Lived experience leadership for organisational and systems change: A scoping review of concepts and evidence

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Language and terms used in the document

Lived experience leadership

This is an emerging term. We approach the review with an understanding that lived experience leadership is activity where people stand up and speak up for the recognition and valuing of lived experience and advancing the movement. This includes informal and formal activity which promote the values and goals of lived experience as relating to empowerment, peer services, social justice and citizenship. Leaders speak up to influence community awareness, organisational culture, policy and politics; leaders create space, pathways and inclusion with others; leaders prompt and support change.

Lived experience leaders include people speaking from personal lived experience of distress, trauma or social disadvantage, as well as those caring for a person living with psychosocial disability.

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Contents

Acknowledgments ... 1

Language and terms used in the document ... 1

Suggested citation ... 1

1 Executive Summary ... 4

2 Introduction and background ... 5

  2.1 The Activating Lived Experience Leadership Project ... 6

  2.2 The role of literature and evidence ... 7

3 Research questions ... 8

4 Search Strategy ... 9

  4.1 Eligibility Criteria ... 9

  4.2 Selection of sources of evidence ... 10

  4.3 Data Charting and data items ... 10

  4.4 Presentation and synthesis of results. ... 11

5 Results ... 12

  5.1 Concepts and Roles ... 12

    5.1.1 Concepts of leadership ... 12

    5.1.2 Informal leadership ... 14

    5.1.3 Consumer or carer consultant roles ... 14

    5.1.4 Lived experience representatives, advocates and advisors ... 15

    5.1.5 Peer Support Workers ... 15

    5.1.6 Systems advocacy roles ... 16

    5.1.7 Leadership of consumer run organisations and services ... 18

    5.1.8 Research and academic teaching roles ... 18

  5.2 Qualities and skills associated with lived experience leadership ... 19

    5.2.1 Skills developed through recovery processes and perspective ... 19

    5.2.2 Knowledge and skills for lived experience culture and organisation ... 19

    5.2.3 Knowledge and skills for peer support roles ... 20

    5.2.4 Skills for peer-based support group leadership ... 21

    5.2.5 Knowledge and skill areas required for influencing change at services and systems level ... 21

    5.2.7 Knowledge and skills for leading consumer run organisations (CROs) and systems advocacy .. 22

5.2.8 Knowledge and skills for articulating key values and navigating dilemmas 24
5.3 Organisational conditions and expectations for lived experience leadership 25
5.3.1 Benefits of lived experience leadership to services, consumers, families and lived experience leaders 25
5.3.2 Issues of recognition, respect and power.. 26
5.3.3 Stigma and discriminatory attitudes 26
5.3.4 Representativeness and preferred knowledge 27
5.3.5 Structural positioning and presence... 28
5.3.6 Access to training and supports.. 29
5.3.7 Personal impacts... 31
5.3.8 The role of allies in lived experience work 32
5.4 Enablers for recognition and empowerment at organisational and systems levels 33
5.4.1 Systems and organisational leadership for valuing peer workforce 33
5.4.2 Systems and organisational leadership for valuing lived experience.. 34
6 Discussion.. 35
6.1 Concepts of lived experience leadership.. 35
6.2 Knowledge and skills and pathways to development 38
6.3 Organisational conditions supporting leadership in mental health services. 39
6.3.1 Enabling leadership at the systems level 41
6.4 Research and knowledge mapping 41
7 Limitations.. 43
8 Conclusion... 44
9 References 45
Appendix 1: Concept map of lived experience leadership: role, skills and organisational experience...... 54
Appendix 2: Focus of research methods and knowledge about lived experience leadership 55
Appendix 3: Search strategy 57
Appendix 4: Data chart of selected papers.. 60

1 Executive Summary

This literature review is about the concept and achievement of lived experience leadership, and the roles that leaders undertake in seeking change, sharing a vision of recovery and enhanced citizenship. It is also about the organisational and system conditions that support leaders across different settings of activity, including traditional mental health services, academia and consumer run organisations (CRO), and the informal places where leaders seek and organise for change.

The review has been prepared to provide evidence to the Activating Lived Experience Leadership Project (ALEL), which is a participatory action research (PAR) project undertaken by the South Australian Lived Experience Leadership and Advocacy Network (LELAN) and the Mental Health and Suicide Prevention Research Group (MHSPRG) at the University of South Australia. The role of the review is to provide an industry level scoping review which maps the key concepts and evidence informing this area.

Lived experience leadership is an emerging concept, and there are several definitional challenges in operationalising a literature search across different settings and context. A search was undertaken to retrieve peer reviewed literature which explicitly focused on leadership, as well as papers which focused on positions where leadership also may occur given the presence of consumers and carers in advocacy, education, peer support, consultancy and research roles.

Sixty-three papers met the inclusion criteria with these representing a diverse range of evidence. Overall, the evidence base is limited, and many studies are qualitative research projects focused on the views and experiences of leaders, managers and colleagues. The research base includes pockets of research across the lived experience workforce, local service advocacy, consultancy, research, education and peer support. The most significant group of papers are mixed-methods studies focused on the operation, structures and outcomes of CROs and leadership in the United States of America and Canadian contexts. Another specific focus of literature is peer support role implementation. The review reveals gaps in how the concept relates to intersectionality, and peer work across diverse communities and social issues.

Identification of key ideas and experiences across the studies shows that lived experience leadership remains a challenge to define. There are different dimensions of leadership and how it is expressed and understood across informal and formal roles, contexts and settings. The review finds that leadership is grounded in the values of the lived experience movement and needs to be understood in terms of peer relationships, empowerment, recovery and change. These values provide the basis and purpose of leadership activity, which is expressed via relationships and roles in CROs, mental health services, systems advocacy, community awareness raising and community initiatives.

With a focus on qualities, knowledge and skills, the review shows that leaders require generic and specific skill sets, and knowledge from areas of mental health, psychiatry, empowerment, peer support, group work, organisational change and management. Leaders need skills to engage with change processes as these occur in relationships with peers, teams and organisations. The change agent role of lived experience leadership requires leaders to act in settings which are traditionally hierarchical and disempowering, including public mental health service contexts, policy discussions and in academic settings.

