LITERATURE REVIEW:
Lived Experience Leadership

Prepared by Ellie Hodges from LELAN (Lived Experience Leadership & Advocacy Network) and Mark Loughhead and Heather McIntyre from the University of South Australia's Mental Health and Suicide Prevention Research and Education Group

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EXECUTIVE SUMMARY

Lived experience leadership is about people with lived experience leading change in communities, organisations and systems. Within mental health, alcohol and other drugs (AOD), mutual aid and recovery and harm reduction, there are long standing movements where leaders have mobilised and activated with their communities to build organisations and innovative programs, to lobby for legislative change, to challenge and reframe community stigma, and to shape the design of health services.

This literature review aims to identify evidence and learning about the organisation and embedding of lived experience leadership across the diverse spaces of mental health, AOD mutual aid and recovery and harm reduction. It describes the findings of studies and articles that relate to multiple areas of lived experience leadership, including concepts and models of leadership, the context of leadership and involvement in consumer and carer led organisations, as well as the experience of leadership in mainstream health services and academia. These are important topics which will be discussed in the development of Victoria's Lived Experience Leadership Strategy.

The review was designed using a single search of various academic databases, supported by limited handsearching across topic and population areas. It includes 172 studies and articles, made up of diverse sources of evidence from qualitative studies, descriptive survey studies, expert opinion study reports and discussion papers. The review also includes findings from systematic and scoping literature reviews and industry reports.

In discussing this literature, lived experience leadership is seen as an emerging concept that is still being defined. We found studies that describe leadership qualities and concepts in both the mental health and AOD mutual aid and recovery areas, with consumer/survivor leadership being the most common framing in mental health. Leadership as defined by the principles and practices of 12-step programs and residential recovery housing (Oxford Houses) was the key theme in AOD mutual aid and recovery literature. Family carer leadership was largely absent from this literature, where carers were included in one mental health paper. Lived experience leadership is active in spaces such as organisational management, systems advocacy and activism, peer work individually and within groups, community activation and education, and research and health practitioner education. The existing conceptual work describing lived experience leadership provides opportunities to reflect, learn and discuss what leading change in each of these spaces means, and how this work is embedded in the purpose, values and collective experiences of lived experience communities. There needs to be further research and writing about lived experience leadership in the areas of leadership experience, collective approaches to leadership and how lived experience leadership is defined, understood and achieved in diverse communities.

When considering organisational models and governance arrangements, most of the literature describes the experience and activities of lived experience organisations in the US, UK and Canada. Trends in the structure of these organisations depict the importance of consumer board control, shared leadership and significant levels of member participation. These characteristics are important in larger organisations which have consumer/peer boards, paid staff and volunteers and which provide multiple services and activities for members. Examples include recovery community centres in mental health and AOD recovery, and various harm reduction organisations. Shared leadership, governance and volunteer activity are also central features of single purpose peer mutual aid movements such as 12-step programs (e.g. Alcoholics

Anonymous) and residential housing (e.g. Oxford Houses) which have been adopted and expanded in different countries. Both large and small forms of consumer/carer organisation have leadership challenges, including sustainability, securing funding, and navigating tensions and dilemmas between organisational/member purpose, and the involvement of, and expectations of funders. These include the need to maintain autonomy and distinct purpose and maintain distinct boundaries from public health and social services. A further challenge is in the capacity of lived experience organisations to involve, support and provide voice for diverse communities, raising the context of how lived experience leadership should be contributing to social justice and equity for multiple priority communities. All of these challenges relate to the effectiveness of policy environments, commissioning bodies and health authorities in recognising and responding to the experiences of lived experience organisations in supportive ways. The literature indicates promising, yet limited evidence for how the unique leadership structures of mental health and AOD mutual aid and recovery centres contribute to recovery outcomes of members, and for how harm reduction user organisations contribute to policy change and health outcomes for their communities.

In mainstream health services, the integration of lived experience leadership in governance structures has faced multiple challenges and barriers, with many of these well documented and common across the areas of mental health, drug treatment services and harm reduction. Many qualitative studies on the experiences of lived experience leaders, advocates and representatives, as well as literature reviews on lived experience involvement, highlight the need for organisational change approaches, improved consumer/peer and carer leadership training and support networks and the growth of infrastructure at systems levels. Change requires shifts in culture, mindset, resourcing, co-production practices and accountability to ensure that lived experience leadership is embedded, valued and effective at governance levels. Experience from some US states on AOD recovery orientated systems of care change projects also highlight the benefits of strengthening peer-based services and leadership involvement through long term collaborative planning and policy realignment with a 'recovery capital' paradigm. More research is needed that focuses on the influence that lived experience leaders bring to service design and resulting health and social outcomes.

A similar range of barriers and challenges, as well as strategies for change are evident in the literature about lived experience leadership in academia and research. There is a need to generate and support the increased presence of consumer and carer academics across public health research as well as develop innovative ways of partnering with, or enabling leadership by lived experience organisations. As in the health service context, these shifts require supportive leadership, proper resourcing, support, flexibility, collaboration and a focus on diversity, inclusion and equity.

This review identifies the following considerations for Victoria's Lived Experience Leadership Strategy

- Research on the concepts of lived experience leadership from a consumer perspective provides a starting basis for leadership training and sector-wide understandings of how leaders lead change as guided by established peer principles and models in mental health and AOD mutual aid and recovery. There is further need to define leadership within all communities including harm reduction and family carer areas. Further research and industry work can generate shared understandings around strategic influence and other nuanced aspects of leadership activity in a variety of roles and positionings. This can be a part of existing workforce development work being undertaken by mental health, AOD recovery and harm reduction peaks but should also

broaden to invite work on lived experience leadership from Aboriginal health leaders, LGBTIQ+ groups, CALD and refugee groups, population-based peaks, and peer groups in the family violence, housing and criminal justice areas.

- Programs and approaches for lived experience leadership training, mentoring and support have been successful in creating pathways to leadership and positive experiences by connecting emerging leaders with opportunities in governance of mainstream services. Resourcing to develop and deliver leadership programs across mental health, AOD recovery and harm reduction areas of lived experience and to create critical and diverse mass of leaders should be considered. Development of pathways needs to reflect intersectionality and intentionally involve diverse communities.

- The development of leadership pathways and opportunities should be coordinated with increased growth of capability to embed lived experience leadership within governance of mainstream services. System level supports can be created by funding a backbone organisation to lead collaborative effort towards organisational change, education on inclusion and allyship, training on lived experience governance and co-production, ways of improving resource flows, and methods for measuring progress and impacts. Broader policy and practice alignment towards agreed visions of recovery, AOD recovery and harm reduction is also important for valuing the perspectives that lived experience brings.

- Local health networks/districts or equivalents and NGO providers should be encouraged to develop aspirational frameworks for improving levels of lived experience governance, tied to development of the lived experience (peer) workforces and peer-led services in their organisations. This includes specialty peer work forces.

- The growth of member-based lived experience organisations, providing services and activities in mutual aid peer support should be supported through a specific program of commissioning. This should occur through a social justice and equity policy focus, where lived experience organisations are commissioned that support local community framings and cultural perspectives on mental health and leadership, and preferred governance arrangements. Organisations could be supported to also deliver activities within the NDIS market, or primary health care funding, or a specific state program.

- Further work should go into identifying and recognising peer-led mutual aid or social and emotional wellbeing programs which can be replicated, adapted, evaluated and supported to grow in Victoria. Investment can follow for inviting trainers to the state to lead learning and for establishing networks of learning, practice and meeting spaces.

- The Strategy should include goals and action plans for developing the scale and capacity for lived experience-led and partnered research in Victoria. Plans should aim to boost capability within lived experience organisations, universities and other research units.

INTRODUCTION

Lived experience leadership, through the efforts of consumers and carers to lead change in mental health services has been evident throughout the history of the user/consumer movement and also in the work of family carers in advocacy and the establishment of support organisations. It has not, however, been clearly defined and researched as a distinct area of knowledge, skill and action in its own right until relatively recently.

In the mental health context, efforts to define and better understand lived experience leadership have been focused predominantly on consumer leadership. In consumer academic writing, this emerged in the mid 2000s where Sarah Gordon[1] and Mary O'Hagan[2], reporting from the Aotearoa/New Zealand policy context, shifted the paradigm framing of consumer action from one of seeking change through involvement in services to one of leading change of services. Consumer leadership was observed in multiple ways, including on personal self-care and recovery levels, as well as in terms of local service level advocacy. The main message however was:

> Central leadership in the managerial and governance structures that plan, fund and deliver mental health services; the provision of service user managed and delivered services and (the) central involvement of service users in mental health advocacy, training, education and promotion (p.365).[1]

The growth of mental health lived experience movements has occurred alongside extensive development of AOD (alcohol and other drugs) mutual aid groups and organisations over many decades. Self-help and mutual aid groups for addiction recovery make up arguably the largest sector of lived experience organisation and leadership when considering the spread of 12-step groups such as Alcoholics Anonymous and Narcotics Anonymous across international contexts and the blueprint that 12-steps programs have provided for other peer group development. [3] Leadership is also evident in the creation of innovative community organisations which harness recovery lived experience and offer programs of advocacy, community learning and AOD recovery through reconnection to employment, education, housing and community life.[4] Leaders express a vision and means of recovery to challenge traditional service sectors:

> It seems crucial to me to support the development of emerging recovery organizations to ensure that they become a valued part of every system of care...it is important that they do not sit in isolation from the other treatment and support services. We must recognize the value of people in recovery and peer supporters in building social supports and expanding recovery capital. It is only through recovery forums and peer-led services that people in recovery can become visible. Once these people become visible recovery champions, they can help people to believe that recovery is not only possible but desirable (p.174).[5]

Lived experience in harm reduction by people who use drugs or people living with HIV or HCP (Viral Hepatitis) has strong histories of activism, mobilisation and self-organisation. The organisation of user leaders is global in reach with established networks and a presence at the United Nations policy level,[6] while there also exist significant user-led organisations working on local law reform, leading harm reduction initiatives, addressing diverse community needs,[7] and offering significant research contributions.[8] User leadership occurs through collective activism, community organisation and contributing:

> The movement is not only about people who use drugs having access to the resources that society can offer, but also society having access to the resources that people who use drugs can offer…The movement is about being at the heart of decision-making, and 'meaningful involvement' ... when policies are being made and implemented, in the spirit of 'Nothing about us, without us' (p.15).'[7]

Similar to mental health lived experience, an explicit focus on leadership may not be apparent in the literature but it is implicit across the various roles of peer leaders in and beyond the AOD recovery and harm reduction movements.

The purpose of this literature review is to examine evidence from literature and research on how lived experience leadership has been understood and embedded in differing service types and contexts, including a focus on whether lived experience leadership features unique styles and dynamics of governance. There is also a need to understand how lived experience leadership has been experienced in mainstream mental health services, AOD treatment and recovery services and harm reduction programs.

The review was commissioned to contribute knowledge to the development of Victoria's Lived Experience Leadership Strategy. The review is broad in that it attempts to understand lived experience leadership across mental health, AOD mutual aid and recovery and harm reduction spaces, reflecting the co-work of peer leaders from these areas in recent policy development and peer work learning frameworks, particularly in Victoria.[9-11] There is also an attempt to describe the leadership of consumers and carers in separate terms, in addition to identifying trends and gaps in the literature.

A key context of the review is the interpretation and implementation of recommendations from the Royal Commission into Victoria's Mental Health System.[12] There are many recommendations that are dependent on the effective realisation and embedding of lived experience leadership. These relate not only to the need for system wide roles for consumers and carers, but also to the development of new service models for various populations, the creation of a lived experience lead agency, trauma services, improved care pathways, crisis support services, integrated supports for people with substance use and addiction and suicide prevention initiatives. Lived experience guidance through the co-design and governance of these new services is expected by people who contributed insights and learning during the Commission period and those who strive to achieve more accessible, caring, effective and accountable services. Leadership via senior lived experience (peer) roles is also required to guide the growth of the lived experience (peer) workforces within services, and the continued development of models of peer support and contributions to transdisciplinary teams.

The review has been planned, researched and written by three lived experience authors who are active in researching, promoting and enacting lived experience leadership as a catalyst for systems transformation. Our recent work in South Australia led to a co-designed vision for the future that grounds our collective work and expresses the heart and purpose of what lived experience leadership is about. We share this with readers to begin and orient the review.

A Vision for the Future

We believe unequivocally that now is the time for lived experience leadership to be developed and embedded in our systems. The need is visible and the conditions for change are right. The vision for lived experience leadership and future services are where humanity and connection are centred and where people with lived experience meaningfully and equally contribute at all levels, to the point that it becomes the norm. Through taking action together a more holistic approach will guide change, and ensure that our language, power, and mindsets, shift beyond biomedical and 'illness' dominated narratives. Upholding rights, giving control to people to determine their own lives and authentic co-design are essential foundations of the changes we seek. Systems are strengthened when discrimination and tokenism are minimised and where peoples' dignity is prioritised. Lived experience leadership across the system, including by and with people with lived experience, is core to this vision being realised and is itself a key driver of the broader systems change that the mental health and social services sector require.[13]

SEARCH STRATEGY

The purpose of the literature review was to find, summarise and describe key concepts and evidence on the organisation and embedding of lived experience leadership at systems and organisational levels. It also aims to highlight gaps in research and analyse how trends in this knowledge can contribute to policy and service development.

The review is an industry-level literature review based on a systematic search approach. The full detailed search strategy is available as Appendix 1. The review has been designed to inform a broad range of questions and to find information about definitions, strategies and actions that can assist the development of Victoria's Lived Experience Leadership Strategy.

Research Questions

The questions of the review were developed by the Project Control Group (PCG) in VicHealth, reflecting many areas of inquiry and interest on lived experience leadership across different settings and the areas of mental health, substance use and harm reduction. The Project Control Group consists of leaders from Harm Reduction Victoria, SHARC, Tandem, VMIAC and staff members from the Lived Experience Branch of VicHealth.

The authors grouped the questions into three broad research questions to guide how the search would proceed.

1. **Definitions:**

   How is lived experience leadership defined across areas of lived experience action and in relation to traditional leadership models?

2. **Models and applications:**

   What are best practice models of lived experience leadership for different settings and contexts?

3. **Embedding:**

   How has lived experience leadership been organised and embedded effectively in organisations and systems?

Operationalising the search presented some challenges, especially about how leadership was termed. Would the search only capture documents using the term leadership? Or would it be broader and include literature where leadership is more implicit rather than explicit, such as in the management of consumer-run organisations or systems advocacy? The PCG and authors decided to proceed with the broader approach which meant that the review covers many areas of action including advocacy and representation, organisational involvement and management, evaluation and research and tertiary level education.

The overall search design was guided by previous literature reviews on consumer leadership and consumer led organisations,[14, 15] including work by the present authors.[16] The search used a very wide set of search terms and a detailed set of inclusion criteria was needed for deciding how literature was included. The focus when including literature was about ways lived experience

leadership is organised and embedded in organisations and systems. There was a focus on using search terms for consumer, survivor, user and peer literature as well as search terms for carer- and family-based literature as two distinct groups. This is important for maintaining a unique focus and space for each group as occurs in the mental health sector.

As the literature review has a broad scope, with limited time and resources to complete, it is important to highlight that this review does not suffice for more focused scoping and rapid reviews in the areas of consumer-run organisations in either mental health, AOD recovery or harm reduction, or on peer involvement in these areas. Similarly, while this review included an interest in peer-led research and evaluation, it would not cover the need for a specific search in this area, where careful searching on terms, and handsearching grey literature would retrieve a wider body of literature. This is especially important in lived experience, as many projects are written as local reports (grey literature) that are not captured by academic databases.

These limits also apply to considering lived experience leadership across different identity groups. Understanding leadership in Aboriginal and Torres Strait Islander communities, culturally diverse communities, LGBTIQ+ communities, and within women's health or other groups would require specific literature reviews in each area. They would also need author teams most appropriate to undertake and guide this work. We write further about some of these areas of research development in the discussion section of the report.

Eight academic database searches were completed, and limited grey literature searches also took place using Google search and examples of key terms. The authors also undertook handsearching in the areas of mental health, AOD mutual aid and recovery and harm reduction and included known articles in mental health consumer leadership. Several periods of follow up handsearching, and redrafting and revision took place upon feedback and consultation with the Project Control Group.

The following results section identifies the results and themes of 172 included studies, reports and discussion papers. Using an approach similar to a scoping review,[17] we have organised findings into different areas or categories, describing and mapping selected evidence about leadership and governance in lived experience organisations, embedding in mainstream health services, research and evaluation, allyship and health professional education. Within each area we map literature in mental health, AOD mutual aid and recovery and harm reduction or intersecting health or disability issues.

