 10% recruitment rate. A further 6 participants (3 pwMND and their partners) were recruited via MND Victoria following provision of an information session to MND advisors and a recruitment post on the MND Victoria Facebook page. There was representation from the 3 metropolitan areas targeted as shown in Figure 2.
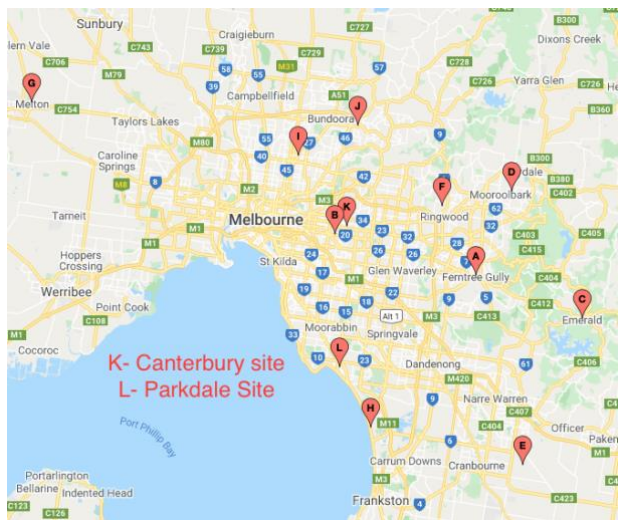

Figure 2 Participants geographical proximity to study sites.

The twenty-one program participants recruited consisted of ten married couples and one widowed pwMND. One couple withdrew in the week prior to commencement due to pwMND requiring hospitalisation for a brain aneurysm. Another couple was attended the first session only then elected to withdraw due to family issues, travel logistics (residing in outer suburbs, location G, figure 2) and lack of motivation from pwMND. Seventeen participants completed the study, representing 9 households. The widowed pwMND attended alone or supported by a daughter or friend who were not included as participants as they elected not to contribute photos or complete outcome measures.

Data collection methods

Intervention program: Appendix 2 outlines the 4-week Photovoice communication intervention program developed, piloted and evaluated at Calvary Health Care Bethlehem. This established program, based on the Wang and Burris (1997) photovoice methodology, was used as the vehicle for data collection required to investigate the research questions. All research group sessions were facilitated by two Speech Pathologists trained in photovoice methodology, one being the lead researcher.

Focus groups - formed part of each of the 4 group sessions in the photovoice program. This involved critical discussion surrounding the themes generated each session. The data comprised visual and verbal/nonverbal communication ie. the photos themselves and the discussion stemming from the photos. A replicable focus group discussion format for each session / each group was employed however the order of questions or probes was conducted in an iterative, flexible manner in order to allow the group freedom of expression and confidence to discuss and reflect on new or potentially sensitive topics triggered by the shared photos of others.

A series of semi-structured and open-ended questions were incorporated into the focus group sessions to add richness to the data. The questions have been pilot tested. Standard questions are utilised (Wang and Burris, 1997) with additional questions designed to tap into "new knowledge" eg. How did using photos increase your communication? What surprised you?

The focus group component of the session occurred during the final 30- 40 mins of each 2-hour session and was audio recorded to provide additional transcript data as required during analysis. Complete transcripts of audio recordings were not completed due to the number of anarthric/nonverbal participants (n=3) and those with significantly reduced speech intelligibility (n=4). Detailed field notes were therefore a critical dataset.

The Focus Group questions and probes used included:
- What type of photos did we share? (coding)
- Did you discover something new? (Probe -What surprised you?)
- How did using photos assist communication? (Probes- self-expression, connecting/re-connecting, expressing opinions)
- How did using photos help you connect socially? (Probes - social participation/inclusion)
- What were the themes identified in our photos/narratives? (Probes – what did we have in common? Contrasting ideas Eg. Assets/issues, similarities/differences, barriers/facilitators, risk/protective factors for QOL)
- Do the photos have potential to trigger change? (Probes- education, awareness, advocacy, influencing policy)
- Are you/we going to take action? Taking Action with PhotoVOICE – Voicing Our Individual and Collective Experience. (Probes - What matters to you?)
- Iterative process / Relevant follow-up questions

Data Sources

1. Photographic Images – Participants were provided with basic photographic training, including methods of taking photos for those with physical limitations. All participants were required to self-select five photographic images per week over 4 weeks to share with the group (aim 20 images per participant). The weekly sessions followed a broad thematic progression from inwards- self, to outwards -family/friends/community.

2. Words/photo narratives – a) written narratives about photographs, b) verbal narratives/discussions triggered by sharing of photos in focus groups sessions.
The Wang and Burris (1997) technique 'SHOWeD' (see Appendix 2) was used to encourage a more detailed exploration of each photo's associated context and narrative. The purpose of these questions is to "identify the problem or the asset, critically discuss

the roots of the situation, and develop strategies for improving the situation" (Wang, 1999, p.190).

3.Nonverbal communication- Written field notes added richness to data in terms of behavioural observation and recording of non-verbal communication, relational aspects, manner and style of communication, vital data in the context of communication impairment, particularly for those pwMND who are nonverbal and/or using AAC. The assistant moderator took detailed field notes during each focus group including the following types of information: quotes, nonverbal communication from participants, photographed screenshots of nonverbal participants written output, wording and timing of probes, key points and themes for each question, follow-up questions, ideas/thoughts of note-taker.

4.Photo-sharing – participant patterns using computer or smartphone technology and social media. Photo-sharing via electronic means and social media is a key component of the CHCB photovoice program, developed in response to the specific needs of pwMND who are at risk of social isolation due to communication impairment. This need is supported by clinical guidelines (NICE, 2016), peak body action plans (MNDA) and MND research recommendations (Caron and Light, 2015). Although I would consider photo-sharing to be a mainstream communication mode, it has not yet become part of 'standard practice' for Speech Pathologists working with pwMND.

Outcome measures

Figure 3 illustrates a systems representation highlighting the variables for measurement.

Dependent variables: social connectedness and quality of life

Independent variable: communication ability (can be manipulated)

Intervening variables: photovoice intervention program

1. Quantitative Tool:

World Health Organisation Quality of Life (WHOQOL) – BREF.

An abbreviated version of the World Health Organisation's self-report tool for assessing quality of life where 26 items are scored 1-5 across 4 domains. Raw domain scores are normalised to a range of 0-100. Statistical data type = categorical, ordinal data.

The tool is a compound indicator measuring four domains including physical health, psychological health, social relationships and environment. There are also two separate questions assessing quality of life and general health.

The tool has been validated internationally by WHO, and also validated with older population, demonstrating high test-re-test reliability (Von Steinbuchel, 2006).

Formal written permission has been granted by WHO for reproduction and use. The tool can be seen in Appendix 3 and is completed by all participants before and after completing the photovoice intervention, then compared. Participants are instructed to answer each question based on the previous 2 weeks experience.

Initial – posted 2 weeks prior to commencement of session 1
Final – completed approximately 1 month after session 4.

2. Qualitative Indicators
- Narratives generated by participant photos.
- Changes in photo-sharing behaviours as a measure of functional communication and expanding social networks to impact QOL
- Participant driven actions (individual and collective) that impact QOL
- A Photovoice Patient satisfaction questionnaire examining outcomes and impacts is completed at the same time as final WHOQOL-BREF, approximately 1 month after session 4
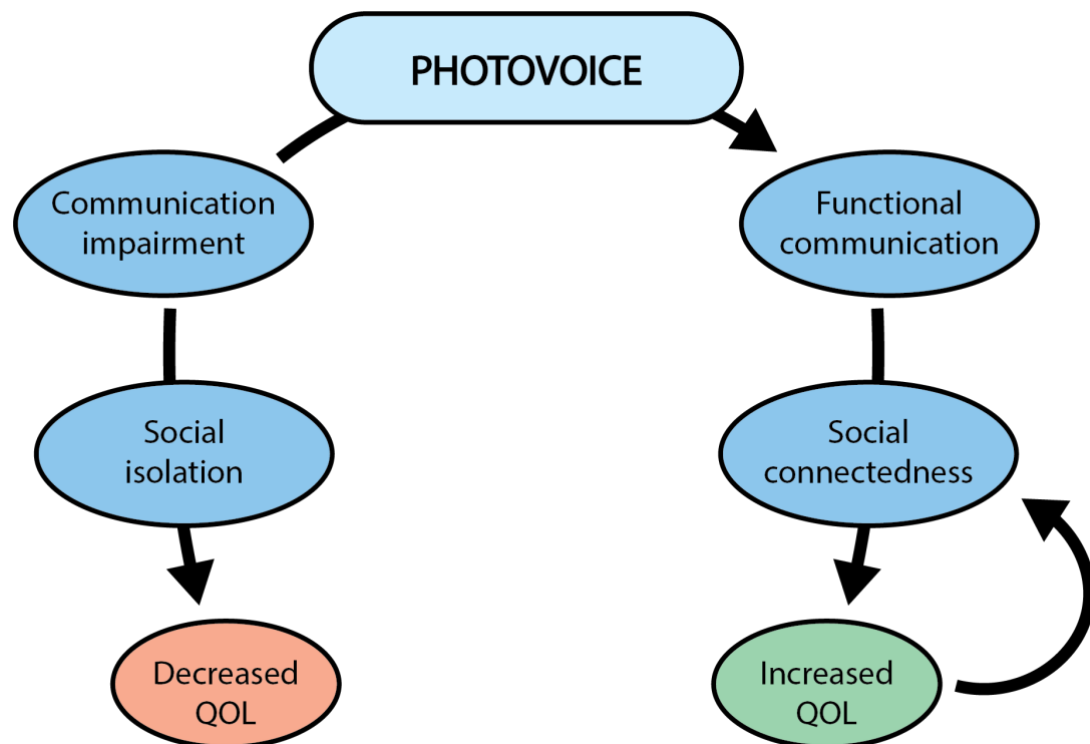
Figure 3 Systems diagram

Data Analysis

1.WHOQOL- BREF

The ordinal data was manually calculated following the steps and formulas in the instruction manual which then converts domain scores to transformed scores, comparable with the full WHOQOL outcome measure which comprises 100 questions.

Mean scores for each domain was calculated for pwMND and for their partners/carers. Mean differences in initial/final transformed scores were reported for these population subsets. Statistical analysis of the significance of these differences was not conducted as the sample size (n=17) is too small.

2.Thematic Analysis

A qualitative thematic analysis was the main focus of this research. Braun and Clarke's (2006) framework for thematic analysis was used to code and analyse the extensive and multiple datasets (photos, and narratives – written, verbal, nonverbal data). Coding of photos was conducted using multiple coders, including participants themselves as the research design is PAR. Deductive coding was also possible as some themes had already been identified in the previous pilot photovoice program mentioned in Chapter 1 (n=46).

The organisation of data, coding and identification of themes was conducted manually on a weekly basis. The Nvivo software package was available to assist data organisation but was not considered to be of any additional value due to the detailed nature of field notes taken on a weekly basis that was superior in capturing the high proportion of nonverbal data critical to this thematic analysis.

3. Participant driven actions

Descriptive analysis of all individual and collective photovoice outputs in terms of actions completed and outcomes achieved.

4. Photo-sharing patterns within participants social network

A brief survey and direct observation of photo-sharing patterns is completed during session 2 and on completion of session 4 to assess change.

- How often do you use social media?
- What is your preferred social media platform?
- How often do you share photos with family and friends?
- How do you share photos?
- What social media groups (chat groups or closed groups) do you belong to?
- Social media activity – how many photos did you post in the last week?
- How many photos did you respond to? (like/comment/share photo)

Bias and data trustworthiness

Sampling and researcher bias were minimised by

- Collecting sufficient data and sample size to reach data saturation. (no new themes evident by completion of third group)
- Multiple data sources to increase data objectivity
- Use of a replicable framework to ensure transparency and reduce bias.
- Multiple researchers involved at separate stages of the project to increase, rigour, transparency and reliability.
- Participants involved as researchers to ensure the integrity of "participant voice" and impartial use of photographic evidence.

Data trustworthiness and credibility was ensured by prolonged engagement in data collection (4 weeks rather than a single interview 'snapshot' approach). As shown in the literature review, data analysis impacts the trustworthiness of a thematic analysis therefore this study employed a series of systematic steps, involving multiple "coders" at regular intervals to reliably identify themes with high levels of agreement. All participants (pwMND, their carers and research facilitators) contributed to coding photos at the end of each session. In the final session of each 4-week program, all participants contributed to analysing patterns in the data (photos and narratives) in order to identify and describe themes. Following completion of data collection, these themes were cross validated with two other professionals to ensure inter-rater reliability, enhance internal validity and reduce potential researcher bias to ensure the data is authentic.

Ethical considerations

This research project was conducted with prior approval by the Research and Ethics Committees of both Calvary Health Care Bethlehem and La Trobe University. People with MND are living with a terminal illness so it is recognised that the photos produced by participants and the ensuing focus group discussions may trigger feelings/emotions which cause distress or expose carer/relational issues. Participant information was provided, and written consent gained from all participants in accordance with CHCB ethics requirements. Participants were made aware of CHCB standard practice allowing referral to internal or external Psychologists if required.

Data storage and use

All data at all stages of this project has been managed in accordance with the Victorian Health and Information Privacy Principles. Identifiable information obtained from the printed measures has been de-identified and entered into a password protected data management spreadsheet.

Photographic outputs generated throughout the program are a standard component of the photovoice action research methodology. Participants retain copyright of their images and provide CHCB with written consent for use of the images as outlined in the consent form. Photo and narrative outputs produced by participants may be used for future actions as determined by the participants. Consent for such use is explicitly sought on the patient information consent form.

Chapter 4: FINDINGS

Characteristics of participants

Table 1 shows the typical pwMND was 21 months post diagnosis, English speaking, male, 61 years old, married, tertiary educated and receiving NDIS disability funding. All but one participated with their spouse, the exception being widowed. Spouses were included as participants in this research. Table 2 details the factors which determine the complexity of communication needs for pwMND. Nearly half of pwMND sample (4/9) were bulbar onset MND, with 75% of this subset being anarthric/nonverbal, requiring alternative and augmentative communication (AAC).

Table 1. Characteristics of participants

Characteristic	pwMND n=9	All participants n =17
Age - years (median)	61 (49 – 81)	60 (46 – 81)
Age – years (mean)	62.5	62.2
Age – years (mode)	56	56
NDIS participants	7 (<65 years)	7/9 households
Gender	2 F, 7 M	9 F, 8 M
Marital Status	8 married, 1 widowed	16 married, 1 widowed
Education	8 tertiary, 1 secondary	13 tertiary, 3 secondary, 1 primary
Preferred Language	English	English
Bilingual/second lang.	2/9	5 /17
Time since diagnosis (median)	21 months (4 – 117 months)	-

Table 2. Factors impacting on Communication for person with MND (pwMND)

	MND phenotype	Speech changes	Communication device (low tech)	Electronic assistive communication technology use	Preferred Social media platform	Mobility	Upper limb function
P1	bulbar onset	Anarthric	boogie board	New - ipad and Predictable TTS app	FB messenger	Ambulant	Independent
P2	limb onset	Moderate	voice amplifier	Planned - Tablet/grid pad with eye gaze	What's App	wheelchair	Full assistance required
P3	limb onset	Mild	none	Demo TTS app Predictable for ipad/iphone	FB messenger	Ambulant	Independent
P4	bulbar onset	Anarthric	pen/paper or ipad	Competent user- ipad with TTS app	Facebook (FB)	4WF or wheelchair	Independent
P5	bulbar onset	Severe	boogie board or pen/paper	New - ipad and Predictable TTS app	Facebook (FB)	Ambulant	Independent
P6	PLS	Moderate	boogie board or pen/paper	New TTS app on phone. User computer/email,	What's App	4WF	Some assistance required
P7 Withdrew	cervical onset	Severe	none	New- Grid Pad 12 with Quha, Alphacore TTS	Facebook (FB)	wheelchair	Full assistance required
P8	bulbar onset	Anarthric	boogie board or pen/paper	New - ipad and Predictable TTS app	FB messenger	Ambulant	Independent
P9	bulbar onset	Moderate	none	Demo TTS apps for ipad/iphone	FB messenger	Ambulant	Independent
P10	limb onset	Mild	none	Planned - Tablet/Grid pad with Quha zono	FB messenger	4WF or wheelchair	Some assistance required

Main findings

Quality of life

A. The WHOQOL-BREF was not sensitive enough to measure the impact of an intervention such as photovoice on quality of life for families living with MND. Figure 4 highlights some broad trends in participant reported quality of life, however the average mean differences from initial to final scores were small and sample size was too small to demonstrate statistical significance.

All pwMND (n=9), completed the pre and post intervention measure. Mean transformed scores highlighted a downward trend in physical health scores by the end of the study, however the changes in other quality of life domains were insignificant.