Experiences of othering and stigma are common within peer support positions and organisational decision making. Issues around unclear structures and vague role definitions, tokenism, lack of inclusion in governance, staff resistance, non-acceptance, and inadequate access to supports are also prevalent in the literature focused on mental health services. Recognition and commitment to change is required to transform the various barriers faced by leaders. The review identifies the role of organisational and sector leaders to act as allies in supporting the quest for lived experience leadership. Allyship involves working with lived experience leaders to coproduce improvements in structures, role clarity, supervision, training, team acceptance, and funding of leadership positions. Common actions can be identified across service, academic and policy contexts.

The vision of leadership expressed across the papers looks towards services and responses to mental distress which are based on inclusion, recovery and peer support. There is a belief by many participants in the literature that people with lived experience can and should be directing, managing, planning and delivering these responses, and developing a system of services which are centred in lived experience.

2 Introduction and background

Across Australia, and within many countries with developed mental health service systems, there has been significant development in the growth of lived experience workforces. This has occurred through the creation of peer support roles within public mental health services and non-government organisations (NGOs), and in CROs. Beyond peer support roles, Australia also has a history of employing people with lived experience in consumer and carer consultant roles, which have been change agents or service development positions within public mental health services or policy units. Both types of employment have occurred alongside of involvement processes where consumer and carer advocates and representatives have volunteered their expertise and skills in shaping the decision making of mental health services, planning and policy. Collectively, the development of lived experience across a variety of roles and activities reflects the ongoing desire of the consumer movement to see a services sector based on human rights, recovery and inclusion (Byrne, Happell & Reid-Searl 2017). This can be tied to the activism and action of a broader social movement of mental health consumer and carers (Gillard et al 2013).

Recent years have also seen calls for a paradigm shift in the concepts regarding inclusion and change in mental health. The traditions of consumer and carer, or community participation have been evaluated by consumer writers as inadequate and limiting, where consumers and carers are invited into forums and settings which reflect ongoing power imbalances. Instead, there has been a demand to recognise the expertise and leadership of consumers and carers who seek change (Gordon 2005; O'Hagan 2009). A focus on lived experience leadership requests a different way of viewing relationships with mental health sector and service leaders and broadens the perspective on who can lead mental health recovery and community responses.

In South Australia, lived experience advocates have noted that the service and sector context of reform, as well as the growth of peer work roles, has meant that the concept of lived experience leadership needs development, shared understanding and a strategic framework. While numbers of employed peer workers have increased in both public and NGOs, we have not had an accompanying development of high-level forums for lived experience involvement service co-design, which advocates would say is essential given the challenges and resources limits that we face[1]. There are of course, examples of high-quality co-design work by some services and policy units, but the authors would argue that South Australia does not have sustained or systematic levels of partnership and co-production. From this flows the importance of understanding how lived experience leadership can be defined, recognised and strengthened as it occurs in different roles and settings, within and across services, the community and broader mental health ecosystem.

This thinking has led to the formation of the SA Lived Experience Leadership and Advocacy Network (LELAN). LELAN has established itself as the lead lived experience organisation in South Australia committed to developing the capability and influence of people with lived experience, nurturing organisational and sector capacity for partnering better with people with lived experience and impacting system improvement agendas to benefit people with lived experience.

Many of LELAN's observations align with those described by Byrne et al. (2017) as factors associated with the need for improved lived experience leadership on a global level. These include problems with understanding, implementation and integrity of peer work roles, the lack of higher level lived experience leadership roles across the mental health sector, and issues with co-option and distortion of recovery values as service providers work with both recovery and medical paradigms.

2.1 The Activating Lived Experience Leadership Project

A key achievement of LELAN has been to secure research and community building funding in partnership with the MHSPRG (University of South Australia). Due to the funding granted from the Fay Fuller Foundation, *Activating Lived Experience Leadership* has been established as a participatory action research and community development project which engages people in defining, recognising and utilising lived experience leadership. The research work will focus on generating knowledge regarding successful lived experience leadership, influence and change, as well as subsequently inform the development of training and learning resources for the lived experience community and sector. These actions will be complemented by community development work which is aimed at mobilising people with lived experience to get active and be involved, at the same time as building networks and pathways for lived experience leadership growth and mentoring and which encourages services to invest in local partnerships.

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[1] While LELAN is functioning as a peak mental health consumer body they do not receive core funding to fulfil this role relying on project funds through government grants and philanthropic support.

2.2 The role of literature and evidence

This literature review aims to identify key concepts and evidence regarding lived experience leadership in the context of systems and service change. The review seeks to inform the participatory action work of the project and help participants to engage with broader experience and evidence on how lived experience leaders have been recognised, valued and used to enable positive change in systems and services. The findings of the literature review, as well as other research activity and evidence, can be used to identify opportunities and levers for change in the South Australian context. With a broad focus on systems change, we can understand how leadership can have an impact on multiple levels. This includes the development of peer support roles and teams within public and NGO mental health services , peer leadership to promote recovery orientated practice (Byrne, Stratford & Davidson 2018, a), consultancy and governance in public services (Cleary et al. 2011), coproducing specific services (Pocobello et al. 2020), forming CROs (Fisher & Spiro 2010), community advocacy and awareness raising, and working at national levels for structural change (Mulvale et al. 2014). There is a building body of evidence for the impact of services and programs which are based on lived experience partnerships or are lived experience led (Grey & O'Hagan 2015).

In terms of the concept of lived experience leadership, there is an emerging literature base. Scholz and colleagues (2017) undertook their review with a focus on leadership within peer and public mental health services. They found that most studies and papers were focused on management in peer run services rather than public mental health services, and that more research was needed in the later context. A particular focus was on exploring the benefits of consumer leadership for services, and hence outcomes for other consumers was needed in future research. The framework for presenting findings in the Scholz review included organisational structures and hierarchy, and internal relationships. Determinants of consumer leadership was a key focus, and here the authors reported findings about the personal factors of consumer leaders, in terms of higher educational, employment related attainment, and personal interests in leadership. Findings about organisational factors referred to the ways organisations may be able to foster and nurture leaders, through a greater sense of community, a stronger culture of empowerment, leadership training and how there are more opportunities for participation in leadership within smaller organisations. The review noted some findings relating to benefits of consumer leadership, observing that included studies focus on self-benefits for leaders in terms of identity related benefits, better networks and supports, and skill-based benefits. The gap on studies reporting benefits for other consumers was highlighted by the review (Scholz, Gordon & Happell 2017).