CONCEPTS AND MODELS OF LIVED EXPERIENCE LEADERSHIP

> Collective leadership. Everyone participates and joins with their brilliance. What bonds us is the eagerness to go the extra mile – not to let the experience isolate us as individuals, to seek companionship with others (Interview participant 16 in Waddingham 2021, p. 19).[18]

This section reports on 12 studies which are centred on definitions and concepts relating to lived experience leadership, including papers which relate to models of leadership. There are five qualitative studies, three multiple methods studies, one descriptive study and three discursive papers. The studies indicate the complexity of lived experience leadership and the different ways it can be framed, communicated and demonstrated. All studies focus on mental health user experience or AOD mutual aid and recovery. No papers were specifically identified for carer leadership or peer leadership models in harm reduction lived experience. The terms of 'user/survivor' and 'consumer' are used to align with the original authors' use of language in mental health focused papers. This practice occurs throughout the review.

User/Survivor/Consumer Leadership in Mental Health

Muscari's descriptive study of consumer leadership of 14 state-wide mental health networks in the US used an existing model of leadership to frame and understand the leadership qualities and actions of network leaders.[19] 14 leaders completed surveys based on Kouzes and Posner's model of leadership practice (a general model, not specific to lived experience). Results showed key leadership practices were clearly evident across the 14 consumer leaders in terms of frequently demonstrating 'modelling the way', 'inspiring a shared vision', 'challenging the process', 'enabling others to act' and 'encouraging the heart'. These are five exemplary leadership practices for building successful consumer advocacy networks and credibility within the movement.

Informal consumer leadership was explored by Piat et al.[20] in a qualitative analysis of emerging leadership within a residential setting. Resident leaders were recognised for their knowledge and fearless approach to voicing concerns on behalf of other residents. Leadership also was characterised by mobilising and bringing consumers together for action, and for being able to provide positive examples or solutions for shared issues. Piat et al. found that leadership occurs when there are pathways for it to develop and relates to sharing knowledge and wisdom, assuming responsibility, and having credibility.

Writing from a user/survivor perspective, O'Hagan[2] argues that the user/survivor movement requires its own model of leadership, one that recognises shared experience of disempowerment and injustice and is grounded in a clear moral purpose for change. The proposed model of user/survivor leadership envisioned by O'Hagan needs to be driven by empowerment and equality goals, based on collective values of the movement, and collective lived experience knowledge. User/survivor leadership should also have a specific stance on having 'power with', rather than 'power over'. The purpose and values of the user/survivor

movement should be the context for accountability and evaluation. Therefore, a unique model is required as neither transactional or transformational leadership approaches are able to represent this purpose, knowledge base and context.

O'Hagan identifies user/survivor leadership occurring at three levels of preferred activity. These include: 1) at the personal level for one's own recovery; 2) at the services level for user/survivor services; and 3) leadership at the systems and policy level.

Focusing on these latter two levels, leadership at the services level is about user/survivor led governance and management decision-making which aligns with and expresses the values of the movement. Leaders here are active across different aspects of service activities and programs. Systems level leadership is described in terms of both designated and non-designated leadership roles. Influence and leadership can be demonstrated from policy makers, system advocates, politicians and researchers. Within the leadership categories, O'Hagan lists key competencies and skills that leaders require[2].

Further development of consumer leadership as a concept has occurred through two Australian qualitative projects from Stewart et al. In a study of stakeholder perspectives[21] consumer leadership was noted as being a complex concept which hadn't yet been clearly defined in the literature. Their analysis found that leadership occurs through the diverse roles that consumers regularly occupy in sectors and services, and that it can also occur informally. Five categories of roles were identified which include: 1) advocacy and representation; 2) peer support work and service provision; 3) education and training; 4) service design and co-production; and 5) funding, management and governance. Stewart et. al. suggests that leadership within these roles can be demonstrated by the key processes of leading with purpose, communicating and applying lived experience, by having influence with others in decision-making, by building and using relationships with other leaders in organisational environments and by contributing to a culture of inclusion and peer support.

A more recent paper by Stewart et al.[22] provides further depth of analysis by exploring the means by which power, self and identity are experienced and realised for consumer leaders. The authors describe that leadership, motivation and belief occur through the leader's development of the 'power of self' as a response to lived experience of institutional and interpersonal features of mental health care, where power is often experienced coercively. Consumer leaders also develop an awareness of systemic level issues that are commonly faced by others as collective knowledge of the movement. Consumer leadership, therefore, has a particular stance of rejecting coercive or 'power over' dynamics and instead seeks to shape institutional and informal power in emancipatory ways. The '*power of self*' concept, in consumer leadership, also provides the authority of knowledge as a basis of influence and directing change, while also being the basis as to how leaders build relationships and work in solidarity[22].

The second paper that explicitly describes a model of lived experience leadership is provided by the present authors[23]. Developed from a participatory action research study, the Activating Lived Experience Leadership (ALEL) model uses an intersectional social justice and social movement lens to define the key characteristics, values, qualities and skills of effective lived experience leadership. As above, the model also places lived experience leadership as leading a movement for recognition, inclusion and justice, where leaders are 'simultaneously active across informal, personal, community and formal organisational spaces' (p. 8). The model is comprised of six core leadership themes: 1) centres lived experience; 2) stands up and speaks out; 3) champions justice; 4) nurtures connected and collective spaces; 5) mobilises strategically; and 6)

leads change. Leadership action is expressed through the values of integrity, authenticity, mutuality and intersectionality and is guided by the principles of staying peer and sharing power. Within the themes of the model, there are 20 key qualities and skills identified as features of effective lived experience leaders. The model was developed within an intellectual grounding and deep immersion in the user/consumer movement yet is also broad enough to be inclusive of carer leadership, as well as peer leadership in intersecting and aligned communities[23].

A significant research piece is the qualitative project of NSUN in the UK, which featured detailed questions, themes, nuances and tensions on the concept of lived experience leadership. Waddingham's[18] analysis unpacks key perceptions about the concept rather than seeking a formal definition of it. There are, however, key themes similar to those detailed in the above studies. Lived experience leadership occurs when leaders act in value informed ways that contrast with oppressive experience and 'go beyond traditional hierarchies in mental health and social care settings' (p. 15). Leaders are also able to de-centre their own experience to create space and hope for others. Like the studies above, lived experience leadership occurs across different spaces of activity and can be evident in a diversity of sector roles.

Waddingham's exploration of lived experience leadership as a concept raises questions about the qualification or threshold of people's level of lived experience to be leaders. Concerns about imposing and avoiding rigid criteria around lived experience leadership and being exclusive, given diversity, were stipulated. There is a need to create spaces where diverse communities are active and visible in lived experience leadership, including valuing the different forms and styles of leadership that have grown in specific communities. Diversity should be visible in training activities and resource development, as well as through networking of organisations.

The conversation about leadership is associated with positional power, with participants being wary about the use and misuse of power, including some leaders claims to representativeness. There are questions about how lived experience leadership is seen as a feature of individuals, defined on qualities and traits, rather than being seen as people contributing leadership as part of collectives. Leadership actions, for individuals, are fluid and according to the needs of the occasion and local movements. Waddingham's analysis reveals mixed views on the value of the concept, and different degrees to which participants are comfortable with the term and title.[18]

Leadership in AOD Mutual Aid and Recovery

Three studies focused on leadership styles of women leaders in Oxford Houses, which are a USA founded peer model of recovery houses operated through democratic decision-making. Davis et al surveyed 40 women and mothers with children about definitions and perspectives of leadership and the qualities they felt were important.[24] Survey results indicated that women felt the organisation of leadership to be an important factor to the success of the Oxford House model, alongside members upholding the rules of the democratically run house environment. This enabled a shared communal process rather than hierarchical model of leadership. The qualities seen as important by participants were being a good listener, an effective role model, having the ability to solve problems and decrease conflict, and abilities to facilitate decisions through negotiation, compromise and encouraging consensus. Being an effective speaker and being well liked were also rated as important by most participants.[24]

Timpo's qualitative study of leadership at Oxford Houses interviewed 10 women about perspectives and experiences, including barriers.[25] The women reported that effective leadership traits were honesty and accountability, and being able to motivate and inspire peers through role modelling. Listening, compassion and kindness were also important qualities. The leaders also saw that their work had personal benefits for their own recovery through greater responsibility and accountability to members and the house. Increased empowerment, self-esteem and confidence were also outcomes experienced by participants. Some of the reported barriers to emerging leadership were seen as conflict, low self-esteem and worth, the need to focus on personal recovery first and reconnecting with family relationships. Some women had also experienced sexist responses from male leaders in the Oxford House movement.[25] A further study with women leaders focused on leadership styles in the context of transformational and transactional leadership. Komer et al.'s survey study with 29 house residents found that the transformational leadership style was associated with higher outcomes than transactional leadership, and that residents used person orientated skills over task orientated skills. Self-identified leaders scored highly on transformational leadership scales.[26]

Hohl's study[27] with peers in the AA movement suggests that emotional intelligence qualities are important aspects of leadership, and that the principles of the 12-step model can contribute to their development. This study included four participants who were active in AA groups and also business leaders, focusing on the concepts of identification, understanding, expression and regulation of emotions in intrapersonal and interpersonal experience. Hohl reports that the key themes of emotional intelligence demonstrated by participants included: 1) empathy and understanding, including 'reaching out' for others in 12-step work; 2) inventory, the process of honest self-appraisal about actions and ethics; 3) humility, associated with being supported by sponsors and learning from experience; and 4) accountability and restitution, which is about taking responsibility for past and future behaviours.[27]

Hill's discursive paper[28] on leadership in the recovery advocacy movement focuses on servant leadership, as a basis for recovery and liberation. He articulates servant leadership as way of 'engaging with the world' (p. 2), which involves transformative healing potential through acts of service. A leader's weakness (or vulnerability) opens opportunities to experience strengths and gifts through mutual aid, whereby helping others promotes personal growth and healing. Giving back to others and harnessing the collective spirit of the recovery community are important processes in setting a vision for overcoming ignorance, stigma and oppression of society's responses to addiction. Hill cites Greenleaf's 10 characteristics of servant leadership as listening, empathy, healing, persuasion, awareness, foresight, conceptualisation, commitment to growth of others, stewardship and building community (p. 7). Hill goes on to describe detailed processes on impacts of servant leadership, anonymity and spirituality in 12-step meetings and peer relationships.[28]

LEADERSHIP AND GOVERNANCE IN CONSUMER AND CARER RUN ORGANISATIONS IN MENTAL HEALTH

This section reports on findings about approaches to leadership, governance and hierarchy in lived experience organisations. It aims to report on studies showing areas where lived experience leadership is embedded robustly and is demonstrated by effective and sustainable lived experience run organisations. A further aspect is to identify challenges that user leaders experience.

Many of the studies used are focused on mental health consumer-run organisations (CROs) and initiatives and explore the impacts of participatory aspects of leadership approaches within CROs and how these are connected to activities, and the empowerment-based outcomes for consumers engaging with them. There was a significant gap in finding articles of a similar focus for family carer-led organisations. Themes from 28 papers are reported in this section. The papers selected included 10 descriptive surveys or other quantitative studies,[29-38] seven qualitative studies,[39-45] four industry reports and consultations,[46-49] five discussion papers,[50-54] one book chapter[55] and one scoping review.[56]

Consumer and Carer Organisations in the United States

The research base for exploring CROs is the most extensive in the US context where the consumer/family carer self-help and empowerment movements have been significantly realised. National survey data[29] from the early 2000s indicated that there were 7 467 organisations operating in the country at that time. This was made up of 3 315 mutual support groups for consumers and/or family,[1] 3 019 self-help organisations[2] and 1 133 consumer operated services.[3, 29] (Definitions for each type are defined in footnotes). Data from a 2012 survey, only measuring incorporated consumer operated services, indicated a decline in numbers with 380 services responding to a survey process.[50]

Goldstrom et al. indicate that all three organisational types perform a wide range of functions within their memberships. These include providing telephone support, social and recreational opportunities, public and community education, advocacy and rights protection and producing resources. Trends suggest that consumer operated services were more likely to provide drop-in centres, face-to-face mentoring or buddy systems, provide training and help members with housing and employment.[29]

[1] Mental Health Mutual Support Group. Defined as a group of people who 'get together regularly on the basis of a common experience or goal to help or support one another. Membership in a group must be voluntary and free. The primary purpose of the group is to attend mutual support group meetings'.

[2] Mental Health Self-help Organisation. Defined as an 'organisation run by and for consumers and/or family members, which undertakes activities to educate them or their community about mental health issues and/or engages in or undertakes political or legal advocacy and/or provides services to consumers or family members. Some mental health self-help organisations sponsor and/or support mutual support groups'.

[3] Mental Health Consumer-Operated Service are 'programs, businesses, or services controlled and operated by people who have received mental health services. With limited exceptions, staff also consists of people who have received mental health services'. P 95

In terms of organisational structures, a continuum generally exists across these organisations i.e. from being informal mutual support help groups towards self-help organisations (also called consumer-run drop-ins) and consumer operated services, in which the latter two types are usually formalised as a non-profit organisation with a board of management and staff.[29, 35] Brown and Wituk indicate that while formalised board – staff hierarchy is often in place, there are conscious efforts to enable shared leadership through collective decision-making and engaging in roles as volunteers, staff, board members, shift coordinators and managers.[55] They and others suggest that consumer-run drop-ins are more likely to reflect grassroots membership interests and retain the passion and warmth of volunteer-based organisations.[55],[30]

As mental health consumer organisations develop in sophistication with grant funding and more complex operations they can struggle to maintain flexibility, and can become more rigid, hierarchical and rules based, and lose independence compared to non-funded consumer groups.[35, 55] CROs can also struggle to maintain participatory processes when their memberships become too large.[36] Brown and colleagues highlight the importance of organisations maintaining open and welcoming meetings and strong attendance and participation from members, where decisions about policy, practice and activities are shared, diverse input valued, and conflict and conduct well managed.[37, 55]

These aspects of organisational functioning and hierarchy have been measured for impacts on multiple levels. In one study, less hierarchical self-help organisations, that involve members in all management tasks were associated with higher measures of organisational empowerment and positive self-stigma among members compared to board and staff consumer organisations.[35] Other research by Brown et al. indicates however that board and staff CROs are still able to provide opportunities for taking on leadership and helping roles, and that participation in these are linked with empowerment and recovery outcomes for members. Members can gain more resources, skills and positive self-worth through the social opportunities and shared leadership offered through participatory consumer operated organisations.[31]

Tanenbaum argues that CROs work to strengthen citizenship as these are community organisations espousing democratic norms and reaching out to establish significant relationships with local businesses, community groups and services.[32] Rye's description of the Empowerment Centre in New York depicts the decision-making that leaders took toward facilitating economic participation and development for both members and the sustainability of the organisation.[51]

Besides measuring recovery and empowerment benefits, there have been efforts to develop and measure the ability of consumer-run drop-ins and consumer operated services to maintain fidelity to key values of the consumer/survivor movements.[33, 38, 46] This has involved the development of tools such as the Fidelity Assessment Common Ingredients Tool (FACIT) fidelity measure. This is a validated framework for evaluating board, membership and operations to ensure these reflect values of consumer control, choice, opportunities for decision-making and voluntary participation.[46] Maintaining fidelity and staying true to equality and mutuality in day to day operations is critical to consumer operated programs, as there are risks that peer support becomes unidirectional, hierarchical and staff directed help, rather than being a mutual self-help process.[52] This potential dilution of organisational ethos and participation risks the unique offering of consumer operated services compared to clinically orientated mental health services.[52]

Systems Level Supports for US Consumer-Run Services

Literature from the US context indicates considerable levels of leadership and systems support beyond grassroots and organisational levels. While many mutual support groups and self-help groups started without funding, the development of consumer operated or run services occurred via national funding under the Community Support Program, which began in 1977. Other nuanced funding programs enabling the development of state-wide consumer networks, national technical and assistance centres, and leadership academies have also occurred.[19] State-wide consumer networks were established as leadership and advocacy organisations (or peak bodies). These were funded to support a membership of smaller peer organisations and encourage the growth and transformation of community-based mental health nationally. Such networks supported leadership via conferencing, training and organisational development.[19] SAMHSA (a federal government branch) funded five National Technical Assistance Centres to assist with various skill and capacity based needs of CROs. In one study, requests for support from CROs were documented in the area of board and policy development, business management and grant writing, strategic planning, recovery program planning, membership and volunteering strategies and to further support organisational leaders.[34]

Consumer and Carer Organisations in Other Countries

The scale of research and documentation about the peer movement in the US was not evident in other countries. Only one paper focusing on two consumer and carer peak bodies was identified in the Australian context (in the ACT),[39] which documented the range of peak body functions. These being systems advocacy, strengthening involvement, consumer and carer voice, developing collaboration and partnerships with policy and community stakeholders, and building organisational membership and sustainability.[39]

Four papers from the Canadian province of Ontario indicated similar findings to the US context, however, with more recognition of organisational challenges. Janzen reported that Ontario had a funding program supporting established consumer survivor initiatives (CRIs) from 1991.[53] By mid-2000 there were 60 CSIs in the province, with a peak body also being developed.[47] Similar to the US context, these CSIs are diverse in responding to local communities, but also share common activities such as one-to-one peer support, self-help groups, skill development, social and artistic activities, community education, community planning, research and advocacy for systems change. Organisational activities to nurture participation and leadership including membership meetings, volunteer roles, conference attendance and recreational events were also common.[53] These have been studied with similar outcomes as those noted by Brown and colleagues above.[31] The CSI organisational operations engage consumers in helping and leadership roles which value their contribution and improve people's sense of power and self-worth.[40]