Domain 1 – Physical health scores showed an average reduction of 8.9 points

Domain 2 - Psychological health – average of 1.5 points lower.

Domain 3 – Social relationships – average of 3.5 points higher.

Domain 4 – Environment – average of 0.7 points lower.

Seven of the 8 carers completed the pre and post measure. The wife of one PwMND contributed photos and participated in two of the four sessions but failed to complete the pre and post outcome measures (WHOQOL- BREF) despite reminders.

For the carers, there was a downward trend in average score for Domains 1, 2 and 3. (range 1.7 – 5.3 points lower) and a small average increase of 1.9 points for environment.
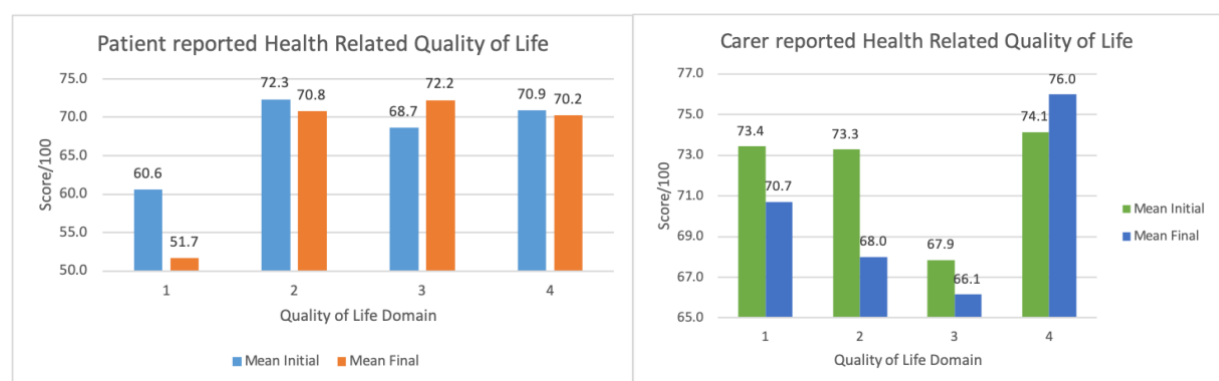

Figure 4 WHOQOL- BREF mean scores for pwMND   *Mean scores for carers*

B. The standard CHCB photovoice impact questionnaire contained a series of binary questions and open-ended responses to examine impact on communication, social

participation and quality of life. This data provided more specific indicators to demonstrate impact of the photovoice program. 16/17 participants completed the questionnaire. Data extracts including patient testimonials can be seen in Appendix 4.

16/16 (100%) of participants reported a positive impact on quality of life

15/16 (94%) reported a positive impact on communication with family

13/16 (81%) reported a positive impact on communication with friends

11/16 (69%) reported an impact on ability to express ideas/opinions to a wider audience

12/16 (75%) reported a positive impact on communicative confidence

15/16 (94%) reported a positive impact on social connectedness

16/16 (100%) indicated they would recommend the photovoice program to others.

Thematic Analysis

Thematic Analysis was completed using the steps outlined by Braun and Clarke (2006)
The following data sets were used

1. Photo outputs: n = 312 (average of 18 photos per participant, coded by participants and facilitators during the course of each 4-week program)
2. Written captions and narratives generated by participants.
3. Verbal and non-verbal data set. Detailed field notes from discussions generated during the 12 focus groups discussions (3 groups x 4 two-hour sessions) Transcripts of photo descriptions or focus groups discussions (from audio recording) were utilised to review certain narratives when more detail was required to analyse, interpret and make sense of the photo in the context of the critical discussion that it generated.

The concept of identifying themes and the process of thematic analysis was discussed with each group of participants during the course of each 4-week program. Some participants were better able to differentiate between codes and themes, than others. Table 4 therefore represents a combination of codes and themes as generated verbatim (written on sticky notes) by all participants, and with all participants (pwMND and carers) contributing equally to this process. Each of the groups assumed their own character, with participant generated themes showing much overlap but also areas of difference.

Table 4 Participant Generated Themes (some themes nominated are codes, rather than themes.)

Group 1 Participants N=6	Group 2 Participants N=5	Group 3 Participants N=6
Relationships: Maintain relationships and build new ones	Church	Being normal
Make the most of what you have got	Food	Communication
Have a sense of purpose	Pets	Things that matter to you
Stopping your universe from shrinking	Adventures	Awareness
Endeavour in sport	Friends become family	Travel
Being interested [in others]	Help from others- people are generous	Social
Having a passion	Social occasions adapted	Family support
Fun and Laughter	Having dinner out in a restaurant	Communicating without speech
Looking outward not inward	Grandchildren	Family support
Commitment to relationships (family and friends)	Close relatives	Living life to its fullest with restrictions
Attitude toward disease	Community groups	Alert people with MND
Belonging to clubs	Friends becoming family	Tasty food but not appealing
Family and friends	Missed abilities i.e. to drive or to walk your pets.	Love without conditions
Passion	Communicate with the grandkids through pictures	Substance to survive
Talk to me	Generosity of good friends	The curse of MND
Using photos to start conversations about the present as well as past memories	Having fun	Awareness
Keeping friendship groups connected	Friends become family	I am not pissed, I have MND
Slightly changing interests to suit changes [caused by MND]	Family and grandchildren [are important].	Means to communicate
Animals	Family	Means to identify
Sport	Friends become family	Family is so important
Enjoying everything you do	Outings/ holidays	Neil Daniher is such a legend
Resilience in every aspect of life	Pets company	Friends provide so much support
Inspiration in my family and friends	Overseas family	Knowledge of condition – assumptions and frustrations
Taking risks	Online support	Social isolation makes life miserable
Love		Family and friends sticking together
Keeping interests alive		Mobility – where can I go?
Importance of family		Mobility limits social interaction
		MND is a connection.
		Share ideas, discuss ideas
		4 walls – need to get out of the house
		Carer support
		Reliable support
		Less stress
		Coping better

By combining the participant derived themes with further analysis of the datasets described, the two Speech Pathologist group facilitators and an independent researcher working together, double coded the data to produce the thematic analysis. The final five main themes and associated subthemes derived from all data sets, the 'data corpus', can be seen in Table 5. To highlight the differences between groups, Figure 4 -Thematic Analysis by Group, is evidence that each group is participant driven, taking on a life of its own. A breakdown of main themes represented by each group is provided in Figures 5, 6 and 7, along with a summary of group characteristics.

Table 5 Themes and Subthemes - The Lived experience of MND

Themes (5)	Subthemes
Identity, self-care and emotional wellbeing	1.1 Health as an asset (Self-care and personal wellbeing) 1.2 Seizing opportunities and living life (dignity of risk) 1.3 Resilience (coping/maintain "normality") 1.4 Loss and grief 1.5 Positive attitude (optimism/gratitude/fun)
Communication and connection	2.1 Communicating thoughts and feelings (maintaining intimacy) 2.2 Communicative confidence (control and choice) 2.3 Bonding experiences (maintaining relationships) 2.4 Expanding communication modes 2.5 Connecting via technology (including social media)
Networks of Support for wellbeing	3.1 Family support is paramount 3.2 Children and grandchildren 3.3 Emotional support dogs 3.4 Sense of purpose (supporting others) 3.5 Expanding personal networks (circles of care – family, friends, community, online)
Maintaining social participation **(Stopping your universe from shrinking)**	4.1 The family network 4.2 Belonging and inclusion 4.3 Community participation 4.4 Keeping passions and traditions alive 4.5 Adapting – barriers and facilitators (how to live with MND)
Taking action **(building social capital)**	5.1 Quest / personal growth narratives 5.2 Active Citizens (agency/capacity to act) 5.3 Having a voice 5.4 Inequalities/tackling discrimination 5.5 Optimism/hope for the future (heroes/villains)
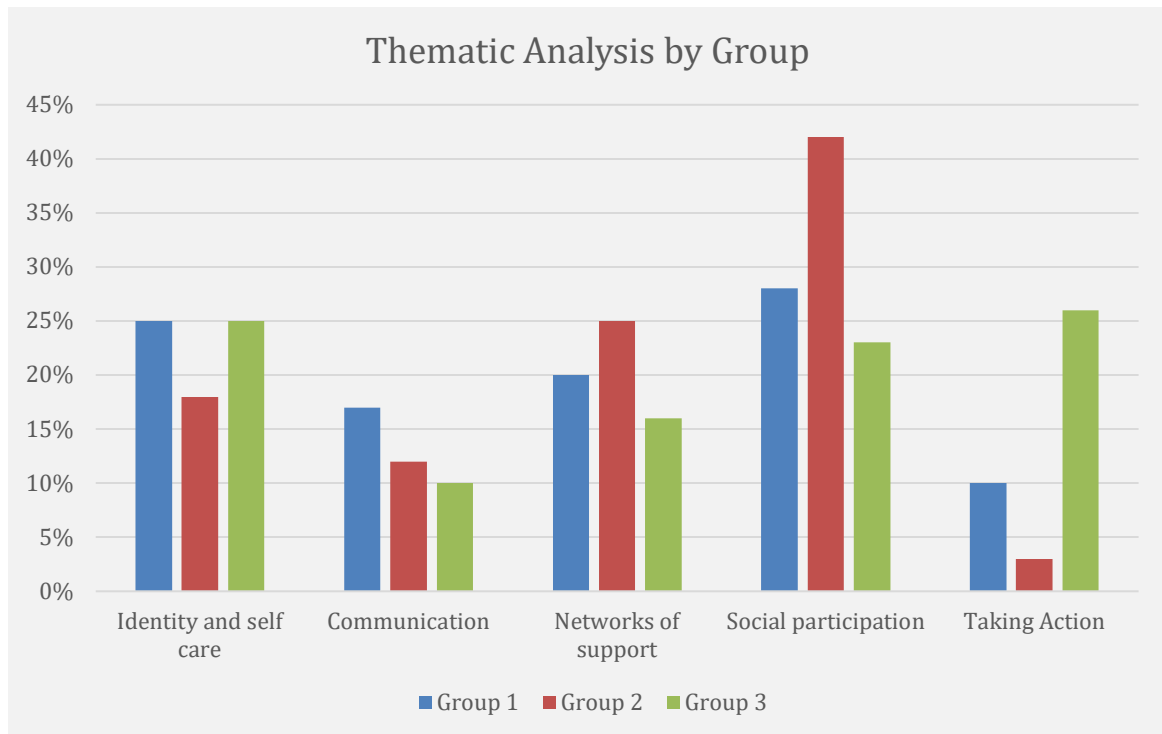
Figure 5 – Thematic Analysis by Group
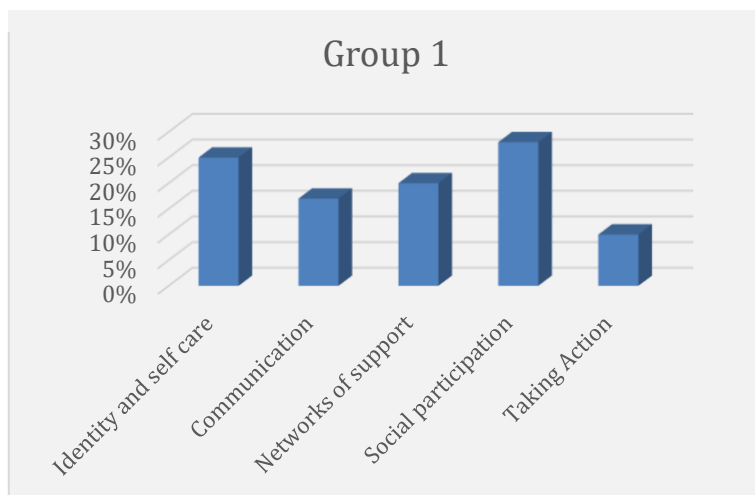
Figure 6 Group 1 photo narratives n=105

Group 1 was the least homogenous in terms of age, degree of communication impairment, n=1 anarthric/nonverbal, n= 1 moderately dysarthric and n=1 mildly dysarthric and time since diagnosis. This group however, had the most in common of all of the groups (family values, interests and passions, occupations), which resulted in a very cohesive group dynamic with all members developing good rapport, allowing exploration of difficult topics in greater depth.

All of the pwMND showed a degree of lability (difficulty controlling emotions), which is common in various forms of MND, and can itself be a barrier to social participation, due to difficulty inhibiting crying. This common link between the participants created a high degree of empathy and compassion between group members that was less evident in other

groups. In Table 3, it can be seen that participants in this group were able to generate semantic themes that demonstrated analytical and interpretive thinking, with an attempt to theorise their broader meanings and implications eg. "looking outward, not inward", "Stopping your universe from shrinking"
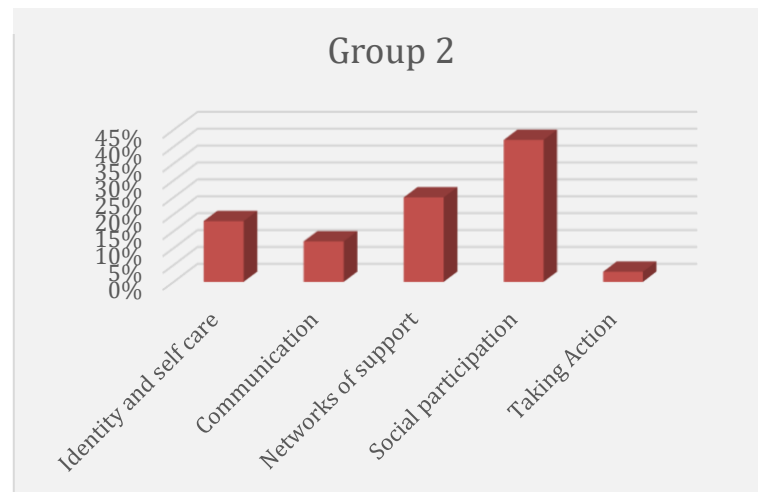
Figure 7 Group 2 photo narratives n= 118

Group 2 were a homogeneous group, aged 65 + and the most communicatively impaired cohort, with one pwMND anarthric/nonverbal and two severely dysarthric, exhibiting very poor speech intelligibility and increased reliance on alternative forms of communication. This group also had the most mobility issues: n=1 wheelchair-bound, n=1 mobility aid, n=1 independent.

Photo narratives relating to maintaining *social participation* predominated and this group also had the highest proportion of photos relating to *networks of support*, with most discussions centred around barriers and facilitators to communication and social connection, as well as the psychosocial impact of increasing social isolation. Skill development surrounding trialling new AAC technology as well as learning how to set-up and use chat groups on social media was embraced by this group as the degree of communication impairment impacted significantly on social participation in day to day life. As one participant noted, "Make me feel much better with the viewing (photos) on iphone!!! It' s harder now that I can't talk to friends on the phone." The group decision-making when generating themes, tended to be mostly at an explicit level, connecting surface meanings of the data ie what was said or written about each photo shared with the group, rather than an interpretive level.
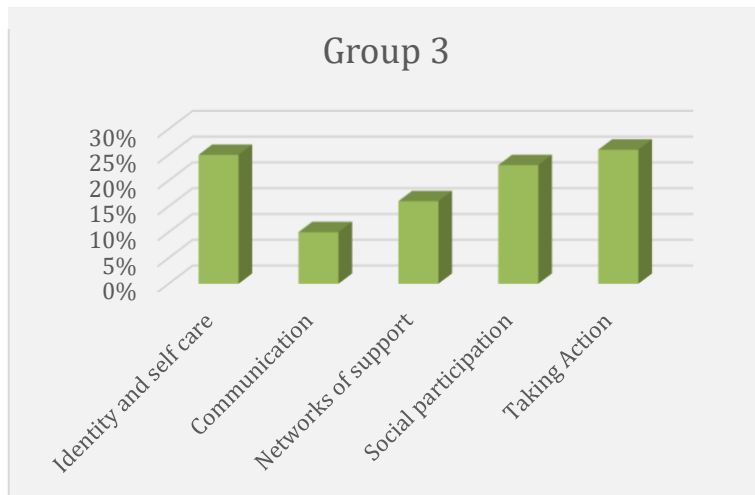
Figure 8 Group 3 photo narratives n=89