One of the key challenges in conducting a review revolves around definitions of lived experience leadership. In a recent paper Stewart et al. (2019) highlight that it is an emerging concept that has been defined in diverse ways. These include referencing lived experience leadership in relation to roles, influence, purpose and values, personal qualities and organisational settings and structures. Lived experience leadership is also understood to occur informally and is not only a feature of formal activity or roles. The authors note that it is important understand this and recognise leadership occurring both outside and inside the mental health system, (Stewart et al. 2019). This understanding has several implications for the review. Firstly, it is likely that a literature review of scientific literature will not capture descriptions of lived experience leadership that have not been developed within academic and professional service settings. Secondly, accounts of lived experience leadership published within mental health journals may privilege the services sector as places where leaders are most active, while under recognising informal relationships and activity. Thirdly, a dilemma arises for the review in that the existing literature of lived experience roles within services may reflect leadership activity, as positions such as consumer consultants and advocates reflect change agent roles. A similar situation arises for peer support work, as these roles reflect assumptions about role modelling recovery, or being recovery leaders amongst clinical environments. A decision on whether search criteria should be broad to include literature only on leadership or literature on roles which nominally should include leadership action needed to be considered. This is clarified below.

The review by Scholz (2017) is important to the ALEL project as it identifies many key areas for development as well as the nature of studies informing the area. We sought to extend this work by engaging in a broader scoping review of studies of leadership as well as reporting on papers published since 2016. We also developed the review to focus on both consumer and carer leadership, as well as leadership across community work, policy advocacy, peer work roles, and public mental health services. The main role of a scoping review is to identify and clarify key concepts in the literature, and to identify the types of evidence and research available. This enables a review to cover the characteristics and factors commonly associated with the concepts and discuss the evidence gaps in the literature base and how research can be conducted in the future. It is not necessarily to produce a definite synthesis of findings, but to map concepts, knowledge and evidence (Munn et al. 2018). In this case, the concepts and knowledge are focused on the roles, qualities and skills of effective lived experience leaders and the organisational conditions and expectations which shape leadership. This in turn informs the project's focus on how organisations can create pathways for people with lived experience to influence systems change.

3 Research questions

The questions of the review have been formulated by the project team in consultation with the ALEL Project Advisory Group. These are:

- What are the roles, qualities and skills of effective mental health lived experience leadership?
- What are effective ways to provide learning and support?
- What are key organisational conditions, and expectations of how roles are established and how people have influence within them?

Asking these questions took place with the awareness that lived experience leadership in mental health may also be informed by lived experience leadership across other social movements, for example the LGBTIQ+, and women's health movements.

4 Search Strategy

A search strategy was developed within the author team and guided by an academic librarian. The search was based on key terms used by Scholz et al. (2017), but extended to include a wider context of community advocacy, education and social change. The search used a combination of MeSH and key terms and tested the searches for results against key papers such as Scholz et al. 2017. Databases searched included Embase, Emcare, Informit Health Collection, Joanna Briggs Institute EBP, Medline, Ovid Nursing, PsychInfo, Scopus and Web of Science. The search strategy from the (Medline) is added as Appendix 3.

4.1 Eligibility Criteria

Suitable peer reviewed papers and studies for the review were required to discuss or conceptualise lived experience leadership roles, purpose and expectations in the mental health context. Papers could also define or discuss organisational conditions specific to leadership. As noted in the above section, this formulation was challenging given dilemmas involved in the diverse definitional basis of lived experience leadership. The authors decided for a broader search criteria which included literature naming leadership directly as well as those articles referring to consumer and carer roles where leadership is an implied aspect of these roles. This move reflected the interests of the ALEL project. Papers which identified pathways to leadership through existing roles could help the project understand what development is possible for people acting in these roles in the South Australian context. The authors understood in making this decision that being in a consumer representative or peer support role does not automatically mean that the person within the role is demonstrating lived experience leadership.

For these reasons, we looked to identify papers focused on:

1. consumer advocacy and representation;
2. the role of consumer consultants;
3. the integration of peer worker roles in public or NGO services;
4. leadership in consumer run services; and
5. training and mentorship.

Papers about lived experience involvement or participation with a significant focus on leadership roles; barriers and enablers were also included. This broad formulation was influenced by our research questions and also the work of Scholz et al. (2017) which included leadership activities across different service settings and contexts. It was also influenced by O’Hagan’s (2009) paper, which identified three levels of leadership. This included consumer leadership relating to:

1. their own recovery;
2. the services level; and
3. the systemic level.

Our focus for including papers has been on the latter two levels of activity.

The authors included papers published from 1999 – 2019. Types of papers included were peer reviewed qualitative and quantitative studies, and discussion or concept papers. We excluded articles which were opinion and editorial pieces, literature reviews, not in the English language and book chapters. Our search strategy did not specifically target consumer led research and higher education, however papers found in these areas were included.

In designing the review, we were aware that significant grey literature exists in the context of leadership (for example government reports, consumer peak body reports). We therefore conducted several grey literature searches using Google advanced search, as well as keeping records of grey literature we found in the main database searches. While not formally a part of the review, this material was considered for informing the background and discussion parts of the project.

4.2 Selection of sources of evidence

The selection of sources was conducted by ML and HM, with each completing title, abstract and full text screening. The database search resulted in the 5207 studies. Hand searching, by working through reference lists and conducting key author searches yielded a further 303 articles. These were imported into EndNote and duplicates removed. An initial pre-screen was conducted to remove unrelated titles. The resulting 681 titles were then uploaded to a literature review management software (Covidence). Two reviewers then independently screened the titles and abstracts using the inclusion and exclusion criteria (ML and HM). Discussion over included and excluded articles occurred to achieve consensus on which studies were included for a full text scan. The process of selection was repeated, with 63 studies being included in the review (See figure 1: Prisma chart below). These studies were then examined for key findings as well as the level of evidence each represented.