Formal study of the Canadian CSIs has not looked at organisational hierarchy, instead they have focused on the various value dilemmas for leaders. These include conflicts that play out between encouraging volunteer led activities or staff led activities, between providing direct services, or system change efforts, and between being autonomous organisations or dependent on government funding.[54] Other organisational and leadership challenges for CSIs were receiving equitable funding, possible absorption into mainstream services, lack of coordination and planning for growth, lack of member diversity and funding of minority or marginalised user

groups, isolation from mainstream policy decision-making and lack of organisational standards and performance measures. Some CSIs also experienced difficulties with governance and management, reluctant leadership and the need for skill development.[47]

Studies and consultancy reports from England indicate a significant history in the development of user self-help and mutual aid organisations with a burgeoning movement during the 1980s.[41] Statistics about the number of groups was not identified in any of the papers.[42] As in the US, organisational structures ranged from informal volunteer self-help groups through to Charitable Incorporated Organisations.[48]

Studies of organisational leaders perspectives indicate that user-led organisations have been successful in establishing strong user control, lived experience ethos and a range of functions in advocacy, peer support, and self-help groups.[42, 43] Budge's study of the Bridge Collective User Group found that democratic decision-making nurtured and challenged members, and engaged them in key processes of negotiating relationships, feeling the responsibility of involvement and sharing power.[44] Like previously mentioned studies, these were linked with personal empowerment and growth outcomes.[44]

Boyce et al. found that non-hierarchical organisational structures were a key feature within four user organisations studied, also indicating that groups faced challenges in maintaining member led decision-making rather than the efficiency of user staff/board led decisions. As membership for each group was in the hundreds, decision-making became more orientated toward committee level structures working from the input of consultation meetings, and other feedback processes with members. The groups also demonstrated innovative community inclusive activities, such as public lectures and meetings which engaged members and supporters.[43]

Leaders in the English user movement face similar tensions and dilemmas as evidenced in Canada. These include tensions between attending to systems advocacy and representation rather than building peer support for local community, and in maintaining autonomy in operations versus meeting funding obligations for programs.[42, 43] Studies indicate these tensions, as well as complex funding and policy environments, require leaders to devise creative solutions[41] and maintain strategic partnerships.[45]

Recent NSUN research outlines some of these challenges in considerable detail. Many groups reported feeling that funders do not understand their role or commitment to directly supporting specific community needs. Groups are often struggling for resources and funding to deliver needed programs, and can be isolated in that experience.[49] While funding sources may be available, White et al. recently found that consumer leaders often experience barriers with inaccessible, inflexible and complicated funding processes. Many groups from minority and marginalised communities including Black, migrant, LGBTIQ+ and asylum seeker groups operate from lower funding levels, and struggle with being framed as mental health user groups given their broader focus. These and other funding expectations have negative results for user groups in terms of organisational insecurity, burnout and fatigue.[48]

Much of the literature reported above has been reviewed in significant depth via a recent scoping review produced by Opie et al. in partnership with VMIAC.[56] This provides a valuable summary of themes for this section. The review identified the following themes:

- CROs are unique from non-consumer mental health organisations in contextual, resource, operational, and service characteristics as driven by peer values and consumer control.

- Structural characteristics of CROs such as wider voluntary participation, shared leadership, member run activities and consumer control contribute to operational success.

- Less hierarchical power structures encourage better levels of member empowerment and sense of ownership. CROs seek to structure democratic decision-making as a key connection to grassroots level values and activity.

- The characteristics of CROs are associated with individual outcomes of recovery, empowerment, self-efficacy and organisational outcomes of participation, and connection.

- Effective CROs provide a supportive community and espouse values of mutuality, safety, lived experience, choice and personhood.

- CROs were seen to have positive organisational climates for supporting peer practice, service quality and enabling career development supports.

- CROs face tensions in maintaining the unique purpose, values and participatory processes given proximity to and integration with mainstream mental health services and the expectations of funding bodies. Sustaining peer organisational and service priorities can be challenging given tension with funding priorities or public mental health service culture.

- CRO leader qualities documented as being focused on purpose, facilitating power sharing and empowerment, peer autonomy, motivation, awareness raising and navigating conflicts.

- Promoting consumer led boards is seen as best practice and key feature of successful CRO operations. Success required board management skills, clear expectations and training.[56]

The review makes many recommendations about supporting the effective functioning of CROs. These cover training for organisational leaders, meaningful career progression and training pathways, growth of senior leadership, need for independent funding, investing in funding availability for CROs, setting stakeholder/funder agreements on expectations, increasing community awareness, role clarity for staff, fair payment for lived experience roles, safe and trauma informed culture and effective integration strategies for mainstream services.[56]

LEADERSHIP AND GOVERNANCE IN AOD MUTUAL AID AND RECOVERY

The review identified a variety of sources and papers which described leadership and governance in the AOD recovery area. Peer leadership and action in this movement represents a vast history of achievement when considering the reach and influence of 12-step programs, as well as many other unique groups and organisations globally. This section includes evidence from diverse sources including four descriptive/quantitative studies,[57-60] four organisational overviews,[61-64] three discursive papers,[65-67] two book chapters,[3, 68] one qualitative case study[69] and one industry consultation report.[70]

Humphreys 2003 chapter on the diversity of AOD mutual aid groups characterises 19 groups in the international context, discussing history, philosophy and approach, and membership.[3] These groups include Alcoholics Anonymous (USA, multi-county), Abstainers Clubs (Poland), Al-Anon Family groups (USA, Canada, Australia, Europe and South America), All Nippon Sobriety Association - Danshukai (Japan), Blue Cross (Europe), Clubs of Treated Alcoholics (Croatia, Bosnia- Herzegovina, Slovenia), Double Trouble in Recovery(USA), Free Life (France), Jewish Alcoholics, Chemically Dependent Persons and Significant Others (JACS) (USA, Aust. Canada, Brazil, Mexico), The Links (Sweden, Denmark), Moderation Management (US, online), Narcotics Anonymous (USA, multi-county), Nicotine Anonymous (USA, Canada, Australia, Brazil, England), Oxford Houses (USA, Canada, Australia), Pui Hong Self Help (Hong Kong), Rational Recovery/SMART Recovery (USA, Canada, England, Australia), SOS/LifeRing Recovery (USA, Canada), and Women for Sobriety (USA, Canada, Australia, England, New Zealand).[3]

Many of these groups have been influenced by the Alcoholics Anonymous (AA) model but vary significantly in key characteristics including the influence of spiritual background, autonomy of members, involvement of professionals and family members. Some organisations have deliberately adopted secular philosophies (e.g. LifeRing/Smart Recovery), and engage with government funding (Oxford Houses, Women for Sobriety). Other organisations take on wider advocacy functions rather than the sole focus on mutual aid espoused in 12-step programs.

Humphreys also characterises organisations that are having varying levels of professional involvement, in contrast to the 12-step programs having minimal professional involvement. This is in comparison to organisations in Europe which can have significant levels of professional influence in decision-making. Therefore, a number of individual studies included in this review give further insights and findings of these organisational characteristics.[3]

Borkman's discursive paper on the historical development of relationships in AA indicate that founding leaders intentionally sought a non-hierarchical and egalitarian form of organisation, that would assist members to avoid temptations of money, power and professionalisation.[66] The formation of the 12-step model, as groups of autonomous individuals, was also about preventing bureaucratic organisation and oligarchic leadership, seen as essential to success and survival. AA developed a model of shared leadership embedded within the core methods of group meetings, and guided by the 12 principles of AA. Borkman lists these methods as: 1) the sharing circle, peers coming together to share experience and stories; 2) co-leadership, where facilitators also remain group members; 3) a guiding belief system and philosophy, which points to solutions and change; 4) geographic and social diversity, which encourages respectful and egalitarian ways for new groups to form; 5) a self-reflexive learning approach – learning through sharing and experience, rather than hierarchical knowledge authority; and 6) the values based

spiritual authority of the group conscious, the consensus of local group members is a foundation of their own groups governance.[66]

Borkman notes that the commitment to egalitarian relations and democratic governance is reflected in the meta rules of AA and in the relationship between local groups, the formal incorporated bodies of AA Grapevine (Magazine publication) and AA World Services (Services and guidance to local groups) and the General Service Board. Local members elect conference representatives who form policy at AA conferences and elect trustees of the Board. Local groups maintain autonomy from each other and are seen as the foundational organisational unit of AA. There are rules about local groups not being able to own property, obtain money from grants, endorse or affiliate with treatment centres to minimise conflicts of interest and to stay true to purpose.[66] The AA model has been highly influential in shaping the development of many other 12-step groups,[66] as well as alternative approaches.

Women for Sobriety (WFS), developed as a specific alternative, secular recovery organisation that responds to women's priorities and needs.[61] WFS also includes peers using other drugs as well as alcohol. The New Life program is its main abstinence based mutual aid program, which includes face-to-face and online group meetings, newsletters, phone support and website information. Local and online groups are led by WFS certified group facilitators, who also undertake group planning, administrative tasks, liaising with WFS and publishing their local groups for recruitment. WFS receives no outside sources of funding and operates its website and online publishing, via donations from members. Unlike the 12-step model, professionals can initiate and facilitate groups, with the aim of supporting eventual peer group leadership. This means they can be run in treatment services [61].

Another peer model which has intentional egalitarian leadership and membership characteristics is the Oxford House movement, which has over 1200 houses operating in the US, Canada and Australia to assist people in recovery regarding drug and alcohol use.[68, 69] Housing operations need to meet basic standards to set up under the Oxford House model as the lead organisation. This model promotes leased housing run by residents where leadership is rotated among all members on a six-monthly basis. The shared leadership and governance occurs through positions of President, Treasurer, Comptroller, Coordinator, Secretary, and Building Maintenance, whereby residents set rules during house meetings and also need to abide by them. This includes fines and penalties for not following agreements.[69] This approach helps create conditions of maintaining abstinence and ensuring member contributions, as well as assisting people to gain skills and experience in financial management, supporting decision-making and resolving conflicts. It also creates safety for residents as all members are encouraged to commit to abstinence, 12-step meeting participation, and avoid disruptive behaviour.[69] Members can also have experience in representing their houses in chapter meetings involving multiple houses.

Researchers consider that the peer support and social environment of Oxford Houses provide members opportunities to take on and role model new behaviours, and activates them as decision makers, rather than them being subject to decisions made by professional services.[68, 69] Harvey and Jason's[60] 2011 study of the organisational climate of Oxford Houses compared to a professional staff therapeutic community found significant higher rates of involvement, support, practical orientation, spontaneity, autonomy, order and organisation, and program clarity compared to residents at the other setting.[60] (See also studies on Women's Leadership at Oxford Houses on page 14).

A further model of housing is provided through Sober Living Houses (SHL). Like Oxford Houses, these reflect innovation in establishing a singular model of peer group organisation which have been in various states and countries. The SHL design enables residents to work together to decide house rules, recreational activities and domestic tasks, with housing leased by a broader peer organisation or through a housing manager. The model has been adopted across some 800 houses throughout California and is supported by two peer coalition networks which provide information, training and guidance to lead the movement. Coalition networks, at times, need to campaign against 'Not In My Backyard' (NIMBY) discrimination enacted by communities and local agencies hoping to prevent new houses being established.[67].

A recent study[59] on the activities of house manager roles indicates that peer leaders demonstrate consistency in promoting social recovery through ensuring resident abstinence, facilitating regular house meetings and involvement, encouraging resident to attend 12-step programs and providing peer support. However, there were significant variations in how house managers used their time in these activities and how expectations were clearly conveyed by guiding peak organisations. The study found training provided to managers was minimal, potentially impacting on the quality of promoting recovery principles with residents. [59]

There were a group of selected papers describing the characteristics and operations of Recovery Community Centres (RCCs), or Recovery Community organisations(RCOs) in the US.[63] These organisations are diverse, multiple purpose, not-for-profit staff/volunteer organisations which offer 'a recovery orientated sanctuary in the heart of the community' (p. 266).[63] Valentine describes core elements of RCOs as being founded on a recovery vision for long term recovery from addiction, having authenticity of the voices of local and diverse communities, of recovery, and independence from other organisations which may dilute or offer conflicting interests.[65] They also need to offer a visible and physical presence as a centre of community organisation, and offer an array of peer based recovery support services.[63] Notable examples in the papers were the Connecticut's Community for Addiction Recovery (CCAR),[63] The RECOVER Project (Massachusetts)[64] and Philadelphia and Pennsylvania Recovery Organization-Achieving Community Together (PRO-ACT).[57]

RCCs offer structured and diverse activities, learning opportunities and workshops, individual peer support and serve as a recovery resource centre for the community in ways that harness local resources, opportunities and people. Visibility and social events are important ways to celebrate recovery and counter stigma. Volunteer peers, family members and friends organise and facilitate most of the programs, workshops and services of RCC.[57] While many activities are peer recovery groups and learning opportunities, peers also engage in significant public education and advocacy activities, to have outreach and impact for recognition of the realities of recovery, and to encourage inclusion (e.g., National Recovery Month events).[65]

RCCs are designed to be a gateway for engagement of people for recovery through participation and attendance in peer support and activities, while also contributing to sustained recovery through growth and change. Opportunities for involvement, training and leadership occur through committee involvement in planning events, decision-making about other policy and operations, facilitating events and activities, and/or leading discussion groups.[64] A number of studies have indicated a link between recovery and personal growth through volunteering in the roles that centres offer, as rated by peers. This includes rewards of giving back, seeing growth in self and others and accountability for personal recovery.[57] Kelly found that study participants volunteering, as a common experience, was rated as the most helpful, as it provided

benefits in terms of increased recovery capital (self-knowledge, esteem and confidence) rather than through increased social support.[58]

While, included studies did not centre on governance structures in RCCs, the papers above reflect that these organisations are non-profit, incorporated bodies which have Boards, and paid staff, including centre managers, volunteer managers and program leaders. It appears that leaders of the organisations are mostly peers in recovery or family members with lived experience, who may also have professional social sector qualifications.[70] The challenges and areas of best practice for the development of RCCs identified from leader experience have included the need to promote recovery specific language, create allies, market recovery to communities, ensure payment to staff, limit negative impacts of peer certification, the need for holistic funding models, maintain trust with members, and promote diverse pathways of recovery.[70]

Dorius et al. indicates that in 2020 there were 169 Recovery Community Centres and 152 Recovery Community Organisations operating in the US across 45 states. They make the distinction between RCCs as being local visible centres, and RCOs as being either statewide or regional network organisations which serve as major advocacy, fund raising and practice guidance organisations.[70] The development of these organisations has been further supported through sequential support funding, such as federal grants including the Recovery Community Services Program, which has funded 73 programs between 1998 and 2007. The funding program was underpinned by principles of resourcing a recovery first orientation, and promoting diversity and inclusion, authenticity, participatory processes and leadership development, while encouraging the development of quality standards and a research agenda. Program level evaluation has included indicators of various outcomes including abstinence, housing, education, employment, social connection and avoiding arrest.[62]

It is evident that similar RCC organisations may be active in other countries but not well documented in research literature. Kidd provides a perspective of three recovery organisations in the UK, and argues about the importance of establishing these centres rather than relying on user involvement in professionally centred systems.[5] These organisations, Uchooseit, the Basement Project and THOMAS, provide training and volunteer roles to build participants internal recovery capital, confidence and esteem, and enable people to then engage in broader systems work, such as sitting on commissioning panels and advisory groups, with more significant community connection, experience and support.[5]

LEADERSHIP AND GOVERNANCE IN CONSUMER AND CARER RUN ORGANISATIONS IN HARM REDUCTION AND INTERSECTING AND ALIGNED COMMUNITIES

User-led Organisations for People who Use Drugs or who Live with HIV

Turning to harm reduction and drug user-led organisations, the review identified 12 papers which described the organisation and features of lived experience leadership. While no papers presented explicitly framed models of leadership, there were important themes characterising the features, functions, context, challenges and innovation of lived experience leadership found in the literature about user-led organisations. These papers described examples of organisations and leadership in Europe,[71], Nordic countries,[72] France,[73] the USA,[60, 67] Canada,[74-76] Australia,[77, 78] and the international context.[7, 79]. The studies included five qualitative studies,[73-75, 77, 78] three discursive papers,[67, 72, 79] two industry reports,[7, 76] one descriptive study[60] and one book chapter.[71] An additional Canadian paper described the links between a user-led organisation and research contribution. [8]

Hunt's[71] 2010 overview of user-led organisations in Europe outlined the significant range and variability of programs and roles offered to members and the local community. Independence and the ability to work to self-determined agendas are a key feature of many organisations and networks, as is the ability to use member mobilisation to challenge discrimination within civic and legal spaces. The range of activities is very similar to that provided by mental health and disability organisations, but also unique to the lived experience of substance use, where blood borne viruses and the need for harm reduction practices shape what activities are undertaken. Navigating boundaries of legality of activities is also a feature of user leadership in these spaces. Various national and global level user networks also exist.