The 6 participants in Group 3 were either still working (n=3), on leave from work (n=2) or recently medically retired due to MND (n=1) Additionally, 5 of the 6 participants were independently ambulant and still accessing the community on a daily basis and two of the couples still engaging in interstate or overseas travel. Changes in role and identity were at the forefront of discussions as pwMND felt they were losing who they were but showed great resilience; their photo narratives providing evidence of how they maintained the desired 'normality' in their lives. In comparison to Groups 1 and 2, this group had a significantly higher proportion of photo narratives relating to the theme of *Taking Action*, which in turn triggered collective group actions for awareness raising and advocacy.
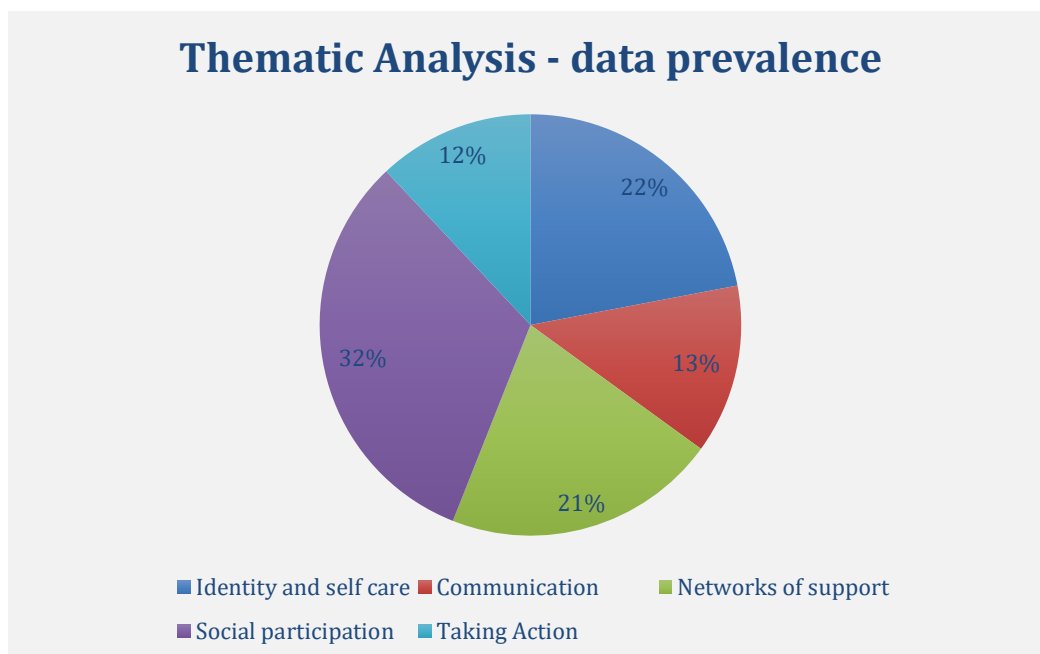
Figure 9 Prevalence of data extracts by main theme, n =312 photos

Figure 9 shows how many data extracts (coded photos + photo narratives) were determined to have a similar underlying narrative. Quantification of the main themes provides information on prevalence however this data is not sufficient on its own to allow conclusions to be drawn. Prevalence is not the only method of data analysis, more importantly according to Braun and Clarke (2006), is identifying the patterns/themes that are of most interest, an interpretative process in which all participants think about how to describe the data, create meaningful links and make collective decisions and that the participants "acknowledge these decisions and recognise them *as* decisions" (Braun and Clarke, 2006 p. 80).

The use of photos is also quite innovative in its ability to identify or acknowledge emotions as well as the underlying narrative. This attention to emotions allowed identification of themes that triggered strong emotion (positive or negative) and were of greater significance to the participants, even if those photos were less frequently represented in the data. As participant trust grew over the course of each 4-week program, unspoken anxieties became safe conversations. Examples included dealing with lability (uncontrolled emotion) and transitioning life roles with associated expressions of emotion including sadness, grief, shame, stress or guilt experienced by both pwMND and carers, particularly related to the inevitable role changes that occur with unplanned early medical retirement. A standard patient satisfaction survey administered in the CHCB Photovoice program on completion of the program indicated participants were positively influenced by the process and no-one experienced undue distress or sought psychological support because of the research project.

> *"I felt energised and positive. I was surprised how stimulating it was and how different MND sufferers' attitudes were. I learnt how evocative certain photos are and how some photos produce different emotions in people. I thoroughly enjoyed each session and getting to know other carers. Inspiring."*
>
> *"Embraced, happy, enjoyed sharing photos and stories with other people."*
>
> *"Pictures were a help in articulating thoughts and feelings."*
>
> *"Using photovoice was good. Sharing photos, it was fun. I liked meeting new people and I realised they're the same as me."*
>
> *"It was a really good experience because it encouraged me that I'm handling the difficulties well."*
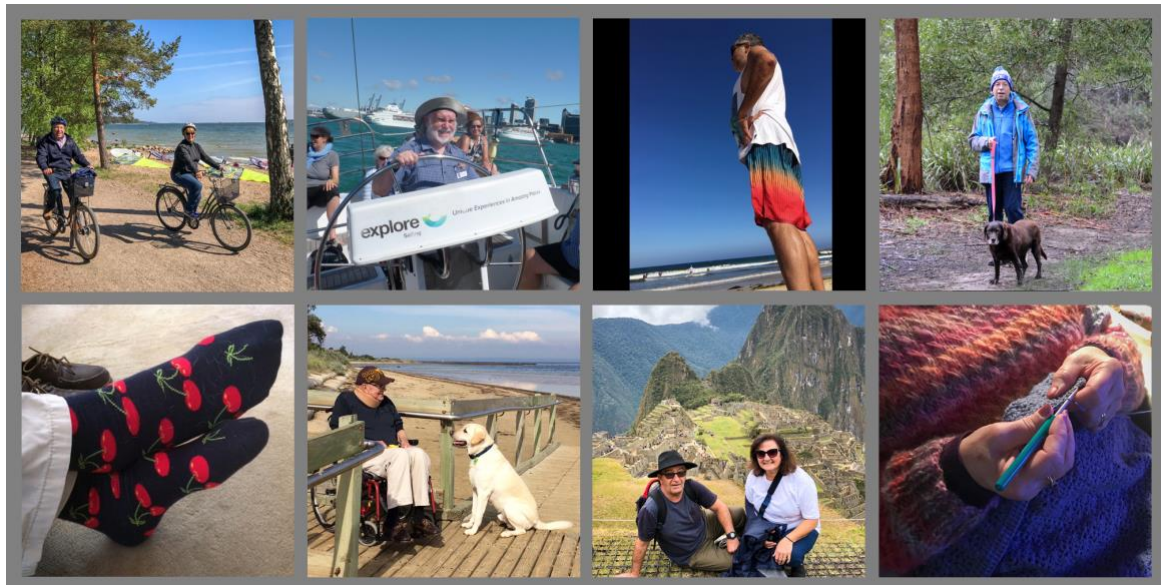
Main theme 1 Identity and self-care

Figure 10 Main Theme 1 -Participant photos with illustrative data extracts

Photo 1 - European adventure – still pursue our love of "outdoorsy" activity "it's how we met" pwMND "I like travelling with someone I love. We have friends all over the world."
Carer "Travel insurance is difficult these days, no-one will touch us"
Photo 2 - Explore. "I will try anything once! So much better than a boring afternoon in a dusty museum."
Photo 3 - "My love of my family, holidays, Hawthorn, horse racing, my dog, the beach, my friends & my house, has made sure I've continued to take risks, continued to achieve things that keep me fulfilled. I push myself to make sure I can keep achieving."
Photo 4 - "Walk Gemma in the morning. Really enjoy walking her. 5km can't do that anymore. Still take her 2-3km."
Photo 5 - "Cherry socks" I like to call them his "cheery socks" because it reflects his personality. Response from pwMND "It's easy to find negative things about MND but hard to find good things…My shoes have a lifetime guarantee!"
Photo 6 - This picture is called 'joy' I think there is no purer joy than watching dogs run free on the beach. This photo is taken at Rickett's Point, where I can get down to the beach via a ramp. Sometimes I think that Wesley (dog) might be the love of my life!"
"Relationships are everything, work on them as if your life depends on them, because it does."
Photo 7 - One of the carers told of a recent trip to Peru in South America. "The altitude in Cusco is high and you actually have difficulty in breathing."
PwMND responds via text on smartphone "my doctor was worried"
"I don't panic and I take it easy." (text to speech app)
Carer- "When I got out of the airport I had a lot of difficulty, I was very heavy chested, so it took me a while to adjust. pwMND on the other hand did very well - He's all good and I'm struggling!"
Photo 8 - Crochet is my passion. It's a family tradition, my family are very artistic.

Participants expressed not wanting MND to consume their lives (subthemes 1.1,1.2). The focus on 'health' rather than the disease itself was considered vital to wellbeing. Seizing opportunities and living life were identified as high priorities for all but there were some tensions noted in this regard: the disparity between medical and personal acceptance of risk, and the barriers associated with seizing opportunities: issues related to fatigue,

physical limitations and transport were commonly discussed. One couple shared many photos of their extended family overseas, expressing intense sadness and regret at a missed opportunity because the medical team advised them it was too late to undertake air travel. Participants agreed they felt they were less risk averse than their treating medical teams and their families. There was a high prevalence of photos related to subtheme 1.2 "seizing opportunities and living life', the narratives reinforcing the importance of dignity of risk and the continuation of a "normal" life despite challenges (subtheme 1.3). The stories shared brought frequent joy and laughter to the group as well as provoking ideas for change.

Caregivers struggled with balancing multiple roles and the need for self-care. The narratives provided evidence identifying protective and risk factors for 'health', providing the basis for participants to reflect on and consider their own health-promoting behaviours.

> *"Painting is a passion of mine. It is my weekly meditation. When I paint the world no longer exists. It helps me to cope with normal life."*

The subtheme of loss and grief (subtheme 1.4) was significant for all participants. particularly when photos prompted discussions around major life changes, which tended to trigger a heightened emotional response, with pwMND and their carers. The power of visual images to tell multiple stories was recognised with frequent occurrences of a similar photo depicting an alternate reality. This underpins one of the key tenets of the power of photovoice, to provide an opportunity to reflect on individual interpretation and attitudes and bring an issue to critical consciousness, the point at which the potential for personal change is ignited. (Catalani and Minkler, 2010). Photo sharing quickly became an effective tool for reflection and a stimulus for sparking new conversations beyond the research setting, one participant commenting:

> *"I'm surprised at the total opposite meaning to two identical photos (photos 4 and 6) Participant X said 'loss' and I said 'joy'. Absolute opposite! It's not a right or wrong judgement, it's a really good illustration of how differently we process the same event. We've told that story a few times to our friends."*

The impact of communication impairment or speech loss was one of the greatest experiences of loss by participants. One carer reflected on feelings of sadness;

> *"sad because X lost his voice so early in the disease. It was his main way of communication, because he was never very good at writing letters, spelling etc. Talking to people gave him great pleasure."*

For pwMND and carers alike, the loss of speech impacted greatly on social participation but also on the ability to work. Of the 9 pwMND, 3 were still working but modifying work hours or roles, with medical retirement inevitable due to the increasing burden of communication impairment. One pwMND was retired at the time of diagnosis, four recently medically retired and three still working at the time of this study. Seven of the eight carers were also working but had reduced work hours, taken leave or ceased work completely to meet increased care needs.

> *"X was working until January this year, but his speech deteriorated fairly quickly so he couldn't do it anymore. His dealings were just talking so he couldn't do it anymore."* Medically retired - Executive project manager.

> *"Communication is key, it impacts on my role at work. I tend to withdraw when in meetings. I just don't engage in conversation. I do do that (email) rather than have a conversation with a client."* (crying) Current occupation -IT project manager.

The narratives told how MND can limit travel, hobbies and pastimes however overall the photo narratives had a positive overtone and there was an equally high prevalence of photos across all groups that displayed personal testimony of resilience with sharing of knowledge, strategies and personal experience related to coping mechanisms, and the strong desire to maintain 'normality' in their lives.

> *"Early on in my diagnosis, I read that someone wrote on some website that "from the moment my dad was diagnosed with MND, he was different. During the first 6 months, I came to the realisation that I couldn't let this happen. I committed to myself that this 'thing' will not define me as a person."*

Main Theme 2 Communication and connection

Figure 11 Main theme 2- Participant photos with illustrative data extracts

Photos 1-7 (left to right) include a sample of photos taken by participants during the course of data collection – sharing 'tips' and demonstrating new skills/individual capacity building

Photo 1 – Photos and text narrative from nonverbal participant - communicating love and intimacy for partner and love of nature/beauty by posting on personal facebook page.

Photo 2 – "I miss communication with people – because of my speech, I feel it is getting worse".

Photo 3 - "Bent thumb thinking. I used to be a copywriter at an art agency, I love writing. I've taken up this blog as a way to empower others and let them know it's ok to be imperfect." Weakening muscles are impacting on ability to use the computer. "I delegate now" An MND Victoria volunteer now assists with typing blog posts and pwMND is trialling eye gaze technology with goal of regaining independence with computer use.

Photo 4 – "that's I communicating with my son, he lives in Singapore, Nicole his girlfriend. Whiteboard show." (using multimodal communication –Facetime call – listening and responding nonverbally or with written words on whiteboard)

Photo 5 – Carers sharing knowledge regarding communication apps and social media platforms.

Photo 6 – Carer – "We are on a What's App group with the kids and in laws, and everyone and we send it (photo) everyday, everyday what the kids are doing, everyday we sharing photos now. We're doing it all the time now, every day, every day! yeah it's much easier (for pwMND) sending the photos than talking." PwMND "cos I can't talk." (couple very excited)

Photo 7 – pwMND narrative – communicating online to remain socially connected. Carer narrative – importance of physical comfort (chair), equipment set-up, accessibility of personal items.

As evidenced in the photos, the action research approach presented opportunities for participants to observe and try new communication equipment or communication strategies in a supportive environment, and with a sense of purpose. As the research project was underpinned by delivery of the piloted 4-week photovoice communication program, all participants developed new skills surrounding different methods of photo sharing (email/SMS/airdrop/chat groups/social media platforms) using smartphones, tablets and computers. The immediate feedback from photo sharing on social media was a positive and engaging experience for first time users during the study period (n=4).

"They're already replying, we've already got responses!"

Table 6 outlines mainstream communication modes that can be modified and individualised to participant needs during the photovoice communication program. With the advent of smartphone technology and social media, photo-sharing is indeed a mainstream form of communication, both face to face and online, and is therefore included as a mainstream communication mode, something not seen in related literature.

Table 6– Mainstream Communication modes (adapted from McKelvey et al. 2012)

Communication channel	Mode (verbal/non-verbal)	Demand	Feedback
Face to face	Both	High	Immediate
Phone	Verbal	Very High	Immediate
Skype or Facetime	Both	Very high	Immediate
Writing	Nonverbal Pen/paper	High	Delayed
Email	Nonverbal Text +/- photos	High	Delayed
Text message	Nonverbal Text +/- photos	Low/medium/high	Delayed
Social media	Nonverbal Text +/- photos	Low/medium/high	Immediate
Photo-sharing	Both	Low/medium/high	Immediate

100% of participants reported they used social media, with 'Facebook Messenger' being the most common platform, followed by Facebook and What's App, all these platforms support photo-sharing. As part of the photovoice program, all participants were taught skills regarding photo-sharing methods on smartphones/tablets, how to download apps from the App store, navigate social media, create a new chat group or join an MND specific closed group on social media. All participants also completed a social network map and identified family or friends and were encouraged to create a new personalised group chat on the social media platform of their choice.

The results demonstrated that two thirds of pwMND successfully expanded their social networks by establishing new group chats on social media, 7/9 reported increased frequency of posting photos on social media and 8/9 increased their overall use of online photo-sharing as a form of communicating with family and friends (any method - social media, MMS or email). The individual capacity building in this regard was integral to expand communication modes which enabled continue or renewed social connections.

Table 7 summarises the increased frequency of these communication modes on completion of the photovoice program.

Table 7 Expanded Communication modes on completion of photovoice program

Participant pwMND N=9	Use of technology to communicate	Frequency of social media use to communicate (any method)	Frequency of photo sharing with family and friends (any method)	Social media Number of group chats or private groups	Social media Active posting or sharing of photos (with or without text)
1	No change	No change	decrease	increase	increase
2	increase	No change	increase	increase	increase
3	No change	increase	increase	increase	increase
4	No change	increase	increase	increase	increase
5	increase	increase	increase	No change	increase
6	No change	No change	increase	No change	Not recorded
7 Withdrew	N/A	N/A	N/A	N/A	N/A
8	No change	increase	increase	Increase	increase
9	No change	Increase	increase	Increase	Increase
10	Increase	No change	Increase	No change	No change
Results	3/9 increased 6/9 no change	5/9 increased 4/9 no change	8/9 increased 1/9 decreased	6/9 increased 3/9 no change	7/9 increased 1/9 no change 1/9 missing data

Participants acknowledged that the photos themselves also provided an inroad to difficult or sensitive topics. The provision of facilitators with expert knowledge related to MND and communication impairment was considered essential to create an environment of trust, to enable participants to share stories they might not have been previously willing to share or even acknowledge. One participant noted that certain topics such as diagnosis were 'difficult' and later reflected that photo-sharing provided a communication mode that enabled easy discussion of topics previously "put in a corner".