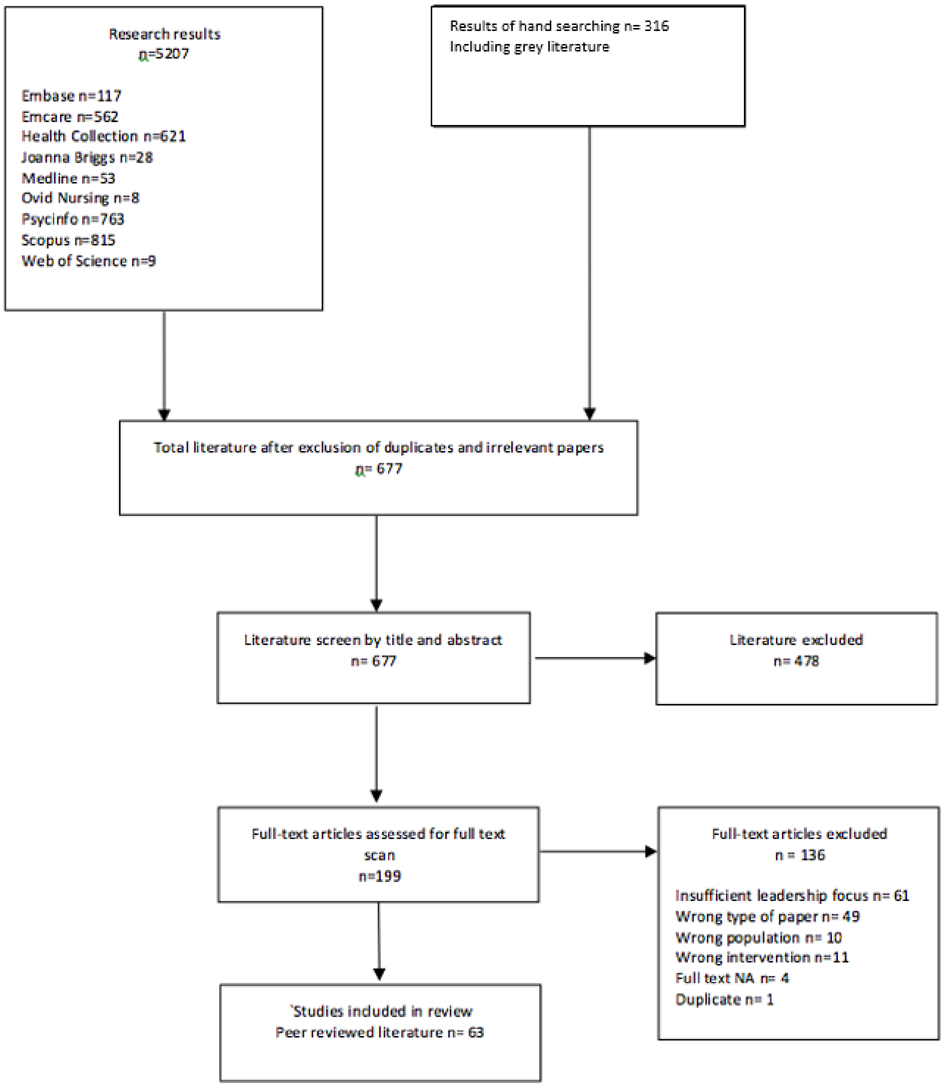
4.3 Data Charting and data items

To assist the consistency of data charting/extraction, both ML and HM developed a draft data chart, which included descriptions of the nature of background and study context, reported participant groups, how findings described, and use of Joanne Briggs Institute (JBI) levels of evidence scales. Data was charted according to study/paper characteristics (country and type of study), study design, data and collection method, types of leadership focus, findings regarding roles, qualities and skills, and findings regarding organisational and systems conditions. Papers were not critically appraised but were allocated according to the JBI meaningfulness or effectiveness scales (JBI 2014). A summary table is available as Appendix 4.

4.4 Presentation and synthesis of results.

The included studies in this review are diverse in terms of language and terminology, the focus of studies, and the methodologies used. There is generally little depth in the field with few studies focused on the same topics and organisational settings.

Table 1: Selection process for included studies



As indicated in Appendix 2, the review found a predominance of qualitative studies which explored the perspectives of consumers and service managers on leadership and organisational expectations within public mental health services. Many of these studies are Australian, with small sample sizes and the work of Happell and colleagues in nursing contexts being prominent. Many of these papers include lived experience academics as part of the research team. The qualitative papers contribute significantly to the understandings of roles, qualities and skills, as well as organisational conditions that enable or thwart the recognition of leadership. Another body of articles are cross sectional or descriptive studies focused on organisational type and leadership in the USA consumer run services. Many of these studies are psychology or social work based and were completed in during the 2000-2010 period of expanded funding to CROs. They reflect an interest in examining how organisational leadership impacts on the empowerment and recovery of members and participants. These outcomes interest the review as they also describe leadership roles and opportunities.

Due to the diversity of studies, results are themed broadly under three sub-headings. These are:

1. The concepts and roles of leadership
2. The qualities and skills of leaders
3. Organisational barriers, conditions and expectations
4. System opportunities

Some studies had findings and observations which were relevant to different areas of the research questions and were reported within the study on two or more occasions. We mapped the various concepts, theme, and findings across the three above categories, and then developed subthemes within each one. This helped to identify that some themes were more prevalent in the literature than others, and that some experiences, e.g. stigma and acceptance, were common across different roles and settings.

The studies have been categorised within *JBI Levels of Evidence for Meaningfulness* (JBI 2014). Most qualitative studies are at level 3 on the meaningfulness level with reflective, expert opinion papers being on level 5. Several studies on consumer organisations and empowerment fit within Level 3.e as observational studies without control groups. There are a number of survey design, descriptive studies which could be regarded as case studies and are at level 4.d levels of evidence for effectiveness (see Appendix 2 for details).