Hunt summarises Goossens 2008 research, indicating that user-led organisations commonly provide:

- Advocacy and policy development.
- Peer support for people living with HIV/AIDs (PLWHA) and for people using drugs.
- Information, education and prevention on blood borne disease.
- Publishing newsletter and magazines, and other media.
- Arranging and facilitating training, seminars and member meetings.
- Accommodation projects.
- Drop-in centres which may be safe injection or drug consumption rooms, or informal Naloxone and Methadone distribution.
- Public awareness raising about issues in the user community.[71]

Some studies provide more detail about the functions of leadership within user-led organisations. Two papers focus on the Vancouver Area Network of Drug Users (VANDU) organisation in Vancouver's Eastside Downtown, which is highly regarded for its impacts and user leadership. A further paper reports on the significant contribution of VANDU members to research in harm reduction outcomes and evaluation.[8] Jozaghi[74] reports that through its systems advocacy, innovative program development, and community action, VANDU creates new conceptual and physical spaces for members. Conceptual spaces are the shifts in attitude and understanding that VANDU creates in community, health agencies and policy circles, where stigma is challenged and the needs of community are heard, understood and legitimised. Physical spaces are the safe places for drug consumption, support and learning that the programs offer community members. Historically, VANDU has demonstrated numerous examples of campaigns and protests which effectively engage and mobilise members in civic action, as well as nurturing the development of new groups which focus on specific interests e.g. housing groups.[74] Kerr[75] reported on some of the organisational processes of VANDU, including the importance of regular monthly members meetings where the Board and attending members plan activities and share information. Meals and a small honorarium are provided to members to recognise contributions. These and other processes encourage a culture of shared responsibility, mutual caring, self-respect and skills development among members. [8]Frank et al.'s study[72] on drug user organisations in Nordic countries describes similar features in terms of functions and processes of supporting membership, through provision of methadone maintenance, needle exchange, drop-in centres and hostels. More established organisations have large memberships with core leadership groups of board and staff. SDUU (Sweden) has 1 375 members and DDUU (Denmark) 641 members, with the Swedish SDUU having sub-branches in different cities. Compared to some of the small user organisations in Finland and Norway, these larger organisations have longer histories, stable long term leadership, and are able to secure core funding from government and other sources.[72]

A notable feature of the innovation of user organisations in the substance use area has been the development of singular focus models which have been replicated across states and countries. Wittman's[67] paper on Sober Living Houses (SLHs) in California provides an example. This model enables residents living in a SLH to work together to decide house rules, recreational activities and domestic tasks, with housing leased by a broader peer organisation or through a housing manager. The model has been adopted across some 800 houses throughout California and is supported by two peer coalition networks which provide information, training and guidance to lead the movement. Coalition networks at times need to campaign against 'Not In My Backyard' discrimination enacted by communities and local agencies hoping to prevent new houses being established.[67]

User leaders have also established the successful Oxford House movement in the US, with over 1 200 houses operating to assist people in recovery regarding drug and alcohol use. This model promotes leased housing run by residents where leadership is rotated among all members. Housing operations need to meet basic standards set up by Oxford House as the lead organisation.[67] Harvey and Jason's[60] 2011 study of the organisational climate of Oxford Houses compared to a professional staff therapeutic community found significant higher rates of involvement, support, practical orientation, spontaneity, autonomy, order and organisation, and program clarity compared to residents at the other setting.[60]

Challenges for User Organisations and Leadership in Harm Reduction

The authors focusing on the experiences of user organisations in harm reduction have recorded significant challenges for the sustainability of user organisations and in user leadership generally. These include the following themes:

- Managing internal conflicts amongst members and leadership groups[71, 75] or conflicts between organisations with diverse user perspectives.[7]
- Skill gaps and limited availability of volunteers to take on leadership roles.[7, 72]
- Instability in leadership including leaders dying prematurely, or being unavailable due to the impacts of use or other life events.[71, 74-76]
- Lack of longer term stable funding or suitable funding cycles.[76 71]
- Dilemmas, and co-option dynamics due to close relationship with social welfare services, or expectations from funders.[7, 72]
- The need for longer term skills and capability development and building a leadership pipeline.[7, 76]
- The need for support from allies in responding to attacks from media regarding stereotypes and criminalisation.[76]
- Ongoing impacts of criminalisation on activism and leadership.[7]
- The need to represent and promote voices of people who are silenced due to criminalisation, stigma, cultural values and marginalisation.[7]

Reports and studies describing these conditions also identify important leadership qualities, functions and skills. These are described not only for leading organisations but also for external influence and change. INPUD's report on the oral history of the user movement,[7] describes activists as using an adaptive mix of strategies for change. These can include negotiation, diplomacy, protest, disobedience, campaigning and research. Leaders also build partnerships and coalitions and often take an intersectional approach in finding common interests and advocacy solutions. Leaders are also seen to work both within and outside of systems, adapting strategies to shape policy and service decisions, while also promoting diverse community needs, and preferences. Due to the contexts of criminalisation and marginalisation, leaders often are navigating irreconcilable interests between policy makers and their communities.

The qualities of leadership for negotiation of complex funding and policy environments are important observations made by many authors,[7, 72, 73, 78, 79] and feature in analysis about the unique context and dynamics of user leadership in harm reduction. On a sociological level, Zibbell[79] argues that the policy contradictions of both public health and law enforcement provide the context and motivating forces for activists and leaders to succeed in harm reduction. Successful leaders articulate the injustices of stigma, criminalisation, lack of health care access and effective programs as health policy and equity concerns and respond effectively using lived experience and community mobilisation to offer effective program responses to reduce harms in the public health interest. These actions then also influence and soften legal provision and law enforcement practices. As leadership and activism produce effective harm reduction outcomes, and influence policy contexts, there are also shifts in perceptions of users

towards being responsible and engaged citizens contributing to public health and taking preventative action. Jauffret-Roustide's 2009 analysis[73] notes similar dynamics of leadership and context but expands on the framing of lived experience. Leaders also frame lived experience as essential and unique knowledge for both policy influence and engaging peers in communities, providing legitimacy, recognition and power for user organisations, and the rationale for involvement and leadership at systems levels.

Similar systems level analysis of leadership has been a feature of the Australian Project: Understanding What Works and Why in Peer Based Programs in HIV and Hepatitis C (W3) framework .[77, 78] Brown and colleagues have mapped leadership functions to better understand the influence and capability of user organisations at systems levels, and for helping leaders to avoid common strategic issues. Working with 90 peer leaders from diverse user-led organisations representing people most affected by HIV and HCV, the project mapped key casual pathways of strategic action for tackling stigma and promoting inclusion. This work clarified the essential processes of: 1) engagement of peers within People Living with HIV (PLHIV) community contexts; 2) the alignment between health system and peer-led responses; 3) leader adaptation to changing community, policy and health system contexts, based on their strategic knowledge of engagement and alignment needs; and 4) sustained influence on the health and policy system. For each of the four processes the project defined detailed key indicators of effective PLHIV peer leadership, activities and health promotion. These included process and impact indicators for meaningful involvement of peers in user-led organisations, policy and health service decision-making and community level activity.[77]

Disabled Peoples Organisations

Research on user-led organisations in the broader disability area reflects mostly similar operations, themes and dynamics in the way leadership is organised and experienced. Two Canadian studies demonstrate that disability user groups also provide unique roles in representing lived experience, providing systems advocacy, mobilising members and building relationships with diverse stakeholders.[80, 81] McColl and colleagues' argue that user-led organisations experience similar ideological dilemmas in relationships with members, funders and policy makers, with the need to manage confrontation/collaboration and legitimacy/co-option dynamics. They also have to navigate decisions about individual or organisational membership and volunteer or paid staff.[81] The study by Hutchinson et al. highlighted that user organisations demonstrate competence in establishing common political agendas, providing authentic voice and accountability for/with disabled people, mobilising successfully to encourage shared ownership and capacity building, and providing strategic policy leadership. The need for rejuvenating leadership while maintaining experienced leaders is a challenge.[80]

A recent report on Disabled People's Organisations[82] in England estimated that there are 395 such organisations across the country. While this indicates a robust presence of user leadership, the report provides extensive details of challenges and barriers that are similar to English mental health specific user-led organisations. These include a lack of a peak body and coordination structures linking local organisations, isolation, lack of long-term core funding, increasingly transactional and uncertain relationships with funders, workforce support and development issues, the need to involve and support diverse/marginal communities, leadership support and the need to develop the next generation of leaders.[82] An earlier Shaping Our Lives (Peak body) report [83] indicates these challenges and issues have persisted for some time,

particularly in terms of insecure funding and the difficulties that funding gaps present for networking and shared knowledge development among diverse service user organisations.

This section of findings has focused on user-led organisations in documenting examples of where lived experience leadership has been effectively established and influential in developing peer-led programs and advocating for systems and policy change. There are key learnings around organisational structures, challenges, conditions, supports and required training across the studies which are discussed later in this review.

MENTAL HEALTH LIVED EXPERIENCE LEADERSHIP AND MAINSTREAM ORGANISATIONS

Embedding Leadership in Mental Health Service Decision-making

This section of the review focuses on how lived experience leadership has been achieved in mainstream mental health and intersecting services. It also documents the challenges, barriers and conditions that impact on leadership.

A 2017 systematic review of consumers in the leadership of mental health services found that most of the literature featuring consumers as leaders is focused on consumer-run organisations as compared to literature demonstrating effective embedding of lived experience leadership in public mental health services.[14] The present review has had a similar outcome. Most of the literature found and informing this review is concerned with challenges and barriers to involvement for consumer and carer advisors in health service governance and advisory structures, where the focus is studied in the context of services and organisations, rather than systems. Much of this work is framed in lived experience involvement, rather than explicitly about consumer or carer leadership in service hierarchies. These results are relevant to consumer and carer leaders' proximity to and presence in organisational decision-making.

The 25 papers included in this section are 17 qualitative studies,[21, 84-99] three discussion papers,[100-102] one descriptive survey study[103], two multi-method studies[104, 105] and two industry consultations.[82, 106] 19 studies were Australian. From available information about settings, 12 papers had participants from mixed settings of government and NGOs, and academia,[21, 85-88, 90-94, 105, 106] while three were from government only [95-97] and one from NGO only settings.[98] Eight papers engaged participants in diverse lived experience roles,[82, 85, 89, 90, 97, 98, 100, 103] four articles were focused on managers and/or colleagues [87, 93, 94, 96] and ten included diverse stakeholders including participants in lived experience roles, managers and colleagues.[86, 88, 92, 95 21, 91 84, 104-106].

The studies share the overall sentiment that the achievement of consumer and carer leadership in mainstream mental health services are variable, uncertain, undervalued and difficult to fully realise or capture. The literature is mostly on structures, roles and experiences of involvement in decision-making, and depicts paradigm conflicts between recovery, human rights, carer inclusion, and the dominance of biomedical and paternal approaches to care. At the same time, the policy imperatives and benefits of consumer and carer leadership are evident across the studies, in terms of the vision of involvement and partnership needing to be achieved, the shifts needing to occur for better care outcomes and better experiences for lived experience (peer) workforces. The literature covers participant samples in both NGOs and government services.

Challenges and Barriers for Advocates, Representatives and Leaders in Health Service Decision-making

The studies identified many challenges and barriers for lived experience leaders and other service leaders seeking to achieve effective and influential levels of partnership in decision-making, service governance, co-design projects and service development. These were themed as below:

- Challenges of coming out or being out, having a public profile and experiencing stigma.[86 85]
- Boundary issues for peers and staff in collaborative relationships.[87, 101]
- Variable understandings and lack of clarity regarding lived experience, lived experience leadership, advisory and representative roles within committee structures and groups.[103, 95, 88, 96]
- Unrealistic expectations on representation and consultation.[21, 88, 97, 102 105]
- Deficit assumptions about leaders, stigma, stereotyping and othering.[85, 86, 97-99]
- Unequal relationships, culture, resources and power sharing due to dominance of biomedical or professional paradigms of knowledge, language and decision-making.[86, 90, 99 91]
- Resistant professional staff members.[86, 97, 98]
- Lack of authentic power and sustained influence within consumer/carer and advisory structure.[86, 92, 91]
- Experiences of burden relating to being the bearer of change and the go-to person.[86]
- Conflicts, tensions, uncertainties and lateral violence within lived experience communities.[86]
- Lack of dedicated infrastructure, resources and capability for lived experience involvement, governance structures, co-production and delegating financial decisions/budgets to peer leaders.[86, 92 95]
- Isolation within roles, e.g. being the only person with designated lived experience in the group.[86 91]
- Organisational change and complexity which impacts on lived experience leaders/advocates experiences of involvement.[105]
- Challenges in structures that enable and support involvement of diverse lived experience, including effective structures for rural settings.[86, 95]
- Experiences where involvement processes do not recognise or support identity, sexuality, gender and culture, or where the description of leadership roles and opportunities do not recognise intersectionality.[86, 100]

- Lack of supports and learning pathways for training,[89, 96, 100] mentoring or peer-based supervision.[86, 94, 90]
- Poor development of, or access to, information and leadership networks.[82, 86]
- Exposure to stresses, inner conflicts and difficult demands due to paradigm conflicts between recovery, lived experience and psychiatry.[86, 93]
- Frustration, fatigue and burnout from slow change processes or feeling devalued.[86, 98]

Strategies for Embedding Lived Experience Representatives, Advisors and Leaders in Governance and Decision-making

The review found no formal evaluative studies on effective embedding of lived experience leaders into the governance of mental health services. Studies, including many of those above, instead make recommendations based on the perspectives and experiences of participants in governance and involvement practices in their organisations. Most of these recommendations are based on challengers and barriers, what is needed to overcome them, as well as recommending what structures, processes and strategies have worked well for participants. The following themes have been consolidated from the studies above, with the addition of Beehler et al.'s qualitative study of US Veterans Mental Health Advisory

Councils,[84] Rosenberg et al.'s study on Swedish User Advisory Councils in Mental Health and Substance Use,[104] and the recent Australian Lived Experience Governance Framework.[106]

- Establish clearly defined, and empowering organisational roles of lived experience leadership, representatives, advisors and other roles and ensure shared understanding across the organisation.[87, 89, 91, 95, 101, 102, 106]
- Upscale and increase the presence and numbers of consumers and people with lived experience on boards and advisory councils and other committees.[86, 99, 100, 103]
- Ensure intersectional and diversity approaches to inclusion and relationships with leaders.[86, 100, 106]
- Ensure decision-making structures such as lived experience councils and advisory or governance groups are well defined with clear goals and processes, are well resourced, sustainable and legitimate across the organisation.[84, 86, 95, 104]
- Facilitate effective meeting structures, processes, decision-making and external communication and ensure these are well known to lived experience members and others in the organisation.[84, 99, 104]
- Provide training and professional development for lived experience leaders in processes, roles, communication and leadership.[84, 97, 101, 104]
- Ensure training and professional development for executive leaders and other staff on co-production facilitation, lived experience leadership, cultural change and challenging stigma.[85, 86, 96, 104]

- Foster allyship and champions among wider staff networks for supporting cultural change.[91, 94, 106]
- Provide information, budgets, resources, time and physical spaces to lived experience leaders to support equitable involvement and rebalancing of power given structural disadvantages.[86, 92, 97, 99, 90, 91, 106]
- Support effective administration, workload and flexibility for lived experience workers.[90, 101]
- Support the growth of leaders through improved mentoring and supervision pathways, external networking and relationship building across the organisation.[84, 97, 101 89, 90]
- Resource co-production processes and enable lived experience to lead on areas of expertise, i.e. defining recovery.[86, 100]
- Ensure organisational commitment and accountability measures towards lived experience leadership are in service agreements, KPIs, quality improvement processes and commissioning processes.[86, 106]

Strategies and actions such as these can be supported at systems level through sharing development, ensuring clarity in policy framework definitions of lived experience leadership, and through committed commissioning of lived experience-led activity and models of care. Consumer and carer peak bodies should play an important role in leadership, information, networking and training development to build capacity and scale of lived experience leadership at state and regional levels.[86]

The Lived Experience Governance Framework[106] offers important conceptual understandings for building the foundations of lived experience leadership at governance levels. The framework centres lived experience from an intersectionality, identity and human rights perspective and argues that lived experience governance is based on restorative, just and accountable organisational cultures and lived experience values, principles, ethics and positionality. Many of the strategies listed above are evident within the framework's five key domains: 1) partnership and co-production; 2) safeguarding, responsibility and power; 3) lived experience involvement, expertise and leadership; 4) transformative workforces and practices; and 5) innovation and continuous improvement.

Embedding Lived Experience Leadership into Lived Experience (Peer) Workforces and Service Delivery

There is a need to consider strategies for strengthening peer-based leadership within the employed lived experience (peer) workforces. The review found two further papers which contributed to this area[107, 108] which is also informed by some of the studies previously mentioned.[86, 93, 94, 97] The review did not include a number of recent systematic reviews on peer support worker implementation as they did not report on peer leadership.[109, 110]

Jones et al.'s large survey study on organisational climate and peer worker experience found that peer-run organisations and peer-led teams gained the highest ratings of supportive climate and support for career development than non-peer-led organisations and teams. The

study also indicated that peer workers had greater depth and involvement in leadership and better status and influence at work in organisations able to provide a positive culture and climate[107].