> *PwMND "it's 4 ½ years diagnosed and we were going out one night recently"*
> *Carer "And he's like I'm going to have to go shopping, these clothes, you know I need some new clothes"*
> *PwMND "I really thought these clothes would see me out"*
> *Carer laughing – "I said - You can't say that!"*

What matters to you?

Communication was collectively identified as the most important key to connecting with others to avoid social isolation.

> *"Being able to communicate with people and express your feelings and emotions".*
> *"If I don't communicate with others, I'm stuck with just me and that is not a pleasant thought. Communication is essential. The more I focus on me, the more I focus on what I can't do".*

Barriers to communication identified by participants were both disease specific and systemic. MND specific including: speech loss or deterioration in speech, fatigue, communication breakdown, failure of services to meet communication equipment needs in a timely manner, loss of communication closeness (jokes, intimacy).

> "Mostly I miss having long conversations and cuddles in bed as X is now in a hospital bed and tires very easily. Also, our social activities have reduced considerably".

> "Tiredness=less energy. Less energy= worse speech, lower ability to be 'up'".

Multiple data sources highlighted the many barriers to communication, particularly for the anarthric (nonverbal) participants. Synchronous communication modes involving rapid exchange between multiple conversation partners at the same time, presenting high demands for those without speech. The photo narrative and field note datasets (refer to photos 4, 6 and 8) highlight the challenges: the lag in contributing to group discussions, conversations moving too rapidly for written expression, missing nonverbal cues because head down writing, reliance on others to communicate detail on their behalf, or reliance on equipment.

One participant with complex communication needs due to weakening speech and dominant arm use expressed his frustration at losing access to mainstream communication modes including his phone, ipad and associated email, internet and social media access for communication.

> "I'm getting to the stage now where I can't use the ...keypads... I'm finding it very hard to use the phone and the ipad…and I've been waiting…This has taken quite a while to get approval. (waiting on NDIS approval for hands-free technology to access computer tablet).

Another nonverbal participant was observed to become very frustrated during a group discussion trying to quickly type a response to a question on his phone, his desire for speed, causing increased error rate and subsequent communication breakdown.

Systemic barriers included feeling stigmatised and lack of knowledge by organisations or the general public leading to stereotypes and discrimination. Many narratives related to communication impairment creating a barrier to maintaining social participation.

PwMND and their carers expressed feelings of marginalisation because others unknowingly applied stereotypes or made assumptions (deaf, intellectually impaired, drunk) or perceived you as disinterested or "rude" for not joining a conversation. Many participants shared the impact of this on them emotionally, expressing feelings such as frustration, sadness, embarrassment, shame and anxiety. The 'hidden nature' of communication impairment in bulbar MND was raised by each group as an issue in public places such as in cafes/restaurants, shops and when travelling, particularly through airports or on public transport.

Facilitators to communication included: patience, knowledge of how to support someone with communication impairment, or "willingness to learn".

> *"Other people don't understand my speech, but they (my family) do. Sometimes I have to say things twice, but they finally understand what I mean. They never give up!"*

Main theme 3 Networks of support for wellbeing

Figure 12 Main theme 3- Participant photos with illustrative data extracts

Photo 1: 'Miss Sunshine' these are our neighbours. They have a little ..the daughter who is 12 now, she's very very fond of X and she said I want to send you a happy text every day ..and so they text each other every day without fail - they've been doing it for 2½ years without fail.. she never forgets, never! It's quite the most incredible thing. She calls him her blue crayon because it's the colour of the sky and it's her favourite colour… and he calls her Miss Sunshine.
Photo 2: Light the night at Fed square - supporting my brother in law who died from leukaemia.
Photo 3: "This is my daughter, she's 20 now. She's a gorgeous girl. This photo..it just brings me joy."(crying).
Photo 4: "I just put that down to love. The dog, Holly she jumps up on the chair. Yeah she licks my right hand every day, she knows, she senses it.. (muscle weakness in right hand) Um, I'm the only

one she jumps up on. Everyone else she'll ah be on the side of the chair. But for me, she uses the foot elevation, if I get it to about halfway up, she uses it as a ramp."

Photo 5: 'Bent thumb thinking' – blog and book. A collection of life stories of resilience written by one participant and shared with others. His advice to participants "To maintain contact and ask for help and share yourself with others and find ways of helping them."

Photo 6: We help our kids by caring for our grandchildren

Photo 7: online courses enabling continued learning from the comfort of a loungeroom.

Photo 8: All participants (n=17) had a football narrative – the family bonds and network of social and emotional support created through supporting a team were very significant

Family support was the most significant contributor to wellbeing but there were also prevalent subthemes highlighting the special significance of children, grandchildren and emotional support dogs. "Nothing better, get involved with what children are doing." All participants communicated the reciprocal love and support shared and the sense of purpose it provided them to be needed by family, including pet dogs, who were considered part of the family by all participants except one couple who didn't currently have a pet dog. There was also a strong theme of the value of expanding personal networks and many photo narratives told of the "generosity, spontaneous generosity of other people" and the meaningful support this afforded.

> "We have a wonderful church community for emotional support. If anything goes wrong, they ask what can we do? It makes such a difference if you feel wanted and worthwhile."

Having a sense of purpose was also an important narrative. Many participants shared photos showing their roles as grandparents and mentors. Carrying on family traditions and instilling family values to children and grandchildren resulted in many positive narratives surrounding the participants perceptions that supporting others was an important role they undertook; "looking outwards, not inwards" surmised one group. There was evidence of formation of new networks forming as a result of the research project itself, as well as significant uptake of both personal and online support networks via social media.

Main theme 4 Maintaining social participation

Figure 13 Main theme 4-Participant photos with illustrative data extracts

Photo 1 - "Get involved with what children is doing. 3 generations of scouts. I was warrant leader 25 years. Dad came Australia through the contact Scouts." Crying (subtheme 4.2, 4.4)

Photo 2 - "Our house is designed for a family that's got good mobility. It doesn't give you a good indication on that photo but my driveway's like that (gestures steepness). So I can't get out of there, the wheelchair doesn't have the grunt to get up there." Frustrated (subtheme 4.3)

"The lady that interviewed us couldn't believe the photos!" (referring to NDIS application).

Photo 3 – This is my carer whose name is Peter. He has helped me a lot, mainly dropping me to the Mauritian Club on Tuesdays, on Wednesdays we go to the bowling club and on Thursdays we go out together even to see my mum at the nursing home and everywhere else I want to go. Peter is a gentleman. I met his wife…I've invited them for my third grandson's First Communion at the church then to the primary school for the party." (subtheme 4.3)

Photo 4 – "St. John has been a big part of my life. Every year the order of St. John have a service of rededication at St. Paul's Cathedral. After the service, members of the order gather with the clergy at the high alter for a photo. Can you spot me? The order of St John is a royal order of chivalry. Members of the order are appointed by the Queen." (subtheme 4.2)

Photo 5 – Jarrod Ruffy. "My neighbour gave me these. I love Hawthorn and football is a great connector. When I go to CHCB, I'm on! I joke with the staff; I feel like I get better care." (subtheme 4.5)

Photo 6 – "Travelling musts" Narrative related to communication barriers and stereotypes, subtheme 4.5, see below

Photo 7 - With mobility decline, caring for a young grandchild was difficult for one participant but two grandmothers buddying up allowed continuation of her usual caring role, with the value adding benefit of a regular social outing to a favourite local café. (4.1)

Photo 8 - "These 4 walls! Social isolation, that's one of the barriers when you're stuck at home". "Getting out! The lack of day to day interaction is challenging. These 4 walls, at times I feel like they're closing in. I need group interactions and regular social connectivity, like meeting at a café, having a forum on Facebook. I've joined a few forums in the US and MND Australia has a forum in its infancy. I'm more of an observer though".

"I have a carer Monday to Friday but there's a language barrier with my main carer, she sits downstairs and watches Netflix or TV." (subtheme 4.5)

'Stopping your universe from shrinking'

Participants shared numerous examples of how important social inclusion is to their social emotional wellbeing and quality of life. All participants expressed that maintaining social

connections really mattered. Despite the obvious barriers, the participant photos depict how they overcome challenges to remain active participants in community life. For those participants who were wheelchair bound (n=3), physically getting out of the house was a significant barrier, requiring carer support and equipment.

Key findings included: The social network provided by immediate and extended family was considered to be the most significant contributor to maintenance of social participation as evidenced by the volume of photo narratives which spoke of belonging and inclusion. Keeping passions and traditions alive was also considered vital by all participants and was usually part of the narrative of social inclusion and community life, which clearly enhanced emotional wellbeing. Those not able to maintain passions and traditions, expressed this detracted significantly from their quality of life. The sharing of experiences, ideas and tips for adapting and overcoming barriers to social participation centred around two main strategies: trying new modes of communication and addressing stereotypes and attitudes that were perceived as a systemic threat to social inclusion. Many participants were <65 years old and of working age, which posed a challenge for pwMND if they rely on alternative carers whilst their partners were at work. "The carer is so important, can make a huge difference to my daily life". Positive and negative experiences with NDIS carers highlighted the value of ensuring a good match between carers and pwMND, which had an enormous impact on communication, social participation and the emotional wellbeing of the family unit. Photo-sharing triggered passionate discussions about social isolation and social inclusion from all participants.

> *"To be accepted with the disability… from your social group, some people just don't know how to handle it."*
> *"It (MND) can be extremely isolating and you do withdraw and that's something that is problematic".*
> *"Reliable, safe care is vital so I can go to work and not feel guilty."*
> *"it's a topic that has caused our friends to think about communication. We have always shared photos, but this adds another aspect."*

Photo 6: 'Travelling musts' "You have to be adaptable in certain circumstances. I lost my cup in South America the first two days we were there. We went hunting for a cup that can help me. And the blender we got with us packed out the first week as well and we went shopping." (non-verbal participant - photo and narrative received via email prior to session to facilitate participant's independent input to discussion). The participant also shared his story via social media (personal Facebook page) enjoying engaging in more nuanced or humorous conversation, the renewed connections with family and friends clearly facilitated by photo sharing.

"Photos, photos, photos, that's all he does now!" (wife of pwMND)

Main theme 5 Taking action

Figure 14 Main theme 5 -Taking Action – photos that triggered actionable participant driven initiatives (photos 1-4 top row, photos 6-8 bottom row)

Photo 1: "The Urubamba River or Vilcamayo River is 650 km long and runs into the Amazon from the Andes and runs pure clean water into Cusco then through the Sacred valley and finally through Machu Picchu township and all these towns pollute the river where you cannot even touch it. It looks beautiful but it is polluted. And it finally runs into the Amazon in Brazil. Someone, everyone, even one person can make everyone aware of this problem and put pressure into the Cusco council to do something to change this outrage action. Maybe filters in the water after Cusco then after Pisaq and then after Michu Picchu town ship. I don't know but all suggestions will help. Let's all get together to change this."

A key finding was the desire for participants to be active citizens and take action on things that mattered to them. (agency/capacity to act). Renewed or enhanced narratives are evidence of the desire to have a voice and contribute to society. Photo one is an illustrative example that demonstrates an individual's passion for the environment and desire to conserve and protect our waterways/oceans through reducing pollution. The photo and accompanying text were posted by the participant on his personal facebook page with a call to action. Following discussion with the group and further reflection, the participant also emailed some photos to the international arm of SeaShepherd.org. to request action.

> Photo 2: "Acceptability of the person with the disability is the biggest issue. You look normal, the staff, the young, they don't understand what you're going through."
> "People judge and make you know….assumptions." "I'm not pissed, I've got MND!"
> Photo 3: Alert! I have MND. Participant sharing ideas for group appraisal to address the 'lack of knowledge' narrative. (photo of wristband available in UK, researched by participant)
> Photo 4: "Everybody is different… different struggles, appearances, different challenges. Accept diversity. Embrace each other." Self-portrait of participant's teenage daughter who has alopecia.
> Photo 5: "Mt Beauty." The 'beauty' narrative – appreciating nature and all art forms for the inherent therapeutic value.
> Photo 6: Singapore -Family meet-up. The 'lack of knowledge' narrative revealed feelings of stress and embarrassment as the couple were forced to separate during customs queue, with an added security delay for examination of pwMND's feeding tube lying discreetly under his clothes (the tube is connected directly into the stomach to allow administration of liquid nutrition if pwMND has weak swallowing muscles)
> Photo 7: Can you tell who has communication impairment? "People can assume because you can't speak, you can't hear. I'm mentally aware and I can hear you! Don't be scared of talking to me." (nonverbal participant communicated via text to speech app)
> Photo 8: Fight MND. "I'm waiting on a trial; I'm just waiting on the call." Representative of the frequent quest narrative- Neil Daniher (the hero) leading the battle to defeat MND, 'the beast'.

Photo seven was planned by Group 3 and taken during a group session to show the "hidden" nature of communication impairment. This was sparked by narratives relating to requirement of a "visual" aid to flag a disability to staff. The photo is intended to pose the question. How do we see a hidden disability? The carer told of a recent airport experience with her husband (bulbar MND, ambulant but anarthric/nonverbal)

> *"I put this on (arm sling) because I have to, and we're being shown the shortest distances to go through security. He's mobile so no-one's paying any attention."*

Active citizens / Having a Voice – Tackling discrimination.
Narratives detailing experiences of discrimination and stereotyping arose on a weekly basis. Through a democratic process involving all participants, decisions were made to prioritise collective actions to stimulate change.

Key points were agreed upon and photos selected for a letter which was emailed to the Victorian Commission for Gambling and Liquor Regulation. The letter called for content revision in Responsible Service of Alcohol Training program (RSA). Following several email exchanges between the group and the Commission, an MND case study/teaching tool was developed and provided. The Commission has communicated that the case study will be considered at the next revision of RSA training content, an outcome is pending. (see Appendix 5)
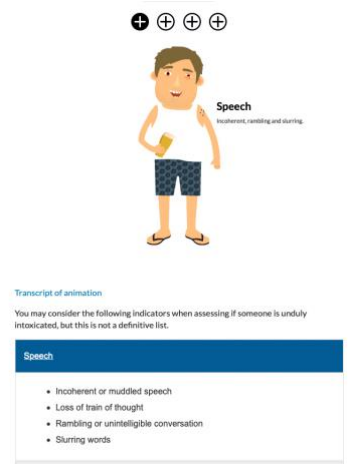

Figure 15 'Dave' Stereotyped RSA training animation

A letter with accompanying photos was also emailed to MNDA, the peak Australian body for MND, requesting wristbands similar to UK MND association with the intent of ensuring critical knowledge is conveyed in the event of a medical emergency for bulbar MND participants, who are unable to speak, and potentially unable to use AAC in this scenario.

Renewed agency: Some participants expressed how photovoice narratives allowed them to overcome what was perceived as a 'forced passivity' that occurs with social isolation and communication impairment.

> *"Normal! Just chatting with everyone is what I need. Sharing photos can show our issues. The photos help understand what we are going through. I can see how useful they could be for education, changing people's awareness; most people don't realise.*

> *"It doesn't matter what you're going through in your life, there's always room to speak for others and with photos you can prove that you can change things in the world."*

The importance of developing MND specific knowledge in the community was also highlighted such as one pwMND's action using photo-sharing to inform NDIS staff of the necessity for equipment to enable him to leave the house safely to access the community.

> *"The NDIS is a great scheme but it's being staffed by non-medical people and they don't understand what the individual's going through."*

Personal growth narratives: Many participants from all three groups, shared their passion for aesthetics, with photo narratives detailing the beauty of nature, architecture and artistic features of the world. Two pwMND (photography and writing interest/hobbies)

collaborated and sparked an action to develop an image library to inspire others living with MND. A selection of photographic images has been provided to CHCB for development of an image library that will be utilised in the hospital environment (waiting areas, wards, clinic rooms) as an art in health 'Living Well' initiative.

Chapter 5 Discussion

Building Social Capital

The thematic analysis yielded rich data regarding the outcomes, impact and nature of change for participants on completion of this study. Participants shared 312 photos that form the evidence of how to live with MND. The photos privilege the participant voice and uncover "truths" about how these individuals see their world, underpinning the individual and collective narratives and the communicative power of the visual image to tell a story, invoke awareness and be a stimulus for social change.

Further thematic reduction pinpoints three recurring outcomes that were of greatest value and most interest in creating the shared sense of identity and understanding required to build social capital. These included:

- Self-reflective inquiry. Participants were highly engaged to understand and improve their world. The duality of narratives such as resilience vs loss, risk taking (participants) vs risk aversion (health professionals) and social inclusion vs exclusion, prompted a continual inquiry into understanding the situations they find themselves in. Social inclusion was the dominant narrative, considered by participants' to be integral for maintaining social participation and building social capital.