5 Results

5.1 Concepts and Roles

5.1.1 Concepts of leadership

This section presents studies which have findings orientated to a range of leadership roles that are regularly undertaken by people with lived experience across mental health. These range from peer support to organisational management. The main emphasis in this section is describing the wide variety of roles that are occurring at different parts of mental health systems in nations such as the UK, US, New Zealand, Canada and Australia. This enables identification of common concepts, experiential issues and points of uniqueness that overlap across these roles.

Sarah Gordon's discursive paper (2005) outlined the importance of articulating a paradigm shift from consumer participation towards consumer leadership. Occurring within New Zealand's policy development at the time, participating consumers had proposed an approach to leadership which is based on control of decision making, collective action and partnerships with health and social service workers. This was necessary to create the shift towards recovery focused services and avoid the limits of being invited to participate in the traditional settings of professional – consumer relationships. The approach to leadership contained three key dimensions:

1) ‘Central leadership in the managerial and governance structures that plan, fund and deliver mental health services;
2) The provision of service user managed and delivered services; and
3) Central involvement of service users in mental health advocacy, training, education and promotion’ (Gordon 2005, p.365).

Another discursive paper to consider is Mary O’Hagan’s proposed model of leadership. O’Hagan (2009) argued that conventional leadership models, including those focused on transactional and transformational approaches to leadership do not meet the needs of a lived experience movement with an explicit purpose, shared history of disempowerment, and collective values of equality. Rather consumer/survivor leadership needs to be guided by these key aspects. These include:

- A clear moral purpose of leadership in seeking equality and empowerment for peers, so that the goodness of leadership is evaluated via these values;
- A shared model of leadership that is ‘power with’ rather than ‘power over’;
- A knowledge base of lived experience, respecting the diversity of lived experience; and
- A leadership which is effective in promoting recovery outcomes for consumer’s lives, and not creating resource intensive forms of organisation (O'Hagan 2009).

The model then raises preferred practices and roles at a) the levels of personal leadership for a person’s own recovery, b) leadership for user survivor services level, and c) at the systems level. Being a leader in your own recovery involves accessing peer support, being a part of recovery education, collaborating with mental health professionals in strengths based work and shared decision making, personalisation and self-directed care (O’Hagan, 2009).

O’Hagan’s model for survivor/user run services sees leadership roles present as articulating the values base of the movement, consumer led governance and management decision making, and being a leader across different activities. At the systems level, leadership occurs within both designated and non-designated survivor/user roles: role for politicians, senior public servants, policy makers, advocates and researchers (p. 7). The model also includes a list of skills and competencies which are reported in the next section.

In a qualitative study of data from stakeholder interviews, Stewart et al. (2019) suggests that the literature in this area does not have a shared definition of consumer or lived experience leadership. Their analysis identifies that consumers and carers within mental health tend to work across different roles, which reflect leadership efforts. Five categories of roles are identified. These include:

1. advocacy and representation;

2. peer support work and service provision;
3. education and training;
4. service design and co-production work; and
5. funding, management and governance.

This study also sought to understand key requirements of leadership which included consumers with developed knowledge of service systems, with leadership skills and capacities. These enable people to facilitate change in their roles with a clear purpose. Leadership is enacted by communicating and applying lived experience, by influencing the awareness of others and decision makers, by building and using relationships in the service or policy environment, and by contributing to a culture of inclusion and peer support (Stewart et al. 2019).

5.1.2 Informal leadership

There is a minimal focus in the retrieved literature on informal leadership. There is one study centred on the leadership themes and behaviours that were apparent within a residential setting of independent living for consumers. Piat, Sabetti and Padgett (2018) reported three identifying traits of emerging leaders in the residential complex as being consumers who have capacity and are recognised for knowledge and their fearlessness in voicing consumer concerns. The study also identified three key behaviours of informal leadership, these being people who represent and speak for the experiences of the group, who are active and mobilise others, and who give positive examples. Further themes emphasised pathways to becoming leaders. These were displaying natural leadership qualities, enjoying a good reputation, projecting experience and wisdom, getting involved, and taking responsibility for the concerns of others.

The qualitative study by Barkway et al. (2012) explores the motivations of consumers and carers entering consultant roles in the sector. The small sample of participants reported that they were motivated by passion and altruism and wanting to share learning from their personal recovery and caring roles. There was also a desire to improve services and reduce negative experiences that they had gone through. Educating others, including providers on ‘what it is like’ was another feature. The authors note that role preparation of participants had included voluntary roles in assisting others and being advocates or support workers (Barkway et al. 2012). This indicates that informal helping pathways are recognised as an important way where people become active and motivated to enter more formal roles in the sector.

5.1.3 Consumer or carer consultant roles

Over the last 25 years, one of the key leadership roles within Australian services has been the consumer or carer consultant. This has been characterised as a change agent role active on levels of service change as well as peer level engagement with consumers and families. A South Australian qualitative study by Barkway et al. (2012) noted that consultants framed their work providing group work, education, involvement and liaison with consumers and carers, helping people navigate services, promoting recovery, advocacy and referral. Using flexibility and openness to promote messages of recovery to clinical teams was a feature of this role. Other papers describe the consultant role as diverse, expanding and complex in nature (Cleary, Walter & Escott 2006; Middleton, Stanton & Renouf 2004). Roles in these studies include policy development and assisting the involvement of consumers and families in service design and consultation processes and helping to have an outward facing role in informing consumer and carer networks about aspects of recovery and involvement practice. These roles require significant skills in collaboration and negotiating relationships for change (Cleary, Walter & Escott 2006). The authors report that consultants can operate in settings where themselves and others have unclear expectations surrounding their systems advocacy action.