Byrne et al.'s best practice model for effective employment of peers in multidisciplinary teams, outlines key strategies for organisational development and change. These are summarised as:

- Whole of organisational commitment to embed peer work as essential core business is reflected in key organisational statements, with long term resourcing and employment at effective scale compared to non-peers.
- Organisational culture and language are developed through openness, learning and transparency and shared learning, respect and collaboration across peers and non-peers.
- Commitment through championing occurs via top-down and bottom-up support.
- Effective pathways, employment and inclusion of peer leaders from intersecting communities, via the specialisation of peer work in different life areas and within specific identity groups.
- Creation of senior or management level peer designated roles with authority to lead supervision and practice development.
- Quality workplace preparation, including informed recruitment processes.
- Training for management and colleagues in peer values and policy and procedure development to guide peer work roles, including HR and administrative guidelines and practices which safeguard authentic peer work values and roles.
- Effective pathways for peer-based supervision, mentoring, networking and professional development.

Among these strategies, the employment of senior peer leaders who can use positional power for influence and change based conversations is a key development.[94] The National Mental Health Commission's *National Lived Experience (Peer) Workforce Guidelines* provide a comprehensive platform for organisational level change, and promotes development in the context of lived experience leadership, and the employment of peer workers in diverse community/identity contexts.[111] Further systems level change can occur through the development of peer practice networks, and the need to ensure new models of care are informed by existing peer methodologies and practice approaches.[86]

AOD MUTUAL AID AND RECOVERY AND MAINSTREAM ORGANISATIONS

Recognising AOD Mutual Aid and Recovery in Recovery Orientated Systems of Care

Specific searches in the AOD mutual aid and recovery area have revealed a significant history in some US states of attempts for systems change that recognise peer workers, mutual aid groups and recovery community organisations within a reorganisation of care and a broader recovery framework.[112-116] Some UK based development has also occurred.[117] Authors writing about *Recovery Orientated Systems of Care* and other areas of collaboration have produced reflective papers describing these projects and/or expert opinion on key strategies.

Writers summarise the importance of a transformational approach to embedding recovery which identifies the importance of integrating person centred planning, building recovery social capital and moving from a focus on clinical treatment and acuity towards a staged ecological model of engaging people with, and sustaining recovery.[113, 118] Recovery social capital is about assisting people to develop skills, support networks, employment and education resources overtime, and recognises that pathways to recovery are diverse and reflective of the knowledge, opportunities and assets embedded in communities, not only those in treatment services.[112, 114, 117] Identified strategies of systems support and/or collaboration which are relevant to the review include:

- Ensuring peers, family members and allies are effectively involved in all stages of planning conceptualisation and development, implementation and evaluation.[113, 118]
- Recognising the vital role of local and specific community resources in initiating and sustaining recovery. These include the transformative power of recovery metaphors, language and narratives from lived experience, and the physical, psychological and cultural proximity of local community groups, the contagiousness of recovery experiences.[112]
- Ensuring services are anchored in communities, by investing in the development of Recovery Community Centres (RCC), and other centres providing peer-based recovery support services in peer learning groups, housing, employment readiness, education etc.[113, 116, 117]
- Working in ways which are genuinely collaborative, recognising and valuing the specific philosophies and cultures of peer organisations and avoiding practices which impose bureaucratisation and data monitoring, co-opt culture, limit flexibility, dilute advocacy and volunteering, or exploit community networks.[3]
- Ensuring peer advocacy and community organising are recognised, valued and funded, rather than limiting investment to expansion of peer support services.[3, 118]
- Supporting faith-based communities and other communities to build and share recovery social capital through seed and small grant funding.[114]

- Appropriate connections with 12-step mutual aid programs[114, 117] in ways which support peer philosophies and recognise preferred referral pathways.[3]
- Funded centres of excellence in recovery work, including peer work and support group practice.[115]
- Promoting support of mutual aid groups through provision of in kind supports (facilities, meeting places, IT and phone service hosting).[3]
- Funding mutual aid technical assistance centres or clearinghouse groups which assist group formation and skills development, and provide public information/directories etc.[3]
- Using reinvestment strategies to build lived experience programs, and innovative ways to attract multiple sources of funding, including block grant funding and access to Medicaid funding for peer specialists.[113, 115, 118]
- Growing peer leadership via training and skills development, more employed positions, training on public speaking and using stories, creating leadership academy programs.[114]
- Using recovery-based language on a sector level, and recovery-based assessment and outcome measures.[112, 115]
- Developing education and training initiatives for attitudinal change towards the recovery approach for all stakeholders, including clinician, provider and communities.[114]
- Ensuring safe and effective peer work development, providing adequate supports, payment, workload planning, appropriate practice boundaries and avoiding negative impacts of volunteering.[113, 118]
- Providing research support with appropriate aims, designs and measures which align with peer group culture and assess needs from the perspectives of group leaders.[3]

White's paper[112] on inclusion of peer and community recovery resources within treatment-based organisations provides 'in reach' strategies for organisational collaboration. These include establishing (non-paternal) contracted/collaborative relationships with RCCs for mentoring, and recovery coaching, and advisory board/staff/volunteer roles, developing effective consumer councils and alumni/graduate associations. RCC members can also provide education and training for treatment centre staff on recovery experiences. Ways that treatments services can support RCCs and community networks include, promotion of pro recovery state and national policy, contributing financially to recovery celebration events, shared recovery reporting and encouraging a service philosophy of choice through multiple pathways and styles of recovery.[112]

HARM REDUCTION AND MAINSTREAM ORGANISATIONS

Embedding Leadership in Drug Policy, Harm Reduction Programs, Drug Treatment and HIV Care

The review identified 16 studies to inform embedding leadership and peer-led programs in the context of substance use and harm reduction policy and programs, in HIV care settings or intersecting areas. These included seven qualitative studies of evaluations or reports on peer involvement/consumer participation projects, redesign and consumer partnerships or peer leader experience [77, 119-124] and three systematic reviews including a focus on peer involvement in drug treatment,[125] the roles of peers in harm reduction,[126] and peer support in homelessness and substance use.[127] Further literature reviews on implementation of peer-led health promotion[128] and peer involvement in policy and programs were selected. A discursive paper on issues surrounding representativeness of leaders was also used.[129] The studies were across diverse country contexts. Outsides of the literature reviews, six studies were Australian,[77, 120, 121, 123, 130, 131] two were set in Norway,[119, 129] and single studies in Canada[132], Ireland[124] and England.[122] There were no specific papers on family or carer leadership identified.

The various literature reviews selected indicated the broad range of studies that have focused on various aspects of peer work and peer leadership, with these representing different roles and settings, including employment in direct peer support activities as well as in advisory roles. For instance, the Marshall's et al. review[126] groups identified roles into five categories: 1) harm reduction education; 2) direct harm reduction and health services; 3) peer support, counselling and referral; 4) research assistance; and 5) advisory committee work.

While most papers have a unique focus, it has been possible to theme findings about organisational and policy embedding from those papers focused on peer involvement in either drug treatment policy/services, AOD recovery settings and harm reduction policy/services. In doing this we make the qualification that drug treatment services can have a focus on inclusion of recovery focused peer programs services while harm reduction programs have a more diverse set of aims and peers engaging in or leading harm reduction may be active substance users, rather than seeking recovery. Most of the studies selected have a specific focus on harm reduction activities (nine papers) while some include a focus on both harm reduction and AOD treatment settings[120, 124, 125, 127]. Miler's literature review, for instance, includes 12 papers on abstinence based 12-step mutual aid programs.[127]. There is, therefore, an overlap in these findings with the earlier section on AOD Mutual Aid and Recovery.

In selecting findings from the literature reviews, industry documents and other studies, we have focused on findings relating to how peer leaders are embedded in mainstream organisations and policy systems. These include the various challenges and barriers that impact on the experience of peer leaders, representatives and advocates, as well as recommended facilitators for better recognition, support, and valuing of peer led programs or policy advice. This focus is broad and recognises that leadership can occur within and across the various roles where peers are active. Challenges and barriers are also features of mainstream organisational cultures and climates which negatively impact on the growth of leadership by peers in defined roles and are thus relevant from this perspective.

Strategies for Embedding Peer Leaders, Representatives and Workforces in Governance and Decision-making

To theme the barriers and facilitating strategies for embedding peer involvement and peer roles in mainstream services we used the categories of organisational and systemic levels, as used in the Marshall review.[126] Barriers and obstacles for achieving the effective involvement of peers in policy and program decision-making are summarised as:

Systemic barriers:

- Continued criminalisation of drug use and people who use drugs.[121, 126, 133]
- Policies favouring enforcement rather than harm reduction.[126]
- Social level stigmatising of drug use and people who use drugs.[126, 127]

Organisational barriers:

- Exclusionary attitudes, policies, programs and service rules[126, 133] including stigmatising beliefs of staff [121, 124, 127, 131, 133] or assumptions that users should be passive.[125, 131]
- Few examples of effective peer involvement practices in other services.[131]
- Gaps in communication and information about existing/proposed peer involvement initiatives.[124, 131]
- Lack of time and resources for organisations[121, 131] or instability of management [120] to enact effective involvement.
- Power imbalances between users and providers reflecting existing hierarchies.[124, 125, 127, 133]
- Unclear expectations and roles on user representation as defined in initiatives.[125, 127, 129]
- Lack of policy leadership and support[121] i.e., peer involvement not being core business.[125]
- Lack of provider/management knowledge for enabling effective engagement and relationships. [131]
- Disregarding the impact of social determinants of health on peer capacities to engage.[121, 126]
- Decision-making is dominated by provider perspectives and does not reflect lived experience.[125, 126]
- Insufficient preparation, training and support of peers for peer involvement[120, 131] or workers.[121]

Systemic facilitators are reported in the above literature to be:

- Improved policy frameworks to enable effective peer involvement.[131]
- Cultivation of positive relationships of programs with the wider community.[126]

- Political and government support.[121, 126]
- Recognition as valuable government program by local health authorities.[126]
- Support of law enforcement (police).[121, 126]

Organisational facilitators include:

- Developing organisational cultures that value and support effective involvement, work to overcome obstacles and have plans for sustainable initiatives.[126, 127, 132]
- Involve peers across frontline services, management and governance.[126]
- Partner with user organisations, networks and leaders,[120, 132] including enabling user organisations to lead development (training and design) on involvement.[131]
- Improve funding and resourcing for effective peer involvement[120, 124, 125, 132] including the development of practices and processes such as 'on day' payment for users.[121, 132]
- Better commitment and support from organisational leaders at all levels.[120, 121]
- Clear expectations and defined roles regarding representation[129] involvement, ensuring alignment between levels of engagement and aims/goals. Use memorandum of understanding (MOU) processes to set agreements and follow existing best practice guides on engagement and allyship.[132]
- Ensure well defined communication pathways internal to initiatives and external to user groups and stakeholders.[124, 125] Develop clear analysis of power around the table and recruit for equitable representation from diverse lived experience communities. Equity considerations include age, race, gender, sexual orientation, physical ability, and geography as areas for developing accessible and culturally safe harm reduction. Set ground rules to foster equal voices and power.[132]
- Use peer navigators who know the service and culture to support emerging/new peers[132] and connect people with peer mentors.[125]
- Provide training to users and providers on engagement process[120, 126], harm reduction principles, cultural safety, trauma informed care principles[132] and service structures and meeting processes.[125]
- Recognise the strengths and value of peer networks and learn from peer feedback.[125, 126, 132]
- Ensure flexible, accessible, and culturally relevant programming.[126]
- Evaluate and learn from peer involvement initiatives.[132]

Various individual studies illustrate some of these themes in practice or add nuances about the experience of peers. Bergs et al.'s study[119] on the transformation of an HIV clinic via a user board led redesign, reported key features of influence and success. These were considered to be the structure and processes of having an autonomous advisory level board with clear expectations, mission and goal setting, diverse membership, strong capacities for consultation with community, suitable time and resources for development, effective presence and

communication with service leaders, training for members, and strong support from clinical leadership.[119]

Brown et al.'s work on systems level peer leadership[77, 123] (the W3 Framework reported earlier) and the work on engagement, alignment, adaptation and influence between communities and policy environments is also important to consider for organisational and systems level leadership. Their framework provides 23 detailed indicators about leadership activity. These include how peer leaders can strategically influence policy circles, and political levels, to ensure community needs and preferences; this aims to facilitate that the preferred scope and design of peer-led work are well understood by policy makers, and then embedded in sustainable ways within harm reduction programs. The indicators provide guidance for the development of new programs, and can be considered as potential indicators for evaluation.[123] The W3 project has also identified the types of organisational evidence that align with each indicator.[130]

Many aspects of effective engagement and adaptation between peers, programs, policy and communities, were reflected by Lorthias et al. in their implementation guidance framework.[128] While their study includes peer initiatives broader than harm reduction and sexual health, their framework identified the importance of engaged relationships between peer leaders, community participants and policy stakeholders, and the supports required at program levels (e.g., recruitment, training, championing) and organisational levels (e.g., climate, readiness and leadership). The processes of building trust, developing capacity, self-organising and adapting programs are required by peer leaders within supportive organisational and policy environments.[128]

The focus on relationship dynamics, and the 'fit' between community expectations, policy provision and program design plays out in the experiences of peer leaders guiding and delivering this work. Miler et al.'s systematic review[127] reported on the challenges of peer-led work in the homelessness and substance use care sectors relating to vulnerability, maintaining authenticity, managing boundaries, responding to stigma, and being valued by employing organisations.[127] Peer workers in sexual health, while effective in building trusted relationships and creating opportunities for mutual learning among peer communities, are often challenged in negotiating structural hostilities relating to HIV status, racism, transphobia, homophobia and anti sex work attitudes.[122] Peer-led responses to marginalised communities that have been neglected by mainstream policy and service provision require heightened levels of resource commitment for working through and supporting communities in these contexts. [95]

Embedding Leadership and the Advocacy Movements for People with Disability

A UK study on representation and advocacy for people with disability and carers found the same range of barriers to service involvement as reported in mental health; power imbalances, not being listened to, tokenism, and inaccessible and inflexible meeting processes. The advocates named key ingredients for successful involvement as equality in collaboration, mutual respect, ownership, effective structures, leadership commitment, effective feedback, and development through training and networking.[134]

Two studies focusing on the leadership and involvement of people with intellectual/developmental disabilities, and family carers have relevant findings for the review.

Caldwell's study of user involvement on university advisory boards[135] reported the need for organisations to provide individualised supports, finance and remuneration, high quality coordination and communication, and leadership development opportunities for effective leadership within board or committee operations. Individualised supports include communication related accommodations (sign, captioning, large print material) as well as consideration of physical spaces and sensory preferences, and processing and preparation time for members. Recruiting new leaders can occur from having strong links to the self-advocacy movement, having presence at user conferences, and focusing on developmental opportunities and mentoring. As stipulated above, genuine involvement and influence occurs via strong executive leadership, recognition and valuing.[135] Caldwell's other study on leadership development[136] highlighted that council and board opportunities are a key developmental opportunity where leaders grow their skills in communicating with influence, making presentations and guiding boards for practices of inclusion.[136]

Allies and Champions in Supporting Lived Experience Leadership

Seven studies in the area of allyship in mental health provide detail about the role of allies[137-140] as well as issues around power sharing,[141] motivations,[142] relationships and challenges.[139, 143] These are all Australian studies with six papers being qualitative studies of allies[138, 139, 141-143] or consumer perspectives and experiences, [137, 139] and one discussion paper.[140] No specific studies on allyship in harm reduction were selected.