- Agency – The participants' realisation of renewed agency or enhanced agency – the self-esteem and emotional wellbeing that comes with taking control and taking action was acknowledged to be protective for their health by giving them a 'voice' and building capacity for engaging in self-care.

- Actionable, participant driven initiatives for individual or collective change was of most importance to participants because it reflected what mattered to them. The participatory action research approach ie 'photovoice' was integral, the equal distribution of power allowing participants more scope and control to determine priorities, collaborate and effect change as part of a 'team'.

Figure 16 is a thematic schema summarising this interpretive analysis in which "taking action" is the foundation that stimulates the changes that in turn lead to improved quality of life.
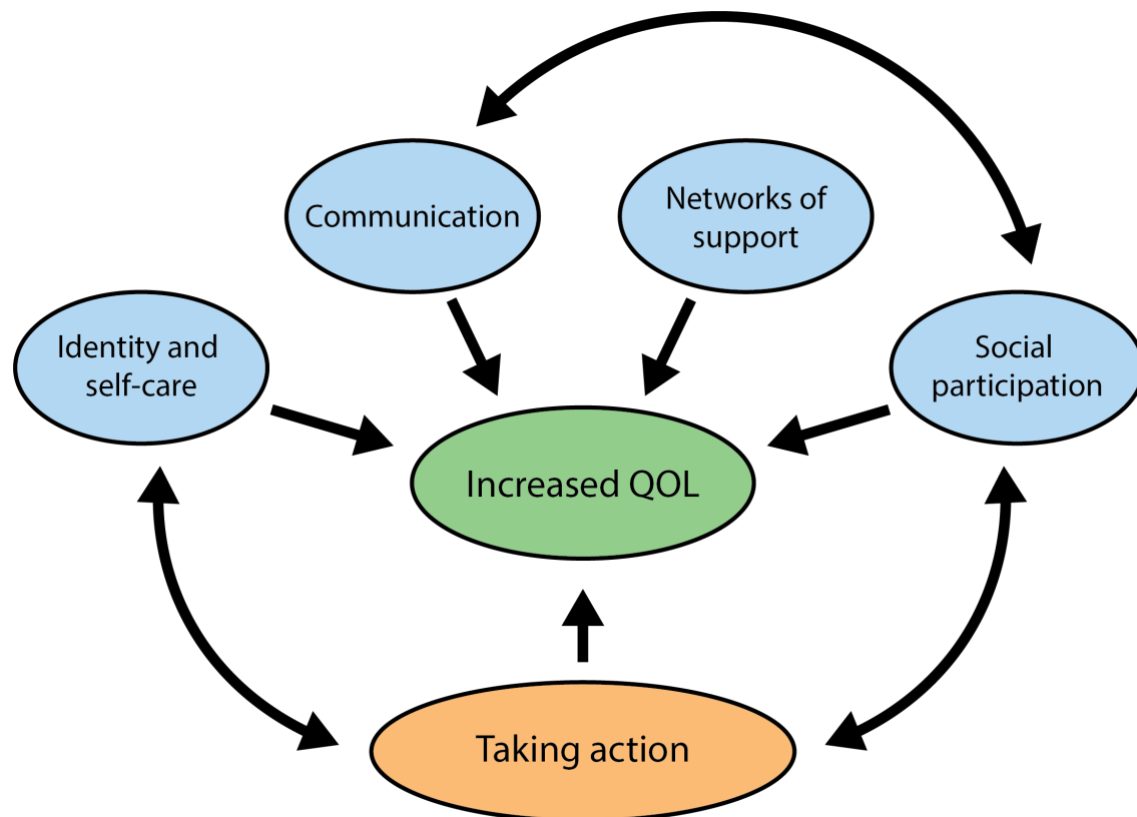
Figure 16 Photovoice impact on QOL. Thematic schema

The value of photovoice in promoting health through self-reflection has been acknowledged in the literature (Latz, 2018), as has the therapeutic value gained by appreciating photos depicting the everyday beauty surrounding us; the intangible 'quality' of people, nature and artistic forms of many varieties. Participants frequently expressed feelings of happiness and joy, to the point of tears, when viewing the photographic images, whether their own or others. This was an unexpected outcome for many, but one that is acknowledged in the growing evidence showing the therapeutic value of sharing and viewing art (APPG, 2017, Fancourt and Finn, 2019). The significant positive impact of the photovoice program on quality of life for pwMND and their carers is evidenced in the patient testimonials (see Appendix 4).

This research also builds on the current body evidence showing how the arts affects the social determinants of health, and their particular role in enhancing social cohesion (Fancourt & Finn, 2019, Gordon-Nesbitt & Howarth, 2019). "Belonging to a social

network of communication and mutual obligation makes people feel cared for, loved, esteemed and valued" (Wilkinson & Marmot, 2003 p.22). This has a powerful protective effect on health. Participants responses to how the photovoice method made them feel are testimony to the impact on quality of life and the group dynamic itself was one of the most treasured outcomes for those who may lack other support companionship or trustworthy relationships in their life. Furthermore, as Wang and Burris (2007) proposed, as well as building critical consciousness, the photovoice process also built a reflective conscious, which engendered personal development through allowing participants time and space to reflect on the stories shared by others.

Individual Practice

The findings from the metasynthesis discussed in Chapter 2 highlighted that agency, the capacity of individuals to act independently and make their own choices was critical to health. The evidence from this research demonstrates that shared photo narratives empowered participants to make significant changes or improve their own practice, which resulted in enhanced capacity to self-care. There was a high level of 'trust' amongst group participants who showed respect, understanding and compassion to each other, which led to reflection on their own practices. The thematic analysis revealed particular behaviours were considered critical to emotional wellbeing and self-care: keeping passions and hobbies alive, the power of positivity and nurturing the emotional connections in your life, particularly family and dogs. The sense of inclusion and belonging afforded by supporting a football team was another very strong facilitator of connecting with others. "Get a dog and barrack for Hawthorn" was an agreed upon 'silver linings playbook' by one group. The emotional support offered by dogs and the positive impact on quality of life was so powerfully conveyed that the only participant dyad without a dog, went to a rescue shelter and came home with a seven-year-old beagle named Harry.

Critical to achieving action outcomes with the population under study, was the expansion of communication modes using photo-sharing, the skills development and individual capacity creating the required link to renew and enhance the social networks that maintain social closeness and support social participation. In contemporary society, internet-based communication is mainstream and perceived as 'normal' and research suggests persons with complex communication needs can especially benefit from online social networking

sites to support communication and enhance social participation (Bay, 2017, Caron & Light, 2015). The findings of this research show that photos provide evidence to inform family or friends in their social network that pwMND are still actively living a 'socially active' life despite MND. This created a focus on 'health' rather than 'disease' providing knowledge, strategies of how to connect and an avenue for people to connect.

Therefore, whilst the Wang and Burris (1997) photovoice methodology principles and processes were embedded in this research, an important practice component, using contemporary mainstream photo-sharing practices was built into the CHCB photovoice program based on the evidence gaps revealed in the literature review conducted.

Collective action, **participant voice and empowerment**
Photovoice researchers, which include the participants themselves, aim to garner the attention of policy makers. It is evident that the power of the photovoice technique has allowed the participant narrative to gain the attention of policy makers in a way that words cannot (Latz, O, 2012).

Taking action encompassed subthemes of agency, having a voice, tackling discrimination and inequalities but also quest narratives, full of optimism and hope for the future. The photos and accompanying narratives formed the basis for grass roots participant driven action resulting in a range of individual and group outputs that undeniably led to a perception of improved quality of life for the participants involved, with 100% of participants responding that photovoice did impact positively on their quality of life.

As highlighted in Chapter 2, only 47% of included studies in the photovoice metasynthesis reported an action component to advocate or promote social change, as is the objective of photovoice research (Wang & Burris, 1997). Of those reported, that action component was usually a photographic display with intent to influence policy makers. The collective actions in this current study were based around the participants collective decision making to expand awareness raising to include specific knowledge building as the participants perceived that the general public lacked knowledge and understanding of MND and how it affects individuals and families. Whilst participants were interested in a photographic display, they collectively chose a more specific path to tackle discrimination and address inequalities resulting from communication disability. All participants shared powerful narratives of feeling marginalised or stigmatised,

invoking emotional and passionate discussions. Whilst a photo was always the common referent, the discussions were animated and employed multiple modalities of communication including listening, speaking (with varying degrees of intelligibility), non-verbal (body language, facial expression, intonation) and frequently additional photos or online sources of information via someone's smartphone.

The examples of collective actions outlined in Chapter 4 were intended by the participants to address systemic barriers to social participation. This included stereotyping and discrimination in the service industries- perceived to be related to a systemic lack of knowledge/understanding by staff employed in hospitality and travel industries, with specific reference to public transport, airports, travel companies, cafés and restaurants.

The notion of communication impairment as a 'hidden disability' was also raised as barrier to social participation with photo narratives showing how communication disability impacted on pwMND and their carers when accessing the community. The Melbourne Airport Hidden Disability program was discovered by participants during the data collection phase of the research project. It is a new initiative launched in September 2019 to alert airport staff to customers with a hidden disability. The program is in its infancy with stage one focusing on Autism Spectrum disorder.

> *"Our Melbourne Airport staff will all be trained in the Hidden Disability Program to ensure that additional care and consideration is provided during your time through our airport and ensures staff are able to assist in your journey. Whether that be guiding you through each step, providing you information or slowing down a process in the customer journey for you, we are here to ensure your mental and emotional health is looked after."*
> *(https://www.melbourneairport.com.au/Passengers/Passenger-information/Hidden-Disability-Program)*

Following the photovoice participants' collective agenda, consultation and sharing of photovoice narratives with the Hidden Disability program staff occurred and resulted in Melbourne Airport's decision to include an MND case study in the staff training package to build awareness around the impact of communication disability in adults and is generalisable to other similarly impacted populations (eg. stroke, acquired brain

injury) The MND case study will also be used in a photographic social story that can be accessed by airport customers who register with the Hidden Disability program.

These customers wear a lanyard which alerts airport staff to their needs as they travel through the airport. Three couples involved in the research project have volunteered to participate in the photo shoot and interview which has been booked at Melbourne airport in late February 2020. This will have a significant impact on knowledge and understanding exhibited by airport staff. Based on its initial success the Hidden Disability program has been funded to rollout in all Australian airports during 2020.

Study limitations:
- **Quality of Life measurement**

Quality of life is a challenging outcome to measure systematically and objectively as it is related to an individual's perception and the context and culture in which they live. "The Constitution of the World Health Organization (WHO) defines health as "A state of complete physical, mental, and social well-being not merely the absence of disease . . .". It follows that the measurement of health and the effects of health care must include not only an indication of changes in the frequency and severity of diseases but also an estimation of wellbeing and this can be assessed by measuring the improvement in the quality of life related to health care" (https://www.who.int).

Studies have found social support to be important in governing a pwMND's perceived QOL (Epton et. al. 2009) therefore there are obvious validity issues surrounding the use of QOL tools that measure physical function in the MND population. There is some support that slower disease progression is associated with higher levels of emotional wellbeing (Prell, 2018) but on the whole, MND research has shown that satisfaction with life is not strongly related to level of physical impairment (Neudert et al. 2004, Tramonti et al. 2012), and that quality of life in MND can be maintained as physical function declines (Robbins et al. 2001). MND specific studies have also found that communication impairment is associated with psychological distress and significantly impacts QOL more so than physical decline (Chio et al. 2004, Mistry & Simpson, 2013), consistent with testimony from participants in this study.

> "Having a voice, I find that to be the hardest thing of the whole MND thing. Mobility changes are easier to manage than speech changes."

The standard CHCB outcome measure, Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS) is a widely used tool that measures the rate of physical decline on ten physical parameters over time and is thus not considered a valid indicator of quality of life. Two patient-centred QOL outcome measures were considered for this research, The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) and the WHOQOL-BREF. The SEIQol is based on the premise that QOL is subjective and therefore the interview-based tool assesses quality of life from the individual's perspective. The SEIQoL has been used to measure quality of life in MND but was not sensitive to change over time although the authors noted the information was useful for informing goals of care in health services in order to achieve increased satisfaction in the areas of life that are felt to be important (Olsson et al. 2010).

The WHOQOL-BREF was selected because it is a validated tool that is based on the WHO definition of quality of life, measuring social, psychological and environmental domains in addition to the physical domain. Despite inclusion of these additional domains, there were issues with specificity and sensitivity in regard to measuring the impact of photovoice therefore the results did not demonstrate any significant change in quality of life. Conversely, the action research methodology yielded rich and compelling evidence that a photovoice 'health promotion' approach did impact on communication and social participation and did result in improved quality of life in MND in accordance with the definition outlined above by the World Health Organisation. The Public Health Association of Australia acknowledges that application of such findings continues to be limited by health organisation barriers such as funding models, reduced understanding and consequent hesitancy by health organisations to drive the cultural and organisational change required to translate findings into patient-centred health care practice (PHAA, 2019).

- **Representation**

A critical question to consider in interpretation of the results is who is represented, and more importantly, who is not represented? Demographic data shows a good spread across different SES suburbs and the characteristic profile was typical although males were overrepresented at 7:2 with current epidemiological data highlighting a male to female ratio of 3:2, according to MND Australia. The inclusion of partners as participants did

balance out the sample to an even gender spread, with ample evidence in the literature to show that carers, in fact the whole family, are affected and need support (Gallagher and Monroe, 2006, Olsson Ozanne et. al. 2012). Barriers to participation may have also included difficulty with transport or distance to study site. These barriers were mitigated by having two sites and offering financial support for transportation if required.

- **Vulnerable populations**

Representation of the communicatively vulnerable in research is another challenge. A recent critical review of the qualitative studies that informed the development of the Australian Hospital Experience Patient Survey (O'Halloran et al. 2019) demonstrated that participants with communication impairment are often intentionally excluded or participation is precluded by study design, lacking the communication support required to participate. Only 10% (4/39) studies evaluated showed evidence that communicatively vulnerable participants contributed to the findings. The authors justifiably question the validity of patient experience outcome measures being developed in Australia if the perspectives of people who are communicatively impaired have not been included. Internationally, this is also acknowledged as an issue and there is increasing recognition of photovoice as a methodology that is more inclusive of those with a range of disabilities (Shumba and Moodley, 2018) due to its ability to overcome common barriers to participation including language, literacy and communication (Catalani & Minkler, 2010), which frequently exclude already marginalised populations such as CALD communities. (Chew 2017). One participant noted "the people who declined are probably the people who would benefit most" and indeed the only dyad to withdraw, did so because of multiple complex barriers including communication impairment requiring use of high tech AAC, transport difficulties, family relationship difficulties and suspected reduced health literacy surrounding the research aims and outcome measures being utilised. Raw scores from the initial WHOQOL-BREF also highlight this participant as a significant outlier on all domains, the low scores suggesting that reduced QOL was itself a critical barrier to engagement in the research. This demographic profile in this case also serves to highlight the impact of SDH, as the demographic profile of suburb, education and occupation is one which has been consistently shown in the literature to be associated with health inequities and reduced engagement in health promoting interventions (PHAA, 2019), which raises the issue that "often the least powerful in a community are the least

likely to participate" (PHAA, 2019 pg.5). This presents a limitation when using small samples for qualitative research.

By nature of MND and communication impairment, recruitment may have been impacted by the barrier of speech impairment and the perceived difficulties associated with participation, including assumptions attached to the nature of photography itself, which in a photovoice study is unlike photography in everyday life. Almost 50% of pwMND participants were anarthric (complete speech loss) with one such participant, initially hesitant to participate because of this. Once familiar with the photovoice method, this participant was highly engaged and demonstrated the most active voice, both individually as well as being a key driver of collective action, which in turn produced outcomes in which photovoice was clearly the change agent.

In this study participants were invited to participate with broad themes and processes (photovoice) already established in the 4-week CHCB Photovoice communication program. This may have influenced whether or not participants photographed what they really wanted, even though each participant self-selected their photos and made their own decisions about whether a photo carried a meaningful story or not. As in the study by Bendell (2017), it was noted that participants tended to take a planned approach to photo taking or a discovery orientated approach, which could also influence the type of photos produced or result in a missed photo opportunity, the process employed, contributing to the style of the group and its collective action direction. Group 3 employed a high degree of planning, and the photos reflected a task-oriented approach to capturing photos to reflect their underlying goals for change, particularly those surrounding combating stigma and discrimination.

The manner in which participant voice is prioritised and disseminated has also been questioned in several reviews of the literature (Harley, 2012, Evans-Agnew, 2016) with suggestions that much photovoice research only serves to raise awareness, without achieving any measurable or concrete social change. In this research, the 'action' outcomes demonstrate that participant voice was prioritised and that participants themselves were the drivers of change that are concrete and will benefit, not only the population under study, but all populations marginalised by communication impairment.