5.1.4 Lived experience representatives, advocates and advisors

Mental health sectors in English speaking countries have had a long-term focus on establishing voluntary lived experience representatives or advisor roles in the context of consumer and carer, and community participation activities. The review retrieved a number of papers which were either explicit or implicit in exploring the experience of these roles, and associated themes of influence, power and impact regarding decision making and planning within services (Bennetts, Cross & Bloomer 2011; Bennetts et al. 2013; McDaid 2009; Rose et al. 2014). Generally, this literature highlights issues on how representative and advisory roles are often poorly defined and lack authentic support within busy and challenging organisational environments (Bennetts, Cross & Bloomer 2011; Scholz, Bocking & Happell 2017b). It also describes contexts of professional domination, resistance and stigma, unexplored expectations regarding representation, and the skills and required capacities of consumers and carers to have impact (Happell & Roper 2006; Scholz, Bocking & Happell 2017b). There is a clear sense in these papers that effective advocacy, representation and advice should be grounded in a collective consumer experience based perspective, and explicit about the power issues that need to be discussed in the change process with decision makers (Bennetts et al. 2013; Happell & Roper 2006). There are also a range of benefits described from improved involvement and co-production with lived experience leaders. These include the credibility and insights that leaders bring to decision making, improved quality of services (Scholz, Bocking & Happell 2018), better connection with consumer networks a reduction in 'siloed' thinking (Scholz, Bocking & Happell 2017b). The findings on representative roles will be explored more fully in the next section.

5.1.5 Peer Support Workers

The literature reflects the peer support worker role as the most prevalent employed lived experience position within mental health services. There were a significant range of studies identified which discussed the role in the context of issues regarding implementation and the range of organisational and role related issues as experienced by peers, managers, consumers and other stakeholders (Asad & Chreim 2016; Byrne et al. 2018; Clossey et al. 2016; Franke, Paton & Gassner 2010; Gates, Mandiberg & Akabas 2010; Gillard et al. 2013). The peer support worker role is most often focused on direct services working within recovery groups or providing one-to-one peer support. Most papers and studies have identified peer support workers employed within clinical mental health services and discussed a relatively uniform set of key issues. These included role ambiguity and role conflict (Hurley et al. 2018), disclosure/boundaries issues with both consumers and clinicians (Gates, Mandiberg & Akabas 2010; Gillard et al. 2013), personal impacts and self-care (Byrne et al. 2018), experiences of stigma and discrimination (Moran et al. 2013), isolation (Moran et al. 2013) and the challenges of working in medical contexts which run contrary to recovery principles (Clossey et al. 2016). While there is an emphasis of peer work in mental health organisations, it is important to remember that peers are often active in support and recovery groups which are fostered in consumer led environments or groups (e.g. addiction-based groups) or in non-clinical settings.

The question of whether peer support worker roles embody aspects of lived experience leadership is not recognised in many of the studies mentioned above. This is an interesting observation, as it is clear that peer workers employed in mental health services are present to role model, promote recovery principles and perspectives (Byrne et al. 2018; Mulvale et al. 2019). Are there implicit expectations that workers take responsibility for advancing peer work beyond their own role?

An International Charter of Peer Support portrays that peer workers lead recovery in terms of mutuality, sharing and modelling:

> *For the purposes of the charter, peer supporters are defined as people who have experienced mental ill health and are either in or have achieved recovery. In their role as peer supporters, they use these personal experiences, along with relevant training and supervision, to facilitate, guide, and mentor another person's recovery journey by instilling hope, modelling recovery, and supporting people in their own efforts to reclaim meaningful and gratifying lives in the communities of their choice (Stratford et al. 2019, p. 630).*

The authors of the Charter highlight that peer support is based on principles reflecting human rights, lived experience of adversity and recovery, mutuality and non-hierarchical relationships, and empowerment. The key practices of the peer support role are 1) to recognise personal resilience, strengths and talents, 2) to support people to take ownership of their decisions, 3) to promote areas of recovery most important to people and 4) advocate for changes 'both in systems of care and in the broader society, to eliminate discrimination; expand opportunities, resources and supports; and improve the quality of care offered to persons with mental health concerns' (p. 631). This last point highlights the change agent as being intrinsic to peer support work.

5.1.6 Systems advocacy roles

Gee, McGarty and Banfield (2015) studied the goals strategies and values of Australian consumer and carer advocacy organisations. Their work reflects key roles as undertaken by consumer and carer leaders working at the systems advocacy level. These roles and activities include:

- building consumer and carer participation, via enabling committee and policy representation and lobbying activities, submission writing. And organising forums with constituents, government departments and ministers.

- enabling voice and recognition for consumers and carers, via coordinating responses and generating unity of consumer and carers concerns and perspectives. Seeking recognition was a key role.
- influencing and improving mental health systems, via promotion and attention on consumer rights and social justice.
- enabling collaboration and partnerships, by building relationship across community, government and non-government organisations, professionals and bureaucrats, with a focus on communication and reporting
- building organisational strength. Advocates worked to strengthen membership, constituency and profile, and promote good business practices, volunteer workforces, and organisational culture. Sustainability was another theme.

'Findings demonstrate what drives consumer and carer advocates and their organisations to contribute to an organized, strong, and unified movement. While they focus on cementing genuine and effective consumer participation in health service and policy, they highly value partnerships based on mutual respect to improve mental health systems and outcomes' (Gee, McGarty & Banfield 2015, p. 1).

These findings are augmented by Janzen et al. (2006) in a study on the systems level activities of 13 consumer run, self-help organisations in Canada. The study identifies the key roles as being:

- Diverse public education and relations activities. Using targeted written media, conferences and events to promote consumer experience, and perspectives, raise public knowledge and shift public opinion and at times specific groups. Recognition and raising community profile as key impacts.
- Political advocacy, focusing not only on mental health reform and policy but also policy associated with housing, transport and social sectors, as well as targeted at professional association. Reported impacts were increased consumer voice and presence in policy development, and favourable policy and funding outcomes.
- Community planning and collaboration. Contributing to service level development and new services within the mental health sector and wider sector including housing, transport, employment, low income and young people. Impacts included increased perception among services of the value of consumer/survivor partnerships, increased presence and influence in decision making and increased profile.
- Action research. Using research methods to generate evidence and information to support the three key roles above. Impacts included boosting the credibility of consumer run organisations and the strengths and awareness of policy recommendations (Janzen et al. 2006).