Happell and Scholz[140] describe the role of allies as using privilege and positioning to promote consumer leadership and inclusion, ensuring authentic voice, respecting lived experience knowledge, staying nonpeer and not speaking for lived experience. Other studies report the role of allies being to support consumer leadership roles and action, enabling access to decision-making and resources, guiding navigation of organisational environments[138] and advocating to create space for consumer-led or co-produced work.[137, 139] Allies can also effectively role model appropriate working relationships for the wider workforce.[137]

Study of the motivations of allies suggest that health leaders and practitioners are orientated via social justice values, believing in the role of lived experience leadership for change, and being inspired and fulfilled by supporting consumer-led service development or research.[142]

Research has also uncovered challenges in dynamics in working relationships between allies and consumer leaders, including naming power imbalances, ensuring more consumers are involved in decision-making,[141] being part of oppressive history and systems, impacts of stigma, worries about being protective or paternalistic, and working through discomfort.[143] Challenges in working with allies include experiencing hidden agendas, allies using power to dominate processes, and allies lacking thorough understandings of consumer perspective.[139]

Knowledge and Skill Development for Areas of Leadership

The review identified a diverse range of papers to provide evidence around knowledge and skill development for lived experience leadership. These include qualitative studies about leaders experiences in guiding user organisations[41, 144-146], and reports and studies on leadership,

advocacy skills or empowerment programs.[147-153] Also included are O'Hagan's paper on user leadership[2], a survey study[34], a training guide[154] and an industry report.[9] Most papers focused on consumer skills and required learning in the mental health area. The papers included on carer leadership are about carer education and empowerment programs.[150-153]

Analysis of these papers showed that the following themes of knowledge and skill development are important for lived experience leadership in the services context. Leaders can develop in the areas of:

- **Consumer advocacy and advisory work**: consumer movement values, mental health systems, positive communication skills, networking, stakeholder analysis, understanding policy and legislation, meeting protocols, decision-making, power and influence, drivers of change, accountability, self-awareness and reflection, use of research, conflict resolution skills and promotion of lived experience work.[2, 147, 148]

- **Family/carer advocacy and consultant work:** co-production processes, promotion of lived experience work, educating other staff, understanding legislation and policy context, working strategically, prioritising and time management, using evidence, working effectively in teams, facilitating and chairing meetings and conflict resolution.[9]

- **Consumer peer work leadership:** addressing stigma and workplace conditions, difficult conversations, embracing leadership, managing dual relationships, self-care[145] supervision, mentoring and succession planning.[154]

- **Governance:** board roles, governance frameworks, power dynamics, risk management, finance and strategic planning.[149]

- **Organisational management:** program management, grant writing, reporting, board development, staffing, conflict resolution, policy development, activity planning, partnership relations, administration, increasing membership, volunteer development, finance, evaluation and research.[34]

- **Strategic leadership:** achieving goals while navigating tensions, dilemmas and multiple points of accountability between peers, stakeholders and funders across sectors, using skills and positioning to ensure organisational autonomy, power sharing with members, peer identity and fidelity.[41, 144, 146]

The review found reports of promising examples of consumer leadership programs such as the West Virginia Leadership Academy,[147] the UK Voices Together[148] program and VMIACs more recent, Consumers in Governance program.[149] We are aware that further consumer leadership training programs are available such as LELAN's Lived Experience Development, Governance & Education (LEDGE) Project and Yale's LETs Lead Academy. SHARC's Industry report details the need for significant investment and development for improving pathways for career opportunities, qualifications and organisational supports for the lived experience (peer) workforces. This is needed to facilitate 'discipline' levels of self-organisation and recognition of this by other stakeholders across sectors.[9]

Family Carer Advocacy, Empowerment and Activation Programs

Regarding family carer empowerment studies, Olin reported on 'Parents as agents of change'.[152] This program was implemented in New York with peer family advocates.[153] Family peer advocates provided mentoring in the following categories: provision of emotional support, action planning, information provision, advocacy and skill development. Improvements were recorded in family empowerment, use of mental health services and self-assessment of skills. Preparing parents to meet with professionals and for attending individual education plan meetings was the most frequent training activity within skills development.[152]

A further study[151] looked at the results of a carer training program which ran over seven years in the US Training topics included history of the disability movement, creating a vision, community organising, inclusive education, action planning, a quality adult life and the legislative process. Increases were significant in knowledge of services and supports. Initially advocacy and clarity of vision also showed significant increases; with the addition of implementing person-centred planning, striking improvements with advocacy and clarity of vision were noted.[151]

One qualitative study from the UK[150] reported on a parent peer-led program. Themes generated from the interviews included knowledge and skills development, personal transformation and peer facilitator qualities. Reflections by participants on the skills and knowledge gained from attending the program provided evidence of the qualities of 'enthusiasm, determination, openness, reflective capacity and status as 'peers' within the local community, are critical to successful program delivery'.[150] (p. 81)

EMBEDDING LIVED EXPERIENCE LEADERSHIP IN MENTAL HEALTH RESEARCH

Coming to the review, we were aware that the service user-led research area has a significant literature base in the UK and that our work, as a generalist review would not result in definitive understanding of this literature. The search was focused on finding papers which described the organisation of consumer or carer-led research efforts, and challenges and enablers for this to happen effectively.

The review identified 12 diverse papers. These were four qualitative studies drawing on the views of other mental health researchers[141, 155, 156] or both lived experience researchers and other researchers[157], three project descriptions of the work of consumer and carer-led groups,[158-160] two discussion papers,[161, 162] one industry report,[163] one survey study[164] and one systematic review on other researcher views.[165] Three papers refer to activities inclusive of carer research.[159, 160, 163] Analysis of the papers reflects several different contexts of lived experience-led research.

The first context is research conceived, controlled and undertaken by leaders of lived experience organisations. In the UK, Faulkner[163] reported on the success of user organisations receiving funding to direct and complete valuable local projects, with projects varying in the degrees of control and organisational autonomy to undertake this work. Challenges that user organisations experience include lack of organisational infrastructure, securing enough funding and resources for the required work, discrimination from local community members, and for researchers, dilemmas around identity, power and boundaries in relating to other users, and processing distress.[163] While reflecting a model of user involvement, user organisations can partner to design and lead practices around how research is conducted with constituent communities. They can also advise on project parameters and implementation.[157] Challenges and enablers involved here include having clear understanding across the partnership, achieving a values base of empowerment to guide research activity, financial resources and contracted relationships, effective information flows and feedback to user partners regarding study processes and designs.[157]

A second context is the formation of consumer or carer specific research groups which can be a part of university environments and/or supported and guided by them. Banfield et al.[160] report on the ACACIA lived experience research unit, a group featuring employed lived experience researchers, including PhD students, that is also guided by an advisory group structure. Key activities of this group include priority setting for research projects, designing appropriate involvement practices for different stages of research, working relationships with local community groups, skill building workshops on research processes, and focusing on tasks for people to readily contribute.[160] Experience from the University of South Wales in setting up a user research group includes the challenges of securing funding, power imbalances in university relationships and in transitioning to a user-led autonomous structure, power imbalances inherent in grant funding requirements, and difficulties in user members agreeing on key directions.[158, 159]

A third context is for organisational development within/with universities to create welcoming and supportive spaces for lived experience researchers and advisors. Studies and papers report that considerable challenges and barriers remain. These include:

- Lack of skills and capability of other researchers to enable effective involvement for young people.[156]
- Lack of cohesive paradigms and approaches to guide lived experience-led research[162] or research process models to foreground consumer research.[165]
- Isolation and low numbers of consumer researchers in research partnerships.[141]
- Research cultures which do not enable other researchers or lived experience researcher effort space, time or resources to build relationships with communities, nurture new researchers, enable flexible completion timelines, or understand co-production.[155]
- Lack of involvement policies, structures and capability within universities.[156]
- Grant funding programs which are not accessible to lived experience researchers due to eligibility rules, or have discriminatory impacts.[162, 163]
- Ableism within admission processes, researcher pathways and academic culture; assumptions and decision-making points which impact on people with psychosocial disability gaining academic roles.[161]
- Impacts of life disruption on lived experience researcher careers (i.e. starting careers at later ages).[155]
- Dilution and co-option of consumer perspectives within the normative context of mental health research.[162]

As in previous sections, many of the above authors make recommendations for ways of strengthening the presence and scale of lived experience-led/partnered research and shifting cultural and organisational practice. These recommendations follow:

- Provide dedicated youth support engagement coordinators to facilitate successful involvement of young people in youth focused research programs.[156]
- Increase flexibility for workloads and timelines to enable meaningful involvement and consumer leadership of research work.[155, 164]
- Develop involvement infrastructure with frameworks, accompanying policies and resourcing.[156]
- Use influence to create ongoing consumer researcher positions in university departments.[141, 161]
- Create an up-scaled pipeline of researchers with declared lived experience and psychosocial disabilities through proactive networking and affirmation action, retention and promotion (not only in designated positions).[161]
- Combat academic ableism through Unit/faculty leadership which challenges deficit language, disrupts barriers to admission and raises visibility of lived experience researchers in conferences, publication and grants boards.[161]
- Increase scale of consumer researchers within specific projects according to co-production principles of balancing power.[141]

- Ongoing training and support for consumer advisors and researchers.[156]
- Build networks of consumer/lived experience researchers to encourage practice development and reduce isolation.[141, 164]
- Provide mentorship to assist emerging lived experience researchers to find voice and process emotional challenges associated with the work.[161]

EMBEDDING LIVED EXPERIENCE LEADERSHIP IN INTERSECTIONAL RESEARCH/KNOWLEDGE PRODUCTION SPACES

There were a variety of papers retrieved in the search which described lived experience-led or partnered research in different contexts. These included two papers in harm reduction, four study reports regarding First Nations people's community-led research, and single papers on trans-led, carer-led, disability-led and survivors of partner violence led research. These papers below are unique in the context of lived experience and relationships with formal research organisations. Therefore, it wasn't suitable to generate themes across them, but rather provide a short description of key features of each approach. All offer important insights and are relevant to intersectionality and aligned perspectives.

Community-led Research by and with First Nations Peoples

Community led research on mental health, substance use and wellbeing with Aboriginal people in Walgett, NSW is described in the report on the Yuwaya Ngarra-li" (YN), partnership.[166] The core principles of community led, culturally connected, strengths focused, holistic and rights based, were achieved by developing defined processes and obligations with the Dharriwaa Elders Group. The group set key protocols, directions, timelines and terms of collaboration for the project, promoting accountability, respect for Indigenous knowledges and methodologies and capacity building for community members. Decisions on data sovereignty and ownership were also important, including how project results were co-authored and co-presented.[166]

A project on the key principles and practices of developing community-led sexual health resources with Aboriginal people (health promotion knowledge/not formal research) in North East Victoria was provided by Chambers et al.[167] Their report placed building trust through reciprocity as the overarching principle guiding partnership activity, and from which other facilitators emerge. The report described those as cultural safety practices, cultural literacy and respect, community-controlled project leadership and ways of ensuring project legacy and sustainability. These are all areas of researcher/partner learning and capability.[167] A community-led engagement framework for Aboriginal Participatory Action Research has been developed in Western Australia. The Debakarn Koorliny Wangkiny (steady walking and talking) framework[168] also places emphasis on the relational qualities of non-Aboriginal researchers in promoting decolonising scholarship and research practice. The seven conditions of the framework are: 1) being motivated; 2) being committed; 3) being present; 4) being teachable; 5) staying connected; 6) respecting status; and 7) continually weaving. These conditions and ways of relating occur as Elders, community and researchers work together through shared storying, on Country immersion and co-design processes.[168]

A Canadian project on training non-Indigenous researchers developed by the Morning Star Lodge and the File Hills Qu'Appelle Tribal Council, details a similar range of key principles and practices for ethical research.[169] Their approach grounds projects in Indigenous health research methodologies and knowledge transmission practices. All projects should be led via Community Research Advisory Councils to prioritise, guide and direct research activity. As above, reciprocal learning, cultural safety and cultural competency processes guide non-Indigenous researcher and community relationships and how data collection, analysis and findings are

produced. Principles of data sovereignty and community governance direct all research products and knowledge dissemination into the future.[169] Another Canadian framework of community led research, derived via the Aboriginal Children's Hurt & Healing (ACHH) Initiative, reported on many similar principles and practices. This has been named as the Two-Eyed Seeing and Kinship approach.[170]

Learning on Research Partnerships with Diverse Communities

The Clare Inclusive Research Group, an Irish user research group of advocates with learning disabilities, continues the above theme of user-led organisation with supports from a university. The group generates research for advocacy purposes. Effective supports include close coordination with university staff, funding and training opportunities, being involved in wider self-advocacy research networks, and having dedicated support workers for group meetings. Research needs to 'make our lives better, make sense to us, reflect our experience and support our campaigns'(p.5).[171]

A focus on the practical aspects of employing peer advisors within research projects on substance use is provided by Greer et al.[172] Their paper describes a framework of peer involvement and partnership, identifying key themes about effective engagement and employment, payment levels, role and project definitions, communication needs, mentorship, and guidelines for collaboration across the project lifespan.[172]

The previously reported W3 study by Brown et al.[173] also recorded reflections on engaging peer leaders and organisations in harm reduction research partnerships. Barriers for partnership include misaligned funding for peer organisations to lead research, the fact that most communities are already experiencing heavy pressures and burdens, and the political nature of policy contexts and funding. Enablers are flexibility in research funding, resourcing and project management, bidirectional trust and commitment, and messaging that makes peer leadership visible and highlights its value.[173]

The theme of community-led research partnerships is also described by Ghanbarpour et al. in a peer-led project with survivors of intimate partner violence.[174] The resulting framework of Community-Led Research (CLR) outlined nine key considerations that reflect trauma informed, research justice and language justice principles. These position peer researchers as key drivers, acknowledge past hurts associated with research, and create conditions for self-care, promotion of safe spaces and help define effective working relationships. The considerations promote peer researcher autonomy, an equity framing of collaboration, and the valuing of culture, language, history, identity and lived experience.[174]

Similar to the earlier recommendation on creating lived experience researcher pipelines in universities, Streed et al.[175] identified eight processes for redistributing research power and resources in the trans health space to trans experts. Pipeline development occurs through supporting, promoting and creating opportunities for trans experts to gain a stronger presence within academies. Mentoring, sponsorship, bidirectional collaboration, and affirming grant opportunities are key strategies to embed. Sharing power, promoting safety, self-reflection and accountability are key principles to guide action.[175]

A focus on carer-led research with carers from minority ethnic backgrounds is provided by Richardson and Laird.[176] Their study explored views of carers on their motivations and interests in generating carer-led projects. While participants reported mixed levels of commitment, they placed emphasis of the supports required to step into researcher roles. These included the need for respite care, training and skills development, local accessible venues, flexibility for meetings and timelines and both interpreting and translation services.[176]

Lived Experience Educators in Nursing and Allied Health Education

Australia and New Zealand have been leaders in initiatives to embed consumer educators into the tertiary education of health professionals. Nine studies suitable for inclusion on this topic were identified, five qualitative studies by Happell and colleagues,[177-181] two literature reviews[182, 183] and two descriptive papers.[184, 185] Only one paper was inclusive of carer involvement in teaching.[184]

Consumers have become involved in teaching mainly through collaborative efforts of academic allies and consumer leaders to establish consumer academic roles or more casual educator roles (sometimes called Experts by Experience - EBE).[181] There have been significant level of studies on positive benefits and outcomes for students and educators involved.[182, 183]

As they occur in academic environments, the challenges faced when developing consumer educator projects or consumer academic positions reflects those reported earlier on embedding lived experience research. These are reported as difficulties in securing funding,[177, 182] developing clear roles and responsibilities so that consumer teachers have reach and impact,[177, 180] variable levels of involvement and preparation, where there are limited opportunities to shape curriculum,[183] and token responses.[177, 182] Attitudinal issues on the part of students and other academics also create challenges, where consumer teachers may be seen as unrepresentative or high functioning,[179, 183] or perhaps too critical of services.[185] Consumer teachers can also struggle with vulnerability, voyeurism and other stresses if using story telling approaches. Other difficulties relate to the dominance of clinical perspectives within education.[183]

In terms of enablers for effective embedding of teaching initiatives, the experience of academic allies indicates the value of finding skilled and credible consumer teachers and collaborating to define effective roles and depth of involvement in educational programs. Developing opportunities for growth and career pathways are important for allies to help support.[180] Embedding also occurs through allies having influence with University leaders to create buy-in and long term support, as well as ensuring both consumer teachers and allies are well connected to lived experience networks.[178] Experience has suggested having a program level approach involving an advisory group, lived experience academic and group of casual teachers to be a solid grounding for ongoing development and outcomes.[184]

In a project aiming to co-produce standards for Experts by Experience teachers, Horgan et al.[181] identified that skill development and training is required in lecturing, running tutorials and using libraries effectively. Other supports include shared mentorship between lived experience and clinician academics, mutual support processes, external peer supervision, induction and orientation processes, emotional and practical support, pre and post session debriefs, and equitable forms of payment.[181]

DISCUSSION

In this section we discuss the trends in the literature and identify gaps that require attention and research. It is organised by the various questions that the Project Control Group had about the literature.

Definitions: How is lived experience leadership defined across areas of lived experience action and in relation to traditional leadership models?

How do we define lived experience leadership?