The Ottawa Charter – A Public Health platform for improving quality of life

Community participation is a "crucial feature of health promotion" as described in The Ottawa Charter which features individual and collective participation as a key principle of public health (PHAA, 2019. pg 2). The Ottawa Charter identifies three basic strategies for health promotion: advocating for health enabling people to achieve their health potential and mediating between different societal sectors to achieve health. (WHO, 1986)

These strategies are supported by the five priority action areas as outlined in the Ottawa Charter for health promotion. which can be applied in making recommendations about creating health for MND.

- Build healthy public policy
- Create supportive environments for health
- Strengthen community action for health
- Develop personal skills, and
- Re-orient health services

These same priorities are evident today in reviews and reports detailing the continued drive to transform health care (Kumah et al. 2017, Consumer Health Forum's Shifting Gears report, 2018) and can easily be applied in making recommendations about creating health for MND that represents their self-identified needs and is person-centred and sustainable.

Sustainability

The importance of specialised knowledge and experience in working with MND and specifically communication disability, is critical to the success of action research as an understanding of the issues faced by the participants and the way they are viewed by the wider community is critical.

As acknowledged in the Real People Real Data Project (Consumers Health Forum 2014), PAR that engages consumers and seeks their stories requires ongoing leadership, time, skill and commitment to act on participant stories, if collective action to influence policy is a desired outcome. This has been the case in this study with ongoing action continuing on many fronts at the time of writing, two months following data collection.

Conclusion

Communication is fundamental to social participation. The use of photovoice methodology presents an innovative method to support participants with communication impairment to participate in research that has a high communicative demand and in fact mandates their right to freedom of expression and opinion.

The findings of this research focused on the use of photovoice as a change agent and the impact this has on communication and social participation, both of which were considered to be crucial to maximise quality of life for people living with MND. Participants included pwMND and their partners, acknowledging the evidence that states the quality of life for carers is equally impacted by MND.

Five themes were derived including:

        1. identity and self-care,

        2. communication and connection,

        3. networks of support for wellbeing,

        4. maintaining social participation and

        5. taking action.

Through the use of photovoice, participants identified community assets and issues that were the drivers for change. Participants developed capacity to create personal change as well as demonstrating they were able to build social capital and create a community culture that is confident and capable of having a voice. A number of outcomes were identified that contributed to improved quality of life. These included:

- expanded modes of communication
- improved communication with family and friends
- new, renewed and strengthened social connections
- increased community engagement
- empowerment – having a voice and be heard
- therapeutic effects of an arts in health approach
- changes in policy or practice

Recommendations and future directions - Creating Health for MND

The research has identified five public health priorities that positively influence communication and social participation for pwMND, their families and the MND community at large. These are represented in a schematic in Figure 17. Based on the thematic analysis, patient driven actions (outputs) and outcomes of this research, specific recommendations regarding patient-centred care for MND are made.

1. Knowledge and understanding

   Health services that demonstrate disease specific knowledge and compassion are highly valued. MND Victoria and CHCB meet these criteria, but there is a lack of trust surrounding NDIS in this regard. A tension does exist between the medicalised environment and the reality of living with MND. Non-compliance with medical recommendations is frequently seen by health professionals as ignorance but viewed by the pwMND and their carers as the assertion of a voice that accepts risk in order to maximise quality of life, in the context of family values and culture. There is a need for peer-based support networks in culturally relevant local settings (online and face to face). The evidence from this research highlights the emotional benefit gained from the shared understanding and social capital achieved through participation.

2. Socially inclusive, compassionate communities

   Social inclusion has been shown to be critical for health therefore increasing community capacity and creating supportive environments for health are integral. Compassionate communities should be considered a societal responsibility requiring a change in social norms and a shift in culture towards social inclusion which reduces stigma and builds individual and collective resilience in the face of loss (Grindrod and Rumbold 2018). Working directly with organisations to provide community insights that can lead to policy change can create advocacy and action pathways that result in concrete changes that benefit the MND community.

3. Tackling discrimination. If there is an opportunity to educate/advocate or influence others, it should be taken. The lived experience is meaningful and carries great weight however a lack of awareness may be related to the inherent

difficulties of those marginalised by communication impairment to have a voice. The use of photos and photo narratives as a strategy to promote social inclusion for pwMND has been shown to be highly effective and can result in concrete change when targeted to a specific audience/organisation.

4. Expanded communication modes

   Individualised strategies are required to ensure communication is not just needs based but nuanced sufficiently to be able to meet the emotional demands of maintaining close relationships. Speech Pathology expertise and knowledge is critical, as is timely access to specialised equipment and support to ensure functional use beyond basic needs. Changes in usual care for Speech Pathology practice is recommended to harness the potential of photo-sharing in all manners (face to face and using digital technologies). Ipad and mobile technology has opened new doors for AAC users (McNaughton et al. 2013), however a move to harness social media and promote communication through social media is integral. The internet and mobile technologies are highly acceptable by pwMND and their support networks because they are perceived as 'normal' and because they are effective. Web-based tools using information and communication technologies to expand the reach and impact of photovoice have been acknowledged (Strack et al. 2015) but are yet to be taken up by MND health service providers despite the plethora of research suggesting persons with complex communication needs benefit from social networking sites to support communication and enhance social participation. (Bay, 2017, Caron & Light 2015). The Consumers Health Forum, has recognised online forums as new frontiers for patient narratives (CHF, 2014), but for the MND population this has failed to translate into patient-centred care with the popular peer-moderated online MND Facebook forums being based in the UK (MND Warriors United) or USA (Living a positive life with MND), lacking the Australian context.

   Working with key stakeholders and peak bodies such as Speech Pathology Australia, The Communication Access Network and the International Communication Project can create advocacy and action pathways that will benefit the MND community

5. Dissemination and application of these research findings to inform the need for organisational change, including targeting relevant stakeholders such as MND

Victoria and MNDA. Social prescribing is one such evidence-based strategy to address the SDH and promote social inclusion. Whilst new to Australia, there is a wealth of evidence from the UK (APPG, 2017, Chatterje, 2018, Fancourt & Finn 2019) that is only now gaining a foothold in Australia but has enormous potential to improve the quality of life for families living with MND if embedded in a patient-centred model of care in specialist MND health services.
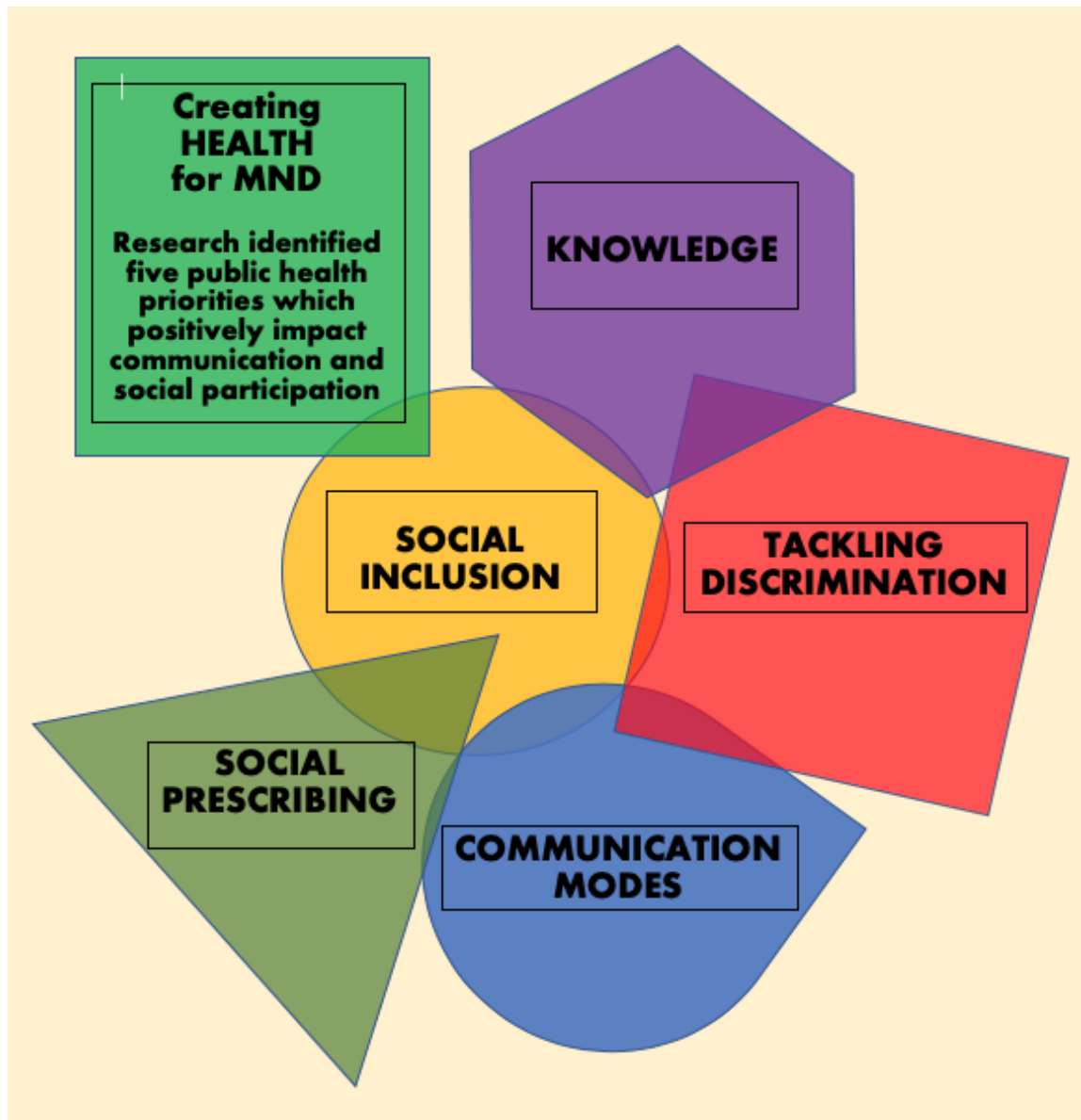

Figure 17 Creating Health for MND

References

Annang, L., Wilson, S., Tinago, C., Wright Sanders, L., Bevington, T., Carlos, B., ... & Svendsen, E. (2016). Photovoice: Assessing the long-term impact of a disaster on a community's quality of life. Qualitative health research, 26(2), 241-251.

APPG. (2017) The All Party Parliamentary Group on Arts, Health and Wellbeing. Inquiry Report. Creative health: The arts for health and wellbeing. Retrieved from: http://www.artshealthandwellbeing.org.uk/appg-inquiry/Publications/Creative_Health_Inquiry_Report_2017_-_Second_Edition.pdf

Australian Centre for Arts and Health (2018) The Art of Good Health and Wellbeing. 10th International Arts and Health Conference, Port Macquarie, NSW.

Australian Government (2013) National Arts and Health Framework. Available from: https://www.arts.gov.au/national-arts-and-health-framework

Ardrey, J., Desmond, N., Tolhurst, R., & Mortimer, K. (2016). The Cooking and Pneumonia Study (CAPS) in Malawi: a nested pilot of Photovoice participatory research methodology. PloS one, 11(6), e0156500.

Balbale, S. N., Turcios, S., & LaVela, S. L. (2015). Health care employee perceptions of patient-centered care. Qualitative health research, 25(3), 417-425.

Balbale, S. N., Locatelli, S. M., & LaVela, S. L. (2016). Through their eyes: Lessons learned using participatory methods in health care quality improvement projects. Qualitative health research, 26(10), 1382-1392.

Bates, M. J., Ardrey, J., Mphwatiwa, T., Squire, S. B., & Niessen, L. W. (2018). Enhanced patient research participation: a Photovoice study in Blantyre Malawi. BMJ supportive & palliative care, 8(2), 171-174.

Bay, S. V. (2017). Communicating Through Social Media: How Persons with ALS Use the Internet to Maintain Social Connections (Doctoral dissertation).

Beaupin LK, Pailler ME, Brewer-Spritzer E, Kishel, E., Grant, P. C., Depner, R. M., ... & Breier, J. M. (2019) Photographs of meaning: A novel social media intervention for adolescent and young adult cancer patients. Psycho-Oncology. 2019;28:198–200

Bell, S., & Menec, V. (2015). "You Don't Want to Ask for the Help" The Imperative of Independence: Is It Related to Social Exclusion?. Journal of Applied Gerontology, 34(3), NP1-NP21.

Bendell, K., & Sylvestre, J. (2017). How different approaches to taking pictures influences participation in a photovoice project. Action Research, 15(4), 357-372.

Bisung, E., Elliott, S. J., Abudho, B., Schuster-Wallace, C. J., & Karanja, D. M. (2015). Dreaming of toilets: Using photovoice to explore knowledge, attitudes and practices around water–health linkages in rural Kenya. Health & place, 31, 208-215.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative research in psychology, 3(2), 77-101.

Brunsden, V., & Goatcher, J. (2007). Reconfiguring photovoice for psychological research. The Irish Journal of Psychology, 28(1-2), 43-52.

Call-Cummings, M., Hauber-Özer, M., Byers, C., & Mancuso, G. P. (2018). The power of/in Photovoice. International Journal of Research & Method in Education, 1-15.

Caron, J., & Light, J. (2015). "My world has expanded even though I'm stuck at home": Experiences of individuals with amyotrophic lateral sclerosis who use augmentative and alternative communication and social media. American Journal of Speech-Language Pathology, 24(4), 680-695.

Catalani, C., & Minkler, M. (2010). Photovoice: A review of the literature in health and public health. Health education & behavior, 37(3), 424-451.

Charmaz, K. (2006). Constructing grounded theory: A practical guide through qualitative analysis. Sage.

Chatterjee, H. J., Camic, P. M., Lockyer, B., & Thomson, L. J. (2018). Non-clinical community interventions: a systematised review of social prescribing schemes. Arts & Health, 10(2), 97-123.

Chen, A., & Garrett, C. G. (2005). Otolaryngologic presentations of amyotrophic lateral sclerosis. Otolaryngology—Head and Neck Surgery, 132(3), 500-504.

Chew, H. S. J., & Lopez, V. (2017). Empowered to Self-Care: A Photovoice Study in Patients With Heart Failure. Journal of Transcultural Nursing, 1043659617745138.

Chiò, A., Gauthier, A., Montuschi, A., Calvo, A., Di Vito, N., Ghiglione, P., & Mutani, R. (2004). A cross sectional study on determinants of quality of life in ALS. Journal of Neurology, Neurosurgery & Psychiatry, 75(11), 1597-1601.

Consumers Health Forum of Australia (2014) Real people real data project. Retrieved form:
https://chf.org.au/sites/default/files/rep-1142-literature-review-using-consumer-narrative-to-inform-better-health-outcomes_0.pdf

Consumers Health Forum of Australia Publication (2018) Shifting Gears — Consumers Transforming Health. A White Paper, Canberra Retrieved from:
https://chf.org.au/sites/default/files/181125_shifting_gears_-_consumers_transforming_health.pdf

Corbin, J., & Strauss, A. (2008). Basics of qualitative research: Techniques and procedures for developing grounded theory.

Creighton, G., Oliffe, J. L., Ferlatte, O., Bottorff, J., Broom, A., & Jenkins, E. K. (2018). Photovoice Ethics: Critical Reflections From Men's Mental Health Research. Qualitative Health Research, 28(3), 446–455. https://doi.org/10.1177/1049732317729137

Dassah, E., Aldersey, H. M., & Norman, K. E. (2017). Photovoice and persons with physical disabilities: A scoping review of the literature. Qualitative health research, 27(9), 1412-1422.

Davies, C. (2016). Arts, public health and the National Arts and Health Framework: A lexicon for health professionals. Australian and New Zealand Journal of Public Health., 40(4), 304-306.

Department of health and Human services (2019) Victorian Public Health and Wellbeing plan 2019-2023. Retrieved from:

https://www2.health.vic.gov.au/about/health-strategies/public-health-wellbeing-plan

Dewey Lambert, P., & Sonke, J. (2019). Professionalizing Arts Management in Healthcare Facilities. The Journal of Arts Management, Law, and Society, 1-16.

Epton, J., Harris, R., & Jenkinson, C. (2009). Quality of life in amyotrophic lateral sclerosis/motor neuron disease: a structured review. Amyotrophic lateral sclerosis, 10(1), 15-26.

Evans-Agnew, R. A., & Rosemberg, M. A. S. (2016). Questioning Photovoice Research Whose Voice? Qualitative health research, 1049732315624223.

Fancourt, D., & Finn, S. (2019). What is the evidence on the role of the arts in improving health and well-being? A scoping review. Copenhagen WHO Regional Office for Europe, 2019 (Health Evidence Network (HEN) synthesis Report 67).

Fenner, P., Rumbold, B., Rumbold, J., Robinson, P., & Harpur, S. (2012). Is there compelling evidence for using the arts in health care? Deeble Institute Evidence Brief, 4(19), 9.