The authors found that community planning and collaboration to be the most common area of activity of consumer leaders at the systems level, with the widest range of impacts.

5.1.7 Leadership of consumer run organisations and services

While the above two studies explored the external facing roles of a lived experience organisations, there are a range of descriptive studies on areas of participation and management style of lived experience organisations. These studies implicitly describe the consumer leadership roles in the areas of governance and board membership, financial budgeting and contracting (Mowbray, Robinson & Holter 2002; Wituk et al. 2008), executive director roles, staff and volunteer management, activity facilitators and peer support workers (Brown et al. 2008; Brown & Townley 2015; Ostrow & Hayes 2015). Tanenbaum (2011) found that consumer leadership strengthens citizenship as organisations and participants can be seen as part of the wider community, not specifically as a mental health service. This occurs through leaderships structures emphasising democratic norms, participation and significant relationships with local community, business and services.

5.1.8 Research and academic teaching roles

The last areas to describe in terms of roles are in the field of academic teaching and research. Lived experience teaching in mental health nursing has a significant basis of evaluation from the work of Happell and colleagues. Teaching roles are provided by either consumer academics with substantive academic positions or by casual teaching staff. A study by Bocking et al. (2019) describes the nature of teaching as informed by lived experience teachers. Teaching occurs via providing a critical analysis of the impacts of treatment and nursing care and appropriate use of personal stories to illustrate personal effects and perspectives. Lived experience teachers can provide authentic classroom discussions about power imbalances, help seeking issues, the details about recovery processes beyond hospital and a more holistic picture of consumer experience. This can include discussion of the wider social determinants of distress including racism, discrimination, isolation and abuse (Bocking et al. 2019). The advantages of teaching also expose students to views they would normally not hear in academic teaching and to encourage a critical reflection on nursing practice and power. This often centres on how mental health nurses can be involved in practices such as forced treatment and restraint which can be experienced as traumatic and damaging for consumers; how nurses can do ‘unconscionable things’ in the context of duty of care (Happell & Roper 2009, p 577).

Consumer academic roles in research have been developed in the last 20 years. These are positions which recognise the need for lived experience led or coproduced research activity. Consumer academics can operate at Chief Investigator levels, be a part of investigator teams, or apply for funding for projects which align with lived experience interests (Happell & Roper 2009). People may also be active outside of the university context in terms of being consultants or independent researchers (Patterson, Trite & Weaver 2014). Apart from being leaders and chief investigators of research projects, people with lived experience can be involved as contributors in different ways. Common roles also include taking part in identifying priorities for consumer or carer focused research, being members of project advisory groups, and contributing directly to the methods within co-design processes, being involved in data collection, undertaking data analysis as well as co-writing publications (Banfield et al. 2014; Patterson, Trite & Weaver 2014). An important focus on producing consumer led and coproduced research is to influence policy and systems development according to preferred values. Russo (2012) highlights that consumer or user led research tends to be focused in qualitative traditions as ‘insider research’, where the researchers have a shared identity and closeness to topics through lived experience. They also tend to adopt methods which redefine research participants as co-creators of knowledge, enlarging their role and ownership in the processes of research activity.

5.2 Qualities and skills associated with lived experience leadership

This section includes studies that identify qualities and skills across the above areas of leadership roles and functions. It also includes papers which have findings relating to the issues, dilemmas and experiences that leaders need to manage in leadership roles.

5.2.1 Skills developed through recovery processes and perspective

Mary O’Hagan’s (2009) proposed model of leadership lists a range of competencies across the levels of individual recovery, services level involvement and systems change. The following skills are highlighted on the level of individual recovery and experience of services:

- Understanding self as experts by experience;
- Knowledge of services, treatments and key options;
- Knowledge of navigating services for benefit;
- Positive communication skills, including assertiveness; and
- Skills for collaboration and negotiation.

5.2.2 Knowledge and skills for lived experience culture and organisation

O’Hagan also lists a range of general and specific competencies for working ‘for the collective good’ of the movement (p. 8). Her generic knowledge and skills include:

- Personal development and understanding of mental health related issues;
- Undertaking diverse views and interests of stakeholder;
- Knowing about the mental health system and navigating this;
- Strategic thinking and judgement of influence/politics;
- Governance and organisational skills;
- Understanding and ability to meet different points of accountability;
- Understanding meeting protocols;
- Positive communication skills; and

- Self-awareness and reflection skills.

The specific skills are those that are about leadership specific to mental health. These are:

- Personal development through distress and recovery;
- Connection and affinity with consumer movement values;
- Understanding critique of treatment, human rights and social justice, inclusion;
- Understanding of trauma impacts and restrictive practices;
- Analysis of power dynamics and co-option;
- Empathy for other consumers;
- Ability to self-disclose for benefit of others;
- Recognition of autonomy for peers;
- Ability to see strengths of others;
- Ability to enable consensus decision making or create space for others;
- Ability to relate to diverse consumers; and
- Ability to be nonjudgmental of others' perspectives and stories (O'Hagan 2009, p. 9).

5.2.3 Knowledge and skills for peer support roles

The above range of knowledge skills and awareness is built upon by other literature. Franke, Paton and Gassner (2010) South Australian evaluation of peer support work training highlighted additional areas of knowledge and skill required for these roles. Their course content and follow up support of peer support workers included an emphasis on:

Knowledge	Skills
• Human rights, discrimination and stigma • Principles of recovery and inclusion • Understanding different mental illnesses • Mental health services, language and resources • Workplace culture and communication • Confidentiality	• Dealing with stigma in role • Promoting recovery and inclusion in peer work roles • Research and sharing information • Connecting consumers with resources • Working in teams • Ethics and boundary setting

Knowledge	Skills
Diverse peer work roles Issues and barriers in communication Recognising own triggers, and needs Professional development and career	Sharing own experience safety Assisting consumers to identify recovery needs and goals Active listening and communication Self-care and wellness Professional development goals

(adapted from Franke, Paton and Gassner (2010, p 182-183)

5.2.4 Skills for peer-based support group leadership

Peer work practice includes working in recovery-based groups. The review retrieved one study highlighting the range of group work skills used. Centred in exploring the experiences of peer group leaders in England, Fieldhouse et al. (2017) report that group leaders need to manage a significant range of dynamics and interests within groups. The roles also included ways of managing workplace relationships and protecting the peer values base of the support groups. Their study highlights key knowledge and skills as:

- Group work facilitation skills;
- Ability to articulate values of mutuality and positive collective identity;
- Ability to create opportunities for involvement and leadership for others;
- Ability to establish democratic decision making;
- Ability to balance need for rules, participation, and accountability; and
- Skills to manage responsibilities and opportunities of group leadership, and dilemmas involved in avoiding bureaucracy (Fieldhouse et al. 2017).