The review indicates that lived experience leadership in mental health is an emerging concept that is still being defined, and to date the published work has been focused on consumer leadership. We did not identify any specific concept work on carer leadership indicating there is a gap in the literature. Included studies have provided detail about the social movement nature of lived experience leadership, and the experiential, authorising, and motivating factors that make up the pathway to leadership and the lens and positioning that leaders express. Research has also described the characteristics, qualities, and actions of effective lived experience leadership in leading change as guided by values of consumer movements. Some articles have offered proposed models[2, 22, 23] which can be used to guide further reflection and research while others have provided valuable commentary about critical perspectives, issues, processes and considerations.[18, 21]

The papers focused on leadership in AOD mutual aid and recovery described key leadership characteristics and qualities for women leaders in Oxford Houses, and in 12Step programs. These papers illustrated the program context of shared leadership as defined by program philosophies and roles for members in encouraging leadership opportunities for members in contributing to group life and recovery aims. Role modelling recovery, peer support, listening, empathy, honesty, accountability, strength in vulnerability, facilitating decision-making, and deep learning were themes about effective leaders in these papers.[24, 25, 27] In Oxford Houses, leadership was organised via rotating roles for all residents which sought commitment and contribution. In 12-step programs such as AA, the philosophy and singular mission of the group, emphasis on group level consensus, spirituality and avoidance of distracting influences, were seen as important features of the successful leadership of local groups and the wider movement.[66] Servant leadership was offered as a model to describe recovery leadership which both aligned with spiritual growth traditions in AA and other 12-step programs, which is also a basis for advocacy and community organisation.[28]

In the harm reduction field, the review did not identify defined concept models of user experience leadership, despite the wide range of leadership activity obviously occurring. However, the Australian W3 work by Brown and colleagues[77, 130, 173] offers a significant framework of systems level functions and actions that reflects the work of peer leaders at policy and community leadership levels. This is a valuable framework for translating across different settings and contexts of lived experience. The gaps in understanding leadership as a concept in family carer and harm reduction spaces points to the need for further research that describes

lived experience leadership in terms of voice, purpose, scope and how it frames community advocacy and organisation.

We did not identify any lived experience leadership concept models from diverse communities or people with intersectional experience within the search. Identifying further writing on leadership in communities, e.g. leadership models from First Nations' perspectives would require specific and focused search projects.

Areas of lived experience expertise and types of leadership.

The mental health literature indicates that lived experience leadership is defined broadly and recognises that leadership occurs beyond as well as within specific roles and areas of activity. There are significant areas of leadership expertise, such as, within organisational management, consumer/community led research and systems advocacy as well as practice expertise in peer support practice, service level advocacy/representative work, research and health practitioner education. Reflection on the findings in mental health from the US and the UK indicates that organisational and social movement leadership is the strongest area of achievement, while Australian articles are more reflective of lived experience leadership seeking change within public mental health services.

Within AOD mutual aid and recovery, leadership areas in the literature were centred on facilitating local mutual aid groups, shared leadership of residential peer houses and in volunteering/working in or managing Recovery Community Centres or Recovery Community Organisations. Similar to mental health, it was evident that leaders engaged across peer support, community organisation, and advocacy, including advice and participation in AOD treatment centres and state policy work.

In the available articles on addiction and harm reduction, the focus of leadership achievement was also focused on organisational and peer movement leadership, and community activation work. This literature reflected a more activist, rights based political orientation, campaign leadership and organising efforts for decriminalisation, law reform and to meet wider life needs (e.g. accommodation and housing). The breadth of activities evident in consumer-run organisations indicates the rich knowledge, skills and expertise both required by and demonstrated by leaders and members.

Is lived experience leadership different to traditional leadership?

There were several observations in the studies on mental health lived experience leadership which indicated similarities and differences with other leadership models. The Muscari study suggests that lived experience leadership practices can be identified and measured using a generalist model of organisational/community leadership.[19] O'Hagan's proposed model indicates the unique place of user leadership in responding to justice-based values and recovery principles of the user movement, which cannot be captured by generalist leadership models such as transformational leadership.[2] The ALEL model indicates that leadership characteristics, values, skills and actions that overlap significantly with other forms of social movement leadership which challenges biomedical perspectives, seeks inclusion, and voices change from peer and intersectional positioning. [23] Commentary on leadership concepts indicates that consumers may be wary or reluctant about leadership due to assumptions about hierarchical

leadership, individualist rather than collective leadership or experience of recognised leaders not displaying peer values in their actions.[18]

The literature on AOD mutual aid and recovery included singular studies using transformational and transactional leadership regarding Oxford House leadership,[26] and emotional intelligence models for leaders with experience of 12-step programs.[27] The use of these models, along with Hill's discussion on servant leadership,[28] showed nuanced ways that mutual aid membership activates leadership qualities of members within the recovery experience and mission of transformation. While lived experience leadership shares much with other forms of social leadership, it is born from profoundly personal and socially challenging experience and is performed in this context.

Models and Applications: What are best practice models of lived experience leadership for different settings and contexts?

Leadership within lived experience organisations: flat and hierarchical organisational leadership.

A detailed review by Opie et al. describes the successful elements of mental health consumer-run organisations as including wider voluntary participation, less hierarchical shared leadership, member-run services and consumer control. These characteristics have been associated with positive levels of member empowerment and sense of ownership, as well as individual recovery outcomes. Effective consumer-run organisations provide supportive and validating community spaces for members, and operate with values of mutuality, safety, choice and personhood.[56] The success and wide spread growth of 12-step programs in AOD mutual aid and recovery is attributed to specific philosophies, approach and design which differentiate the groups as informal, peer-run meetings and intentionally maintain these boundaries. Many other peer groups have emulated autonomous participation, member shared decision-making and distance from clinical services.[3] Oxford House and Sober Living House leadership also portray successful governance and leadership structures.[59, 69]

Similar to mental health, there are also many established board incorporated, paid staff community organisations which operate successfully with community level impacts. The volunteer capability and community facing role of these organisations provide pathways of recovery leadership for peers and improved self-knowledge on recovery, coping skills, confidence, and social connection.[58, 63]. Collectively, these knowledges, skills and pathways are a key part of what has been termed as 'recovery capital' by AOD recovery academics.[58, 112, 116] An observations about the US Recovery Community Centres is that family member leaders can lead organisations, and are reported as a key part of volunteer populations. [63, 70]

The evidence available to the review also indicates that tensions exist in the experience of lived experience organisations between maintaining non-hierarchical relationship of membership and the need for incorporation and board level management. Commentators on consumer-run organisations in the US and UK describe organisations as having established hierarchies of board members, executive staff and employed staff, as organisational aims become more complex and responsible to funding sources.[52, 55] This development contrasts with the history of these organisations often beginning as mutual aid, self-help groups with flat models of shared leadership. These commentaries indicate that both forms of leadership are dependent on

organisational purpose and requirements to fit within legal frameworks of community organisations in their jurisdictions. The literature illustrates the dilemmas that organisations face in developing hierarchical models, often between staying as volunteer based organisations relying on the sustained leadership of a small group, versus the need to secure funding to provide stability and provide opportunities for growth of programs. Peer values, approaches, language and advocacy goals can also be diluted and co-opted by funding requirements or the influences of larger clinical treatment organisations[3] Maintaining voluntary peer support can also be challenging in the context of calls for paid staff roles and impacts of peer certification/professionalisation.[52, 70] Reports from the UK on user organisations indicate that smaller groups face the risk of dissolving due to lack of financial supports. This is a constant concern as organisations which have once received funding have closed due to competition, burnout and the reduction of funding programs.[49, 82]

A further dilemma evident is that organisations which do develop hierarchy and larger memberships risk losing shared participation and leadership across the membership, and undermining values of democratic decision-making and equality. To counter this consumer/user run organisations need to develop forums, working groups and programs which encourage participation in strategic decision-making and operations for larger groups of people. VANDU was the most sophisticated example found in the review, as an organisation which facilitated shared action in campaigns, multiple peer programs, and offshoot groups focusing on specific needs.[74, 75]

Are there best practice models of lived experience organisational leadership.

The review did not identify the term 'best practice' used to describe models and approaches to organisation and governance. However, as indicated above, the US literature does depict key characteristics of effective consumer-run organisations as unique organisations that are able to operationalise their purpose and values base into governance and member run activities. This was reinforced by the development of evaluation tools such as the FACIT fidelity framework for evaluating whether services were operating to the values base as peer-run organisations.

The review did identify also that there are multiple forms of peer group programs and models which could be further investigated as to how they operate as autonomous groups that use a particular movement or approach to peer practice, facilitation and governance that is defined by a guiding author/body. Those identified in the review included the Oxford Houses movement[68], Sober Living Houses[59, 67] and Self Advocacy Chapters[136] in the disability area. We are also aware of others including Hearing Voices groups and Alternatives to Suicide (Alt2Su) groups, peer respite models and long-standing groups such as Grow and AA. The method for better understanding governance arrangements in these groups would be through focused literature review or case study research.

There are several observations that can be made about best practice and the questions about efficacy, impact, longevity and fidelity of lived experience organisational leadership.

The first is that autonomous forms of organisation seem to provide the best basis for lived experience leaders to build, share and offer peer-based programs, leadership opportunities for members and advocacy work. Autonomy is a central feature of self-help groups which have a

singular focus, as well as incorporated organisations which have developed multiple services and activities for members,[186] which provide supportive organisational climates for peer work.[107]

A second is that the growth of incorporated consumer-run organisations has occurred where national funding programs have supported peer defined, empowerment models. For instance, SAMHSA (Federal Mental Health Agency) has had various funding streams for peer support/self-help groups and consumer and carer network development in the US, which has encouraged the growth of consumer-run organisations over the 1990s and early 2000s. This occurred for both mental health and AOD Recovery Community Centres. Organisational capacity building and leadership skill development, through academies, and technical assistance centres was also supported by federal funding in the US.[34, 55, 62] In the AOD recovery orientated care area there examples of states using diverse funding sources to build the capability of peer leadership and peer based recovery support services[114, 115] The importance of funding is also observable in the UK disability space (which includes mental health user organisations), where national and local trust funding has supported the growth of user organisations. Reports from the UK, indicate however that commissioning and funding for user organisations has been problematic due to restrictions and misunderstandings of purpose which undermine consumer and carer autonomy[48, 49] (user organisations in the UK refer to both consumer and carer-based organisations).

A third observation is that impact, effectiveness, longevity and fidelity within organisations has been measured only in limited ways. The most encouraging developments found were the studies that measured the link between organisational and social participation in consumer-run organisations with empowerment or recovery outcomes for members, frameworks for measuring organisational fidelity to consumer values, and the W3 project for an emerging evaluation framework on the various system level actions of lived experience leadership.[130] The work on organisational climate and effective support and facilitation of peer support practice is also valuable in indicating the impact of how lived experience-led organisation provide the right conditions, pathways and environments for peer practices.[107]

While it is evident that lived experience-led organisations do have a focus on contributing to change on social determinants impacting on their members, in terms of law reform, community education and projects which promote better access to housing, employment and education,[8, 51, 65, 67, 71], there needs to be more focus on measuring the links between organisational leadership, operations and outcomes on these levels. Much of the literature about volunteering and participation measures impacts on personal recovery levels (e.g. hope, confidence and social skills) rather than on improved social health outcomes. Future research should focus on the efficacy of harm reduction programs, HIV care and peer led AOD recovery and mental health work, in ways which makes links with the decision-making and influence that lived experience leadership has made to the design and operation of programs. We identified a significant number of articles about efficacy of peer led harm reduction programs in HIV and HCV areas that focused on improved health outcomes but did not describe leadership in design. There is a very significant story of peers leading in harm reduction policy and programs, that is not being measured adequately from a leadership perspective. [187, 188] Similar observations can be made about outcome studies in mental health and AOD recovery peer work.

Fourth, a significant issue in the existing literature on mental health lived experience leadership and organisations is how organisations and sector development engage with or support the voices of diverse lived experience communities. The US mental health literature was silent about this, while the challenges of consumer/user organisations effectively involving or networking

with migrant, asylum seeker, LGBTIQ+ and other marginalised groups was recorded in some UK[48, 49] and Canadian literature.[47] There are multiple aspects to how established leadership is challenged in organising for diversity. One aspect is how existing framings of the user/survivor movement and lived experience may be too narrow and exclude diverse groups who may have different understandings about mental health or different forms of community leadership. [18, 49] Another aspect is that, framing on user involvement may also exclude diverse or marginalised lived experience organisations as they don't identify as mental health organisations in their purpose or role, yet play significant community wide representation and advocacy functions.[49] A further aspect is the lack of resources, time and capacity to build effective shared understanding and networks across these organisations.[83] In the AOD mutual aid and recovery area, there was an awareness to include and fund diverse communities of recovery, including diverse faith communities but descriptions of inclusive leadership and membership at organisational levels was not evident in selected studies and papers.[63, 70] These are themes that will be further discussed.

Embedding lived experience leadership: How has lived experience been organised and embedded effectively in mainstream organisations and systems.

Lived experience leadership and mainstream health services.

While the review retrieved quite an extensive literature base of articles about lived experience organisations, we found that there was less information available that described it as effectively embedded in publicly funded mental health, drug and alcohol services or harm reduction services (both government and NGOs). The overall focus of included studies was to detail well known challenges and barriers for involvement of lived experience advocates, representatives and leaders in the governance of public mental health services, as well as studies and reviews relating to peer involvement in AOD treatment services and harm reduction, and the experience of disability advocates. They indicate that lived experience leadership in mainstream services engenders mixed experiences of inclusion, progress and being thwarted by various dynamics in health service environments. The challenges to overcome include misunderstandings of roles, under-resourcing of inclusion structures, impact of stereotypes, power imbalances, varied commitment by other service leaders, and influences of wider change fatigue and service pressures.

While there is significant knowledge about levels of involvement for ensuring that lived experience leaders have voice and inclusion, and the benefits offered, there is less evidence about how mainstream organisations effectively implement inclusive decision-making and shift culture and practice. We only found one study linking the work of a lived experience advisory group with a co-designed and subsequently implemented service model.[119] With these gaps in knowledge, there is a significant need for further primary research and evaluation on how embedded lived experience leadership and partnerships have implemented new service models and influenced organisational culture. Specific literature reviews of co-designed projects are also likely to identify more detailed evidence.

From the wider range of included studies, a narrative synthesis emerges on the recommended strategies and conditions required to recognise, support, resource and embed lived experience leadership at governance levels. These were largely defined by qualitative studies, consultations, project reports and literature reviews on what is needed. Recommended strategies and enabling conditions relate to both organisational and systems levels activity. They include:

- Clearly defined roles and empowered governance structures, reflecting aims and values of lived experience leadership, and the involvement of lived experience organisations, including groups that role model, and celebrate recovery (mental health and AOD).
- Increasing the scale and presence of lived experience leaders, including the conscious planning for equitable presence of diverse and marginalised community groups.
- Effective resourcing of lived experience governance structures and co-production processes, including budgets that leaders can direct, and administrative supports.
- Education and preparation of wider organisation workforces, stakeholders and funders on lived experience leadership, which also challenges deficit, stigmatising, ableist mental models.
- The development of organisational cultures founded on cultural safety, trauma informed care, AOD recovery principles, harm reduction principles, epistemic justice and restorative just culture.
- Strong support of executive leadership, clinical leaders and allies, leading to whole of organisation commitment and accountability on implementation, progress and service evaluation.
- Pathways for training, mentoring and networking of emerging and established lived experience leaders.
- Partnerships which recognise and support peer-run organisations, advocacy roles and recovery principles, avoiding dynamics of paternalism, co-optation, and exploitation. These can include contracting of peer organisations for mentoring, consultancy and provision of peer services, quality working relationships, communication, decision-making and meeting processes, including accommodations and practices that support diverse communication and participation needs, and rebalance power.
- Creating leadership positions within the lived experience (peer) workforces that have strategic influence, support the growth of the lived experience (peer) workforces and specialists and guide related program/service development.
- Systems policy development based on recovery principles which reorientate care frameworks to include funded roles and contributions of diverse peer-run organisations, supported by the presence lived experience leadership at all levels of planning, implementation and evaluation.

There are several points of discussion related to these findings. The first one, as noted by Rose et al.[105] in the UK context is that that involvement processes often reinforce an individualised role for leaders on service level committees. Where leaders are present as individuals rather than representatives of consumer or carer organisations there is a disconnect for the role of lived experience organisations in having influence in health services and in the likely support for local leaders on committees. There is also less accountability across to lived experience organisations.

In the UK AOD recovery area, Kidd makes the point that peer-run organisations provide a backbone and community for members to develop leadership skills, and then provide important supports as these leaders engage with treatment service committees.[5] Mainstream organisations therefore need to recognise and involve peer-run groups at organisational partnership levels.

Another point is that the concept of consumer leadership was forged, in part, from the need for consumer influence and expertise to be above and beyond processes of involvement.[2] This is so that the wide scope of consumer leadership could be recognised and supported as a force for centring lived experience-led activity, managing services, and developing peer solutions on policy and practice levels. Lived experience leadership is about setting the vision for transformation and justice. This vision then also provides a context for evaluation and accountability for how solutions have been implemented and how people using services experience them.[86] This recognition seems to be most apparent in US states that have undertaken AOD recovery orientated systems of care change processes, where attempts have been made to reorientate and fund new programs that respond to different parts of the recovery journey, including a focus on reconnection with education, housing, employment and justice through funded peer/other supports, and shifts within treatment services towards a recovery paradigm[113, 114]

Discussion is also needed on diversity, equity and intersectionality at organisational levels, as challenges in this area impacts on the points above about organisational level representation and accountability. How lived experience leadership can avoid replicating and reinforcing existing disadvantage, marginalisation and inequity needs to be considered. The review did not find specific papers centred on how lived experience leadership or consumer, carer, peer involvement literature effectively organises across diverse and marginalised communities, to ensure a breadth of voice, input and proposed solutions to organisational and systems policy. In Australian papers, there was little mention on connections of the lived experience movement with Aboriginal and Torres Strait health leadership and the community controlled health sector. There is a need for a deeper level of understanding and writing about diversity and intersectionality in the way both involvement and leadership are understood, resourced and actualised within service governance.