Fisher, F., Philpott, A., Andrews, S. C., Maule, R., & Douglas, J. (2016). Characterizing social communication changes in amyotrophic lateral sclerosis. International Journal of Language & Communication Disorders.

Flanagan, E. H., Buck, T., Gamble, A., Hunter, C., Sewell, I., & Davidson, L. (2016). "Recovery Speaks": A Photovoice Intervention to Reduce Stigma Among Primary Care Providers. Psychiatric Services, 67(5), 566-569.

Gallagher, D. and Monroe, B. (2006), 'Psychosocial care' in Palliative Care in Amyotrophic Lateral Sclerosis from Diagnosis to Bereavement, D Oliver, G D Borasio, D Walsh (eds), 2nd ed, Oxford University Press, New York.

Genoe, R., & Dupuis, S. (2013). Picturing Leisure: Using Photovoice to Understand the Experience of Leisure and Dementia. The Qualitative Report, 18(11), 1-21. Retrieved from https://nsuworks.nova.edu/tqr/vol18/iss11/1

Glegg, S. M. (2019). Facilitating interviews in qualitative research with visual tools: A typology. Qualitative health research, 29(2), 301-310.

Gordon-Nesbitt, R., & Howarth, A. (2019). The arts and the social determinants of health: findings from an inquiry conducted by the United Kingdom All-Party Parliamentary Group on Arts, Health and Wellbeing. *Arts & health*, 1-22.

Grindrod and Rumbold (2018) HELP Healthy End of Life Project (HELP): a progress report on implementing community guidance on public health palliative care initiatives in Australia. Annals of Palliative Medicine, 2018 Apr;7(Suppl 2): S73-S83

Harley, A. (2012). Picturing reality: Power, ethics, and politics in using photovoice. International Journal of Qualitative Methods, 11(4), 320-339.

Hobson, E. V., Fazal, S., Shaw, P. J., & McDermott, C. J. (2017). "Anything that makes life's journey better." Exploring the use of digital technology by people living with motor neurone disease. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 18(5-6), 378-387.

Hergenrather, K. C., Rhodes, S. D., Cowan, C. A., Bardhoshi, G., & Pula, S. (2009). Photovoice as community-based participatory research: A qualitative review. American journal of health behavior, 33(6), 686-698.

Kabel, A., Teti, M., & Zhang, N. (2016). The art of resilience: photo-stories of inspiration and strength among people with HIV/AIDS. Visual studies, 31(3), 221-230.

Kühnlein, P., Gdynia, H. J., Sperfeld, A. D., Lindner-Pfleghar, B., Ludolph, A. C., Prosiegel, M., & Riecker, A. (2008). Diagnosis and treatment of bulbar symptoms in amyotrophic lateral sclerosis. Nature Reviews Neurology, 4(7), 366.

Kumah, E., Osei-Kesse, F., & Anaba, C. (2017). Understanding and using patient experience feedback to improve health care quality: systematic review and framework development. Journal of patient-centered research and reviews, *4*(1), 24.

LaDonna, K. A., & Venance, S. L. (2015). Picturing the experience of living with myotonic dystrophy (DM1): a qualitative exploration using photovoice. Journal of Neuroscience Nursing, 47(5), 285-295.

Lal, S., Jarus, T., & Suto, M. J. (2012). A Scoping Review of the Photovoice Method: Implications for Occupational Therapy Research. Canadian Journal of Occupational Therapy, 79(3), 181–190. https://doi.org/10.2182/cjot.2012.79.3.8

Latz, A. O. (2018). Reading in the mirror and advancing the proliferation of photovoice: A book review. The Qualitative Report, 23(12), 2989-2991. Retrieved from https://nsuworks.nova.edu/tqr/vol23/iss12/7

Lewin, S., Glenton, C., & Oxman, A. D. (2009). Use of qualitative methods alongside randomised controlled trials of complex healthcare interventions: methodological study. Bmj, 339, b3496.

Light, J., & McNaughton, D. (2014). Communicative competence for individuals who require augmentative and alternative communication: A new definition for a new era of communication?

Light, J., McNaughton, D., Beukelman, D., Fager, S. K., Fried-Oken, M., Jakobs, T., & Jakobs, E. (2019). Challenges and opportunities in augmentative and alternative

communication: Research and technology development to enhance communication and participation for individuals with complex communication needs. Augmentative and Alternative Communication, 35(1), 1-12.

Madsen, L. S., Jeppesen, J., & Handberg, C. (2019). "Understanding my ALS". Experiences and reflections of persons with amyotrophic lateral sclerosis and relatives on participation in peer group rehabilitation. Disability and rehabilitation, 41(12), 1410-1418.

Maratos, M., Huynh, L., Tan, J., Lui, J., & Jarus, T. (2016). Picture this: Exploring the lived experience of high-functioning stroke survivors using photovoice. Qualitative health research, 26(8), 1055-1066.

McNaughton, D., & Light, J. (2013). The iPad and mobile technology revolution: Benefits and challenges for individuals who require augmentative and alternative communication.

Mckelvey, M., Evans, D. L., Kawai, N., & Beukelman, D. (2012). Communication styles of persons with ALS as recounted by surviving partners. Augmentative and Alternative Communication, 28(4), 232-242.

Meyrick, J. (2006). What is good qualitative research? A first step towards a comprehensive approach to judging rigour/quality. Journal of health psychology, 11(5), 799-808.

Minkler, M. (2000). Using participatory action research to build healthy communities. Public health reports, 115(2-3), 191.

Mistry, K., & Simpson, J. (2013). Exploring the transitional process from receiving a diagnosis to living with motor neurone disease. *Psychology & health*, *28*(8), 939-953.

Motor Neurone Disease Australia (2018) Action Framework. Retrieved from: https://www.mndaust.asn.au/Documents/MND-Australia-Action-Framework.aspx

National Institute for Health and Care Excellence. (2016). Motor neurone disease: assessment and management. NICE guideline [NG42].

Neudert, C., Wasner, M., & Borasio, G. D. (2004). Individual quality of life is not correlated with health-related quality of life or physical function in patients with amyotrophic lateral sclerosis. *Journal of palliative medicine*, *7*(4), 551-557

Newby, P. (2010). *Research methods for education*. Pearson Education.

Olsson, A. G., Markhede, I., Strang, S., & Persson, L. I. (2010). Differences in quality of life modalities give rise to needs of individual support in patients with ALS and their next of kin. Palliative & supportive care, 8(1), 75-82.

Olsson Ozanne, A., Graneheim, U. H., Persson, L., & Strang, S. (2012). Factors that facilitate and hinder the manageability of living with amyotrophic lateral sclerosis in both patients and next of kin. Journal of clinical nursing, 21(9-10), 1364-1373.

O'Halloran, R., Douglas,J., Cruice, M. (2019) Representation and reporting of communicatively vulnerable patients in patient experience research.

Overby, H., Eggert, E., Stluka, S., McCormack, L., & Meendering, J. (2018). PhotoVoice: Engaging school communities in wellness efforts. Journal of nutrition education and behavior, 50(2), 203-205.

Papoulias C. (2017). Showing the Unsayable: Participatory Visual Approaches and the Constitution of 'Patient Experience' in Healthcare Quality Improvement. Health care analysis: HCA : journal of health philosophy and policy, 26(2), 171-188.

Prell, T., Gaur, N., Stubendorff, B., Rödiger, A., Witte, O. W., & Grosskreutz, J. (2019). Disease progression impacts health-related quality of life in amyotrophic lateral sclerosis. Journal of the neurological sciences, 397, 92-95.

Prevo, L., Stessen, K., Kremers, S., Wassenberg, M., & Jansen, M. (2018). Shining light inside the tunnel: using photovoice as a strategy to define the needs for health promotion

among families of low socioeconomic status. International journal of qualitative studies on health and well-being, 13(1), 1542909.

Public Health Association Australia (2019) Community Participation: Collective and individual participation in public health and primary health care policy and service delivery.Background Paper. Retrieved from: https://www.phaa.net.au/documents/item/3817

Raw, A., Lewis, S., Russell, A., & Macnaughton, J. (2012). A hole in the heart: Confronting the drive for evidence-based impact research in arts and health. Arts & health, 4(2), 97-108.

Robbins, R. A., Simmons, Z., Bremer, B. A., Walsh, S. M., & Fischer, S. (2001). Quality of life in ALS is maintained as physical function declines. *Neurology*, *56*(4), 442-444.

Russinova, Z., Rogers, E. S., Gagne, C., Bloch, P., Drake, K. M., & Mueser, K. T. (2014). A randomized controlled trial of a peer-run antistigma photovoice intervention. Psychiatric Services, 65(2), 242-246.

Russinova, Z., Gidugu, V., Bloch, P., Restrepo-Toro, M., & Rogers, E. S. (2018). Empowering individuals with psychiatric disabilities to work: Results of a randomized trial. Psychiatric rehabilitation journal.

Sakellariou, D., Boniface, G., & Brown, P. (2013). Experiences of living with motor neurone disease: A review of qualitative research. Disability and Rehabilitation, 35(21), 1765-1773.

Seitz, C. M., & Strack, R. W. (2016). Conducting public health photovoice projects with those who are homeless: A review of the literature. Journal of Social Distress and the Homeless, 25(1), 33-40.

Shellikeri, S., Karthikeyan, V., Martino, R., Black, S. E., Zinman, L., Keith, J., & Yunusova, Y. (2017). The neuropathological signature of bulbar-onset ALS: A systematic review. *Neuroscience & Biobehavioral Reviews*, *75*, 378-392.

Shumba, T. W., & Moodley, I. (2018). Part 2: The feasibility of utilising photovoice method and the World Health Organization Quality of Life instrument in evaluating the Community-Based Rehabilitation programme in Namibia: A pilot study. *African Journal of Disability (Online)*, *7*, 1-24.

Sitter, K. C. (2017). Taking a closer look at photovoice as a participatory action research method. Journal of Progressive Human Services, 28(1), 36-48.

Smith, J. A. (Ed.). (2015). Qualitative psychology: A practical guide to research methods. Sage.

Strack, R. W., Orsini, M. M., Fearnow-Kenney, M., Herget, J., Milroy, J. J., & Wyrick, D. L. (2015). Developing a web-based tool using information and communication technologies to expand the reach and impact of Photovoice. American journal of health education, 46(4), 192-195.

Teti M., Majee W., Cheak-Zamora N., Maurer-Batjer A. (2019) Understanding Health Through a Different Lens: Photovoice Method. In: Liamputtong P. (eds) Handbook of Research Methods in Health Social Sciences. Springer, Singapore

Thomas, T. L., Owens, O. L., Friedman, D. B., Torres, M. E., & Hébert, J. R. (2013). Written and spoken narratives about health and cancer decision making: a novel application of photovoice. Health promotion practice, 14(6), 833-840.

Tomik, B., & Guiloff, R. J. (2010). Dysarthria in amyotrophic lateral sclerosis: A review. *Amyotrophic Lateral Sclerosis*, *11*(1-2), 4-15.

Tramonti, F., Bongioanni, P., Di Bernardo, C., Davitti, S., & Rossi, B. (2012). Quality of life of patients with amyotrophic lateral sclerosis. *Psychology, health & medicine*, *17*(5), 621-628.

University of Florida (2017) Talking about arts in health. College of the Arts, Centre for Arts in Medicine, White Paper. Retrieved from:
https://arts.ufl.edu/site/assets/files/106496/uf_cam_language_whitepaper.pdf

Volpe, C. R. (2018). Digital diaries: new uses of PhotoVoice in participatory research with young people. Children's Geographies, 1-10.

von Steinbüchel, N., Lischetzke, T., Gurny, M., & Eid, M. (2006). Assessing quality of life in older people: psychometric properties of the WHOQOL-BREF. *European Journal of Ageing*, *3*(2), 116-122.

Walklet, E. (2018). Capturing health-related quality of life in adults with Charcot-Marie-Tooth disease: A digital photovoice investigation (Doctoral dissertation, University of the West of England).

Wallace, L. S., Wexler, R. K., McDougle, L., Miser, W. F., & Haddox, J. D. (2014). Voices that may not otherwise be heard: a qualitative exploration into the perspectives of primary care patients living with chronic pain. Journal of pain research, 7, 291.

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. Health education & behavior, 24(3), 369-387.

Wang, C. C., Yi, W. K., Tao, Z. W., & Carovano, K. (1998). Photovoice as a participatory health promotion strategy. *Health promotion international*, *13*(1), 75-86.

Wang, C. C. (1999). Photovoice: A participatory action research strategy applied to women's health. Journal of Women's Health, 8(2), 185–192.

Wheeler, K. J., & Early, J. O. (2018). Using Photovoice to Explore Quality of Life Factors of Adults With Crouzon Syndrome. Qualitative health research, 28(3), 357-370.

Whoqol Group. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological medicine*, *28*(3), 551-558.

Williams, S., Sheffield, D., & Knibb, R. C. (2016). A snapshot of the lives of women with polycystic ovary syndrome: A photovoice investigation. Journal of health psychology, 21(6), 1170-1182.

Wilkinson, R. G., & Marmot, M. G. (2003). Social determinants of health: the solid facts. World Health Organization.

Wong, S. S., George, T. J., Godfrey, M., Le, J., & Pereira, D. B. (2019). Using photography to explore psychological distress in patients with pancreatic cancer and their caregivers: a qualitative study. Supportive Care in Cancer, 27(1), 321-328.

World Health Organization. (1998). *Programme on mental health: WHOQOL user manual* (No. WHO/HIS/HSI Rev. 2012.03). World Health Organization.

The World Health Organization Quality of Life (WHOQOL)-BREF (2004) Downloaded from: https://www.who.int/mental_health/publications/whoqol/en/

World Health Organization, editor Declaration of Alma-Ata. International Conference on Primary Health Care; 1978 6-12 September 1978; Alma-Atta, USSR. Retrieved from: http://www.who.int/publications/almaata_declaration_en.pdf.

World Health Organization. The Ottawa Charter for Health Promotion. First international conference on health promotion, 1986: WHO; 1986. Retrieved from: https://www.who.int/healthpromotion/conferences/previous/ottawa/en/

Yi-Frazier, J. P., Cochrane, K., Mitrovich, C., Pascual, M., Buscaino, E., Eaton, L., ... & Malik, F. (2015). Using Instagram as a modified application of photovoice for storytelling and sharing in adolescents with type 1 diabetes. Qualitative health research, 25(10), 1372-1382.

Calvary | Health Care Bethlehem

Appendix 1- Participant Information and Consent

> **'Photovoice' impact on communication and social participation for improved quality of life in Motor Neurone Disease'**

You are invited to take part in '**Photovoice' impact on communication and social participation for improved quality of life in Motor Neurone Disease.**

Please read this Explanatory Statement in full before deciding whether to participate. Please contact either of the following clinicians via the phone numbers or email addresses provided if you would like to participate or if you require further information regarding any aspect of the project.

Ms. Nicole Jackson
Senior Speech Pathologist/Allied Health Manager
Calvary Health Care Bethlehem
Phone: 9595 3474
Email: Nicole.Jackson@calvarycare.org.au

Mr. Nicholas Jackson
Speech Pathologist
Calvary Health Care Bethlehem
Ph: 9595 3388
Nicholas.Jackson@calvarycare.org.au

About this research

This research uses 'Photovoice' which is an Action Research approach. This is a communication process by which you can represent yourself to others using different photo-sharing techniques.

What it will involve:

You and a family member will attend **four x 1.5hrs** small group sessions at either our Parkdale site or at MND Victoria in Canterbury. The program focuses on communication and social participation. You will take photos using a device (camera, phone or ipad). You do not require photographic expertise to participate in this project. Each session has two Speech Pathology facilitators to help everyone actively participate. In the sessions, you will share photos and discuss the photos taken. Each week will have a different theme: identity, family friends and community. The photos will depict your experiences, as well as illustrate things that help or hinder you in terms of communication and staying socially active.

Proposed Dates: Mondays commencing 29th July (Canterbury) or 5th August (Parkdale)

Tuesdays commencing 6th August (Parkdale only)

Why were you chosen for this group?

You have been selected for involvement in the group because you have Motor Neurone Disease and have seen a speech pathologist here about changes to your speech.

Consenting to participate in, or withdraw from the group

Participation in the groups are voluntary. To give your agreement to complete the group, you must sign and return the consent form below. You may withdraw your consent at any stage, and any details you have provided will also be withdrawn. Furthermore, your participation or non-participation in the Forum will in no way impact your treatment at Calvary Health Care Bethlehem.

Possible benefits and risks to participants

Our own pilot program and similar programs internationally indicate that it is likely that there will be a benefit from participating in this participatory action research group, as it is targeted to your specific needs and interests and aims to raise awareness of your needs.