Within lived experience communities, there is a growing understanding that allyship is a key role for leaders in clarifying their own positioning and in relating to, acknowledging and supporting the concerns and priorities of other (allied) lived experience groups. This approach, learned from how LGBTIQ+ communities articulate allyship, means seeing diversity across different lived experience issues (e.g. drug use, living with HIV, homelessness, suicide related crisis, people living with BPD) and social identities (neuro-divergent people, culturally diverse community groups, LGBTIQ+ groups, veterans, Etc.).[86] Building allyship and inclusivity entails reflection on framings about lived experience and how leadership is organised. As an example, this approach creates space for a larger movement that can better recognise and support Aboriginal and Torres Strait Islander health leadership, kinship, and social and emotional wellbeing, trauma and healing models.[86, 106] Enhanced relationships would entail reciprocal learning and discussion of shared values, the place of human rights and building trust.

Mainstream organisations need to also be developing more sophisticated understandings of diversity and intersectionality, as service provision is a point of common experience (or exclusion) for all communities. As clinical governance is often focused on one dimensional diagnostic and biomedical conceptualisations of distress, there is a need for lived experience

governance to reflect the complex and multiple interests, and priorities of communities, promote human rights and ensure accountability in the ways diverse voices are included, heard and responded to.[106]

The need to see lived experience leadership from a systems perspective has been a significant sector level conversation that is best evident in the AOD recovery[112, 118] and harm reduction literature.[77, 126] Systems level thinking is seen as essential for driving the growth and embedding of lived experience leadership. Many of the strategies summarised earlier can be facilitated and supported by policy change processes which invite long term health and community sector collaboration, establish collective vision and language for change, and commission the growth of lived experience pathways of advocacy, leadership training, networking and service delivery.[86, 113, 114] This means building the capability of lived experience organisations and networks, as well as the capability of mainstream health service governance, and involvement processes at the same time. Collective leadership and backbone project leads can use policy and funding levers to drive expectations for change in health services and in policy units.[113, 115] The W3 project identifies many important roles that lived experience leaders undertake to guide expectations and service development which works for specific communities,[173] and also reflects that lived experience leadership works at political levels to shape both public health and law enforcement.[79, 126]

A systems perspective can also enable a broader policy guided response towards social justice, equity and intersectionality, and how lived experience leadership can be commissioned and resourced within and across communities. Frameworks such as the Intersectionality Based Policy Analysis Framework[189] provides a useful guide for planning, as will engaging with priorities and directions of specific policies for Victoria's priority communities.[190-193]

Lived experience leadership in research and evaluation.

While limited, there were significant papers focused on lived experience-led or partnered research and evaluation included in the review. Discussion of the research work can identify the various forms of collaboration with involvement between lived experience organisations and academia, as well as the need for guiding frameworks on how lived experience leadership is embedded. The studies provided examples of organisation and collaboration including:

- Lived experience groups directly funded to lead and undertake research.
- First Nations community led research partnerships with academia.
- Unincorporated lived experience research groups supported by university partnerships.
- Lived experience research groups developed within universities.
- Partnerships between lived experience organisations and university-based research teams.
- Employment of peer researchers and creation of advisory structures within research units or universities for specific projects.
- Development of lived experience academic career pathways/pipelines within universities.

The reported studies reveal a range of challenges and lessons learnt relating to provision of best supports for lived experience-led research. In respect to embedding lived experience researchers within universities, a range of recommended strategies were evident, and included familiar themes of addressing power imbalances, providing accommodations and flexible roles, challenging deficit mindsets and stigma, the need for allyship and support from academic leaders, accessible funding sources and security of tenure, strengthening networks, visibility and learning pathways, and effective structures for inclusion and decision-making.

The frameworks of community-led research partnerships with First Nations communities featured rich learning about ways of supporting community leadership to set the directions of research and practices for valuing, prioritising, learning from and utilising Aboriginal knowledge systems. They also describe important practices of cultural safety and capacity building of community skills, and forms of cultural governance and sovereignty regarding research ethics, data, outcomes and legacies. The lessons learnt from these collaborations offers guidance for broader lived experience research partnerships with Aboriginal and Torres Strait health leaders and community members as co-researchers.[169] The studies point to the important development of cultural governance as a form of governance that can be embedded in research partnerships for strengthening all aspects of design, implementation and accountability from Aboriginal and Torres Strait Islander communities perspectives.[194]

The experience of diverse lived experience groups and organisations leading their own research was mostly from the UK and reflected challenges in securing appropriate and accessible funding for infrastructure and administration as well as research work itself, while maintaining autonomy when collaborating with academic and/or supportive partnerships plus retaining organisational boundaries when relating to constituent communities as researchers.[158, 163, 171]

The insights from this section of the review suggest that further work is needed to describe the various forms of organisation and embedding of lived experience-led research. There are implications at multiple levels (including organisational) for consumer/carer groups and universities, to promote and privilege lived experience-led research with the provision of research funding.

A significant gap in the selected papers was how lived experience-led or partnered research conceptualises intersectionality and involves diverse communities. It is important that new qualitative research projects plan for addressing intersectionality in terms of governance, priority setting, recruitment of diverse groups, data collection, analysis and reporting.[195]

There should be opportunities for lived experience groups to set and shape research agendas, to guide how funding can be capacity building for lived experience organisations, in terms of research skills and project implementation. As indicated by some of the included papers, there is also the need for further conceptualisation of lived experience-led research in terms of paradigm and methodology developments,[162, 165] as well as frameworks for co-produced evaluation and research. There should be opportunities to consider how frameworks can be developed that are meaningful and useful for the diverse peer areas of mental health, AOD mutual aid and recovery and harm reduction.

Skills and knowledge to enable lived experience leadership.

The review has identified a small range of papers focused on skill and knowledge development for lived experience leadership, with these mainly being in the mental health area.[9, 147-149] There have also been many papers pointing to the need for training and education for lived experience leaders and wider workforces in terms of understanding the scope, purpose and pathways of lived experience leadership, involvement and co-production processes, recovery perspectives, the role of allies, clinical leaders and executives for service and systems change.[5, 9, 56, 124] The following are key points to consider about areas of development that stem from the literature:

- Lived experience leadership has been a basis of learning within specific leadership academies and programs, mainly focused on systems advocacy and involvement in governance processes.
- Family and carer organisations have successfully delivered family advocacy and systems navigation programs for carers. These have occurred alongside of the longstanding work of running mutual aid/self-help carer programs.
- There are multiple areas of knowledge and skills development required for consumers and carers to run lived experience organisations. These include board governance and skills for managing dilemmas and setting strategic priorities given diverse expectations of communities and policy makers. Programs for technical assistance have been successful in supporting the growth of skills and business practices, and offering training, education and support.
- Services creating opportunities for involvement often organise training sessions for leaders, advocates and representatives, although the quality and depth of these opportunities often vary and may be service centric rather than grounded in lived experience perspectives.

Recommendations and frameworks for embedding both lived experience leaders and the lived experience (peer) workforces call for training for the wider workforce. This training covers multiple areas including education for challenging ableism, sanism and stigma, allyship and training about lived experience roles in governance and education and lived experience (peer) workforce roles at organisational levels. Gaps in expertise about creating conditions for involving diverse groups and recognising intersectionality need to be addressed through the development of suitable training and capability building.

An important reflection on skills development is about supporting the role of peak consumer and carer organisations to provide training and learning opportunities with community members, and also service providers.[9, 149] Definitions of lived experience and lived experience leadership can vary across sectors. It's important that training and education reflects a shared understanding of key definitions, values and principles, such as those definitions developed at national[111] or state levels.[9] Peak bodies already provide examples of leadership training and are well placed to guide training as well as learn from advocacy or leadership training developed by other lived experience groups and leaders.

Developing training can build on promising work around reflection and learning tools for embedding lived experience leadership. The recently published Lived Experience Governance Toolkit[196] includes some of these tools and identifies many other resources.

Allyship.

The included papers on allyship in mental health research and service spaces provide value in terms of how provider allyship is understood and experienced. There are multiple issues surrounding allyship to be further explored.[137, 142, 143] These include how provider allyship can be strengthened, as most organisational change studies highlight the importance of champions and supporters of lived experience for change. It also includes how clinicians coming out with lived experience can also take on ally roles. Further, allyship is an important positioning within lived experience communities and further learning is needed for a deeper understanding of 'being allies for each other' and building ally-based relationships within and across mental health, AOD recovery and harm reduction policy, research and services.[86]

SUMMARY AND POLICY IMPLICATIONS

This literature review has attempted to identify patterns of evidence and learning about the organisation and embedding of lived experience leadership across the diverse spaces of mental health, AOD mutual aid and recovery and harm reduction. In conducting a broad search strategy, it has reviewed the findings of studies and articles relating to concepts and models of consumer and lived experience leadership, the context of leadership and involvement in consumer and carer/peer led organisations, as well as the experience of leadership in mainstream health services and academia.

The review included 172 studies and articles, most of which were single qualitative studies, descriptive survey studies, expert opinion study reports and discussion papers. A number of systematic and scoping reviews and industry reports were also included. Overall, the evidence base sits mostly at levels 3-5 on the JBI levels of evidence for meaningfulness.

The review finds that lived experience leadership is a developing concept that has promising levels of definition and understanding. It is understood within user or consumer leadership contexts, with carer leadership being included only in one significant study. There are available models of consumer/lived experience leadership which can be used as a basis for discussion, learning and growth across diverse areas of lived experience, and interpreted across and within different roles and activities. Lived experience leadership is active in spaces such as organisational management, systems advocacy and activism, peer work individually and within groups, community activation and education, and research and health practitioner education. There needs to be further research and writing about the nuances of lived experience leadership in terms of experiences of being a leader, having strategic influence, and working collectively within specific areas of lived experience.

In terms of organisational models and governance arrangements, the experience and activities of consumer organisations in the US, UK and Canada reveals several trends in the forms of governance and leadership. This includes the development of larger peer-run organisations with multiple services and activities for members, where participation and shared leadership can occur. And it also includes single purpose mutual aid groups, such as 12-step programs (e.g. Alcoholics Anonymous and Narcotics Anonymous) and residential recovery housing (e.g. Oxford Houses) which have been replicated and adopted in many different places via networking and support. There are examples of successful and sustained leadership within each approach. Both approaches express the importance of autonomy in enabling lived experience leaders to organise and develop collectively, while also having distinct separation from clinical services.

Sector level commissioning has supported the growth of funded lived experience organisations in both the US and UK, including networks and peak body roles. Commentary highlights health equity gaps in commissioning where funding isn't provided to adequately support lived experience groups from diverse communities or gaps where existing organisations fail to involve, support and provide voice for consumers and carers with multiple experiences of marginalisation and harm.

The integration of lived experience leadership in mainstream health services presents mixed outcomes regarding levels of involvement, influence and achievements. Barriers and challenges are well documented, and studies indicate that organisational change approaches are needed, along with improved consumer and carer leadership networks and infrastructure at systems levels. Shifts in culture, mindsets, resourcing, co-production practices and accountability are

needed so that lived experience leadership is embedded, valued and effective at governance levels. Whole system level of care reorientation projects have been attempted in some US states and UK regions which have improved recognition, valuing and embedding of AOD mutual aid and recovery groups as the stewards of 'recovery capital'.

A similar program and systems change process is recommended within academia to generate and support an increased presence of consumer and carer academics across public health research. Strong and vibrant lived experience organisations and networks are also able to lead or partner in research projects if appropriate resourcing, skills development, support, flexibility and collaboration are provided. An improved social justice and equity lens is needed to broaden the reach and inclusiveness of lived experience leadership and its formulation in diverse communities.

This review identifies the following considerations for Victoria's Lived Experience Leadership Strategy:

- Research on the concepts of lived experience leadership from a consumer perspective provides a starting basis for leadership training and sector-wide understandings of how leaders lead change as guided by established peer principles and models in mental health and AOD mutual aid and recovery. There is further need to define leadership within all communities including harm reduction and family carer areas. Further research and industry work can generate shared understandings around strategic influence and other nuanced aspects of leadership activity in a variety of roles and positionings. This can be a part of existing workforce development work being undertaken by mental health, AOD recovery and harm reduction peaks but should also broaden to invite work on lived experience leadership from Aboriginal health leaders, LGBTIQ+ groups, CALD and refugee groups, population based peaks, and peer groups in the family violence, housing and criminal justice areas.

- Programs and approaches for lived experience leadership training, mentoring and support have been successful in creating pathways to leadership and positive experiences by connecting emerging leaders with opportunities in governance of mainstream services. Resourcing to develop and deliver leadership programs across mental health, AOD recovery and harm reduction areas of lived experience and to create critical and diverse mass of leaders should be considered. Development of pathways needs to reflect intersectionality and intentionally involve diverse communities.

- The development of leadership pathways and opportunities should be coordinated with increased growth of capability to embed lived experience leadership within governance of mainstream services. System level supports can be created by funding a backbone organisation to lead collaborative effort towards organisational change, education on inclusion and allyship, training on lived experience governance and co-production, ways of improving resource flows, and methods for measuring progress and impacts. Broader policy and practice alignment towards agreed visions of recovery, AOD recovery and harm reduction is also important for valuing the perspectives that lived experience brings.

- Local health networks and NGO providers should be encouraged to develop aspirational frameworks for improving levels of lived experience governance, tied to development of the lived experience (peer) workforces and peer-led services in their organisations. This includes specialty peer workforces.

- The growth of member-based lived experience organisations, providing services and activities in mutual aid peer support should be supported through a specific program of commissioning. This should occur through a social justice and equity policy focus, where lived experience organisations are commissioned that support local community framings and cultural perspectives on mental health and leadership, and preferred governance arrangements. Organisations could be supported to also deliver activities within the NDIS market, or primary health care funding, or a specific state program.

- Further work should go into identifying and recognising peer-led mutual aid or social and emotional wellbeing programs which can be replicated, adapted, evaluated and supported to grow in Victoria. Investment can follow for inviting trainers to the state to lead learning and for establishing networks of learning, practice and meeting spaces.

- The Strategy should include goals and action plans for developing the scale and capacity for lived experience-led and partnered research in Victoria. Plans should aim to boost capability within lived experience organisations, universities and other research units.

Limitations

There are some limitations for this review. As a broad-based industry literature review using a single search there may have been papers missed that would be found in more specifically planned searches, such as a focused search on user-led research, or advocacy and involvement or training, or searches specific to mental health, AOD mutual aid and recovery and harm reduction areas. The project did not allow the time capability to conduct extensive handsearching in every topic area. Also, as the authors are most active in the mental health area, the quality of the search for identifying and using papers in the AOD recovery and harm reduction, and disability areas may have been limited by having less familiarity in these spaces, and less knowledge of existing search terms, and descriptions of leadership. With these limitations, the authors point out that specific literature reviews for each topic area and for each population would likely yield a fuller range of literature, and enable higher levels of rigour in meeting review methodological processes. The review aimed to describe available research and identify gaps in knowledge, rather than critically appraise and synthesise the evidence into key findings. Readers also should consider that while many lived experience authors have contributed to or led included research projects, much of the research has been led by scholars in nursing, public health, social work and other disciplines. The positioning of research authorship has an influence on the scope and direction of projects as well as the interpretation of findings.

APPENDIX 1 – SEARCH STRATEGY

Accessed here.

APPENDIX 2 – TABLE OF INCLUDED STUDIES

Accessed here.

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ABOUT LELAN

LELAN is the independent peak body in South Australia *by*, *for* and *with* people with lived experience of mental distress, social issues or injustice.

Our systemic advocacy targets the mental health and social sectors in South Australia, whilst our thought leadership and expertise on lived experience, leadership and governance is borderless.

By centring the experiences, collective insights and solution ideas of people with lived experience in all of our work, as well as being immersed in the lived experience community from grassroots to strategic and governance levels, we demonstrate the principles, practices and change dynamics that the social sector is calling for and desperately needs.

We have extensive experience and a proven methodology for leading lived experience-led and/or co-creation initiatives, frequently with a focus on sensitive issues and including groups that bring divergent perspectives to the conversation.

LELAN's vision of a world where people experiencing distress retain their dignity, autonomy and human rights – no matter what, will be achieved when:

- The capability, influence and expertise of people with lived experience and lived experience communities have grown.
- People with lived experience and lived experience communities have authentic partnerships within the mental health and social sectors.
- Lived experience-led systems reforms that directly benefit people with lived experience and the community are common practice.
- LELAN's thought leadership and innovation are recognised as industry leading and are recognised as industry leading and influence best practice standards.
- LELAN is a strong, sustainable and impactful organisation.

LELAN was founded in 2017, pivotal pieces of work completed in partnership and/or led by us with the lived experience community include the groundbreaking *Model of Lived Experience Leadership* that launched in 2021, as well as *The Lived Experience Governance Framework* and *A Toolkit to Authentically Embed Lived Experience Governance* that were released in July 2023 (all available at www.lelan.org.au/shared-resources).