It is possible that consideration of certain topics could be emotionally distressing for some people. If this occurs, you can be referred to a clinical psychologist working at Calvary Health Care Bethlehem. Alternatively, referral to counselling services in the community near to your residence can be provided.

Confidentiality

All information collected will be confidential. Only the clinicians associated with this group will have access to original data. Your information will be combined with other participants' and all identifying information about you will be removed.

Storage of your information

All data, including paper questionnaires and documents, recordings of sessions, and computer files will be kept in password-protected electronic files and secure research storage at Calvary Health Care Bethlehem. Only clinicians will have access to data. In line with legislation covering research procedures, after seven years the paper data and recordings will be deleted. Electronic data will be kept indefinitely.

Outcome

Have your say: you will be part of the research process! Together we will identify individual and collective themes that help us understand what makes your quality of life better.

We hope the results of this research project will help our organisation and others to focus on your specific needs and develop better services for people with MND.

Results

Research findings will be made available via the publication of journal articles, and may be presented at conferences. A summary of research findings will also be provided to participants who are interested.

If you are interested in receiving research results/publication, please register your interest by emailing Nicole.Jackson@calvarycare.org.au

Counselling Services

Calvary Health Care Bethlehem
152 Como Parade West, Parkdale, 3195
9596 2853

Complaints

If you have a complaint or any concern about any aspect of the project at Calvary Health Care Bethlehem then you should contact the General Manager, CHCB on 03 9595 3290.

CALVARY HEALTH CARE BETHLEHEM
In the Tradition of the Sisters of the Little Company of Mary

PARTICIPATION CONSENT FORM

PROPOSAL/PROTOCOL NAME:
'Photovoice' impact on communication and social participation for improved quality of life in Motor Neurone Disease.

INVESTIGATORS:
Nicole Jackson, Nicholas Jackson - Calvary Healthcare Bethlehem
Dr. Bruce Rumbold, Dr. Peter Higgs – La Trobe University, Melbourne

1. The nature and purpose of the research project, the details of any and all associated risks have been explained to me and are specified in the Patient Information Sheet. I understand, and agree to take part in this research project.   YES □   NO □

2. I understand that I may not directly benefit from taking part in the research. YES □   NO □

3. I understand that, while information gained during the study may be published, I will not be identified and my personal health information will remain confidential. YES □   NO □

4. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future. YES □   NO □

5. I have had the opportunity to discuss taking part in this investigation with a family member or a friend. YES □   NO □

6. I understand that photos, by their nature, may be identifying. I agree that photos taken and chosen voluntarily by me as part of the Photovoice research project may be used by the research team as examples in illustrating the findings of this research in relevant professional forums such as presentations, workshops or written publications. YES □   NO □

7. I agree that photos, photo narratives and focus group transcripts resulting from my participation may be used for future projects at CHCB for the purpose of health promotion activities which increase awareness of living with Motor Neurone Disease. YES □   NO □

Name of Subject: _____

Signed: _____ Date: /   /
                (Participant)

I certify that I have explained the study to the patient/volunteer and consider that he/she understands what is involved.

Signed: _____
                Nicole Jackson – Principal Investigator

Appendix 2 – Photovoice program outline

PICTURE POWER	Picture Power for MND A photovoice communication program

Picture Power for MND Communication Program Outline

Description of the 4 week Photovoice program developed, piloted and evaluated at Calvary Health Care Bethlehem
Participants: pwMND, primary caregivers, facilitators x 2 (Speech-Language Pathologists trained in use of photovoice methodology)

Facilitator Roles:
- To enable participants to discover the power of photography as a tool for communication and how they can harness this potential to communicate their stories, ideas and opinions.
- To encourage participants to consider who their audiences will be and how their images will be received
- To encourage participants to believe in the importance of their voice and the value of their way of seeing. (The PhotoVoice Manual www.photovoice.org)
- To promote photo-sharing as a primary communication mode for creating enhanced or renewed social connections with family, friends and community.

Session 1 / Week 1: IDENTITY

- Define key terms – communication, social participation, quality of life
- Present powerpoint presentation outlining participatory action research and introduce photovoice methodology (Wang and Burris, 1997)
- "Communication toolbox" verbal, non-verbal and visual communication methods.
  Alternative and Augmentative communication methods – low tech and high tech (show and tell)
- Discuss practical methods of taking photos and ethics /consent for taking photos.
- Methods of photo sharing / photo sharing tips using technology
- Powerpoint presentation and Brainstorm week 1 photo challenge "Identity".
  5 photos to be completed during the week by all participants (pwMND, carers and facilitators)
- Visual literacy activity ('Picture This' resource for conversation and reflection)
- Visual storytelling.

Photovoice 'SHOWED' – Acronym, prompts for telling the story behind the photo, to form a bridge to potential actions. Notion of 'critical consciousness' based on reflection through dialogue and action (Wang & Burris, 1997)
  o What do you **S**ee here?
  o What is really **H**appening here?
  o How does this relate to **O**ur lives?
  o **W**hy does this concern/strength/situation exist?
  o How can we become **E**mpowered through our new understanding?
  o What can we **D**o?

Brainstorm photo ideas – Provide prompts to think about "barriers and facilitators" to communication

  o How does speech/communication change impact on your quality of life?

  o What helps or hinders communication with others? (settings - where you live, work and play)

  o What helps or hinders social participation /feeling connected?

  o How can you tell /represent this story with a photo? (photos you already have or take new photos)

Session 2 / Week 2: FAMILY

- Participants upload 5 digital photos (email/USB/airdrop) for projected slideshow.

- View slideshow – participants share and describe their selected "identity" photos with accompanying narrative using a variety of verbal and non-verbal communication methods (speech, written, AAC, partner-assisted)
- Photo-elicited critical discussion with whole group – explore priorities and concerns, reflect on personal and collective "voice", identify potential actions for change – personal, organisational, community.
- Add caption or text narrative to 1-2 photos of choice
- Present 'Family' powerpoint presentation: brainstorm ideas for weekly challenge (5 photos)
- Activity 1 -Circles of Care – Participants complete circle of care template – self – inner circle, extended family and friends with satellites representing communities of belonging (groups/clubs etc)
- Activity: 2 -Social media use and online communities. Information provision and relevant examples. Facebook, Facebook Messenger, Instagram, What's App.
  Online MND Communities:
- Collect data on number of current chat groups and online communities.
- Facilitators provide 1:1 time with each dyad to provided individualised support and skills building as required – communication methods, identifying communication strategies, providing support with social media set up eg forming chat groups to increase connections within circles of care.

Session 3/ Week 3: FRIENDS/COMMUNITY

- As above – upload photos, view slideshow, group discussion triggered by broad theme of "family", add written captions/narratives to 1-2 selected photos
- Review photo-sharing methods used during week, including use of social media and barriers to use.
- Continue to provide support to develop social connections through photo-sharing within circles of care. Target existing, new and renewed social connections (circles of friends and community satellites)
- Activity – What matters to You – individually (written) then as group.
- Group discussion- changes in communication and social participation using photovoice methods. Opportunity for extended narratives. Discuss emerging ideas for action/change – identify individual and collective goals.
- Powerpoint presentation and brainstorm ideas for final photovoice challenge – Friends (5 photos) and Community (5 photos)

Session 4/ Week 4: OUTPUTS and ACTIONS

- As above - upload photos, view slideshow, group discussion triggered by broad theme of 'friends' and 'community', add written captions/narratives to 1-2 selected photos.
- Coding process is completed by whole group– viewing all printed photos from program spread out.
- Thematic analysis by all participants. Summary of key points arising from sessions 1-3 (focus groups) is provided and participants produce written "sticky notes"
- Critical discussion with whole group – Photovoice impact on communication and social participation, explore priorities and concerns, reflect on personal and collective 'voice', identify potential actions for change – personal, organisational, community.
- Identifying messages to convey and audiences to target to achieve desired impact/change.
- Produce or plan photo outputs: Examples include but are not limited to: letters, educational resources, and public displays.

1 month Follow-up (individual): Outcomes, impact and Sustainability
- A routine 1 month follow up session is conducted with each participant and caregiver dyad (face to face preferably or by phone/email if appropriate)
- Provide additional skills building, troubleshooting as required.
- Closing the loop – review proposed actions, responses received and required follow-up.
- Complete outcome measures and end of program questionnaire/patient satisfaction survey.
- Document ongoing functional communication needs, goals and follow-up required.
- Provide handover to usual treating Speech Pathologist in patient's Multi-disciplinary health team or disability team (NDIS)

6 month Follow-up (individual): Outcomes, impact and Sustainability
- As above

1. **Prompts for sharing and discussing selected photos (developing 'critical consciousness')**

S   What do you **S**ee here?

H   What is really **H**appening here?

O   How does this relate to **O**ur lives?

W   **W**hy does this concern/strength/situation exist?

E   How can we become **E**mpowered through our new understanding?

D   What can we **D**o?

(Wang and Burris, 1997)

P   Describe your **P**icture

H   What is **H**appening in your picture?

O   Why did you take a picture **O**f this?

T   **T**ell us about your life / the context of this photo

O   How can this picture provide **O**pportunities for us to improve our life?

(Catalani and Minkler, 2009)

2. **Focus Group Questions**

Facilitator Trigger Questions – Photovoice "new knowledge"

1. What surprised you?

2. Did you discover something new?

3. How did using photos assist communication?

4. How did using photos assist social participation / social connections?

Facilitator Trigger Questions – "barriers and facilitators"

1. How does speech/communication change impact on your quality of life?

2. What helps or hinders communication with others?

3. What helps or hinders social participation /feeling connected? (being part of a group or community)

THE WORLD HEALTH ORGANIZATION

QUALITY OF LIFE (WHOQOL) -BREF

The World Health Organization Quality of Life (WHOQOL)-BREF

© World Health Organization 2004

WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks.**

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5

20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

Do you have any comments about the assessment?

_____

_____

[The following table should be completed after the interview is finished]

		Equations for computing domain scores	Raw score	Transformed scores*	
				4-20	0-100
27.	**Domain 1**	(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18 ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐	a. =	b:	c:
28.	**Domain 2**	Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26) ☐ + ☐ + ☐ + ☐ + ☐ + ☐	a. =	b:	c:
29.	**Domain 3**	Q20 + Q21 + Q22 ☐ + ☐ + ☐	a. =	b:	c:
30.	**Domain 4**	Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25 ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐	a. =	b:	c:

* See Procedures Manual, pages 13-15

Appendix 4 - Photovoice Impact questionnaire

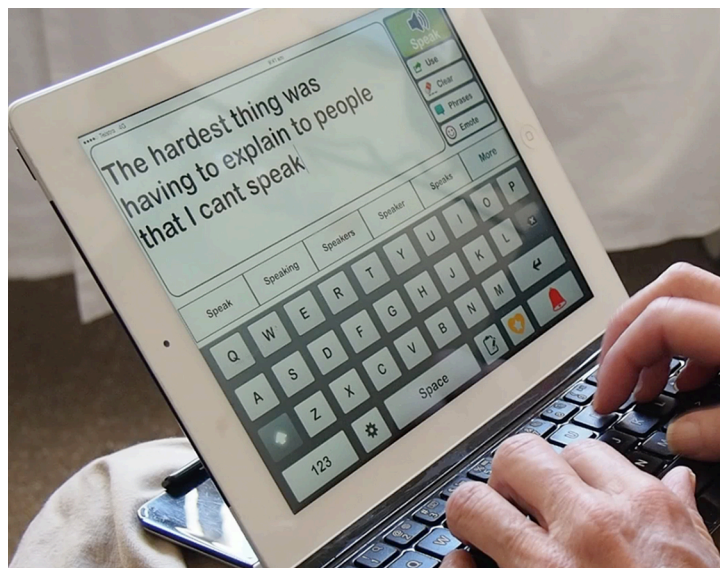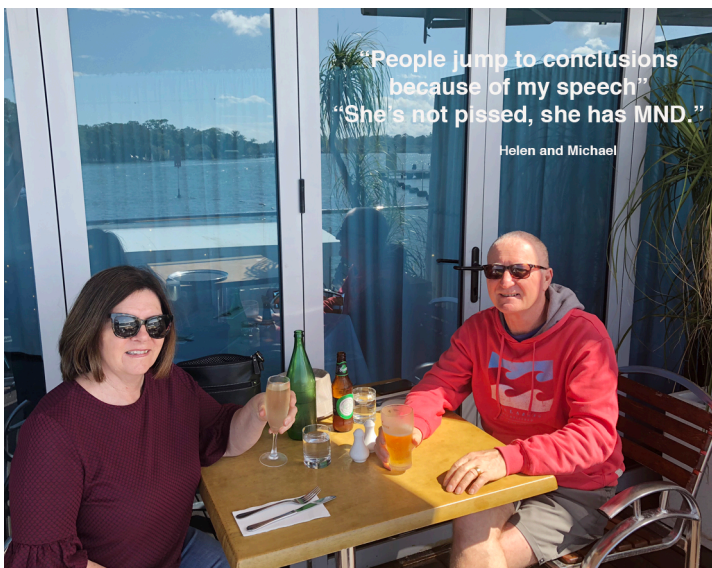N= 16   (16/17 participants completed the end of program questionnaire)

Did the photovoice program have a positive impact on_____?	PwMND n= 9			Partner of PwMND n=7			N=16
	Yes	No	Unsure	Yes	No	Unsure	Overall Positive impact N=16
Your quality of life / wellbeing?	100%			100%			16/16 100%
Communication with family?	100%			86%	14%		15/16 94%
Communication with friends?	89%	11%		71%	29%		13/16 81%
Your ability to express your ideas and opinions to a wider audience?	67%	11%	22%	71%	14%	14%	11/16 69%
Confidence with communication?	100%			43%	43%	14%	12/16 75%
Social connectedness?	100%			86%	14%		15/16 94%
Would you recommend the program to others?	100%			100%			16/16 100%

Photovoice impact questionnaire – Participant testimonials

Participant	Photovoice Impact – Describe how the photovoice program made you feel
1	Uplifting group. Sharing what you do. Faster. Write everything down (slow)
2	It was a really good experience because it encouraged me that I'm handling the difficulties well. I found it really interesting, how two identical photos can have the opposite meaning. Like the dogs – X said loss and I said joy, absolute opposite, we've told that story to a few friends.
3	Initially uneasy but then comfortable after the first session. "Included" and important as part of a team. The photos are something that we share on facebook and instagram and emails to keep family and my network in the loop.
4	Allowed for further communication with friends, added more depth communicating with photos. (from transcript)
5	Make me feel much better with the viewing (photos) on iphone!!! It' s harder now that I can't talk to friends on the phone.
6	Using photovoice was good. Sharing photos, it was fun. I liked meeting new people and I realised they're the same as me.
7	Withdrew from study
8	Made me feel normal, no different to when no disease.
9	I felt really good about my participation. Every time I went there, I was surprised. More so about how photos can tell a story. It was very important to me. I shared photos with my family and friends. I didn't realise the importance of photos, now I share everything.
10	Normal! Just chatting with everyone is what I need. Sharing photos can show our issues. The photos help understand what we are going through. I can see how useful they could be for education, changing people's awareness; most people don't realise.
11	Sad because pwMND lost his voice so early in the disease. It was his main way of communication, because he was never very good at writing letters, spelling etc. Talking to people gave him great pleasure.
12	I felt energised and positive. I was surprised how stimulating it was and how different MND sufferers' attitudes were. I learnt how evocative certain photos are and how some photos produce different emotions in people. I thoroughly enjoyed each session and getting to know other carers. Inspiring.
13	Embraced, happy, enjoyed sharing photos and stories with other people.
14	The program was a positive experience for both of us. Sparked conversations with our friends. The facebook chat group we set up was a great success, sad that pwMND didn't get to use it more (deceased in month following program)
15	Very happy
16	Withdrew from study
17	Realise it's important to stay connected with family and friends via sharing photos
18	In touch with others
19	Missing data. Didn't complete

Motor Neurone Disease

MND can cause weakness
of speech and swallowing muscles.
Speech can be slurred or lost.
This can be mistaken for intoxication.
Imagine the challenges of
not being able to speak!

"People jump to conclusions
because of my speech"
"She's not pissed, she has MND."

Helen and Michael

The hardest thing was
having to explain to people
that I cant speak

Responsible Service of Alcohol Training
Some tips from people living with MND
and communication disability

I enjoy going out and socialising with my family and friends, just like you do.

My speech may be slurred or I may have no speech at all, take the time to listen and give me time to communicate with you.

I am not drunk, treat me with courtesy and respect.

I am not deaf or stupid. You don't need to shout or talk slowly to me.

Look at what I am writing. I may need to write or use text on my phone or a communication app to communicate with you. Some people use an app to convert text to speech.

"It is so good when you are treated like everyone else,
no different" (Con, age 56, Melbourne)

Photovoice for MND, Calvary Health Care Bethlehem