5.2.5 Knowledge and skill areas required for influencing change at services and systems level

While there were several papers focusing on the experience of consumer representatives and advocates, there were only two papers with a specific focus on advocacy skills. The article by Stringfellow and Muscari (2003) focuses on the work of the West Virginia Leadership Academy, which has been leading an empowerment program in the USA context. The academy has prepared hundreds of consumer leaders since the late 1990s, with participants attending from different USA states. The descriptive paper by Newton et al. (2013) highlights the achievements of a UK based program called *Voices Together*. Both papers indicate a range of advocacy practice skills, with Stringfellow and Muscari providing more detail on skills which generate influence:

- ‘Meeting facilitation and protocols;
- Ability to work in groups;
- Understanding of the consumer advocates/ leader role;
- Understanding mental health issues, marginalisation, discrimination, stigma;
- Advocacy, policy development and planning skills;
- Understanding of power dynamics and empowerment;
- Skills in presenting issues with influence;
- Using important information sources, research for leverage;
- Strategic thinking and judgment;
- Conflict resolution and constructive responses to resistance;
- Collaboration skills;
- Public speaking and presentation skills;
- Communication and assertiveness skills, confidence to speak up;
- Understanding health systems and policy contexts; and
- Self-awareness and ability to reflect on self and others’
  (Stringfellow & Muscari 2003, p. 143-144).

Stringfellow and Muscari describe how the program encourages graduates to practice their advocacy and empowerment skills by becoming active at local and state-wide level. Graduates are supported by ongoing group teleconferences and assisted in joining local committees, boards of consumer run services and state policy councils. while also being encouraged to speak at conferences.

5.2.7 Knowledge and skills for leading consumer run organisations (CROs) and systems advocacy

Several studies on CROs highlight a range of knowledge and skills required by leaders. These range from those associated with organisational leadership in the areas of governance, decision making and business management, leadership in terms of voicing the values and collective viewpoints of the peer recovery movement, externally facing skills in negotiating relationships with stakeholders and having influence.

The Wituk et al. (2008) study of requests made to a USA Technical Assistance Centre by 27 associated CROs indicate the range of skills and knowledge that consumer leaders regularly seek in establishing the operations of their agencies. The role of Technical Assistance Centres in the SAMHSA funded programs is to act as a support organisation to build capacity and competency for funded consumer services. The authors studied the frequency and categories of requests made, noting that grant writing, reporting, board development business management and managing staff to be the most common categories for assistance sought. Remaining areas of support were provided for conflict resolution skills, policy development, activity planning, partnership and collaboration, transport, membership strategies, volunteer development, strategic planning and increasing public awareness (Wituk et al. 2008).

Development of competencies for managing organisations towards the values base of the movement is noted in USA studies. A national survey of 380 CROs by Ostrow and Hayes (2015), found that consumer-controlled organisations were more consistent in involving members in decision making and relied on larger volunteer workforces than those organisations with less peer control. This reflects less hierarchical organisational structures and more lateral peer-based relationships throughout the organisations. A related finding of increased participation was also a finding in the Mowbray, Robinson and Holter (2002) descriptive study of the management structures of 32 drop-in centres. Organisations with consumer-controlled boards, which made planning and budgetary decisions and signed contracts for service, achieved higher levels of participation of peers in organisational and service-related operations (Mowbray, Robinson & Holter 2002). Control of decision making enables autonomy and peer centred spaces.

A series of studies by Brown and colleagues (2008) provides further insight and findings toward participatory leadership. There was a significant focus on measuring the nature of empowerment and recovery that occurred in CROs. Brown et al. (2008) examined ratings of recovery for 250 participants of 20 different organisations and found that participating in social support activities had a greater impact on recovery that being involved in empowering participating experiences (i.e. being involved more in leadership activities – called organisational empowerment). The authors concluded that both types of participation support recovery and recommended that CROs promote empowering environments. This can be achieved through volunteering, organisational decision making, planning group activities, formal leadership roles, and managing conflicts and conduct (Brown et al. 2008). In a further study from the same data set, Brown and Townley (2015) found that participants engagement, measured through rates of attendance, is most associated with a perceived sense of community within the organisation, but was also positively associated with perceived organisational empowerment, shared leadership and peer counselling. The authors noted that one of the challenges of CROs is how to promote opportunities for leadership when organisations become large in membership. There is a negative association between larger CROs and the number of people that can benefit from becoming active as a leader (Brown et al. 2007; Brown & Townley 2015).

In further work, Brown developed a framework to understand the nature of empowerment, relationships and personal change within CROs. Using descriptive survey results with 194 consumers from 20 CROs, the authors Brown (2009a, a) mapped 18 areas of personal change and 7 key experiences as reported by consumers. The top 5 personal change categories were improved self-esteem, better social skills such as listening and communication, increased activity and getting out of home, improved coping and problem-solving skills in dealing with stress and being more outgoing and getting more from social interactions. Brown concluded that the social environments of CROs promote a range of social and personal development opportunities for participants over time, through roles such as friendship and leadership. Both are helper roles and require skill building. Benefits that flow from CRO membership can include emotional and information resources, positive self-appraisal, coping skills and interactional accomplishments. Over time, identity transformation can occur where participants become more independent more outgoing and more self-assured. These findings are supported by an in-depth narrative analysis of 7 participants in another study (Brown 2009b). The themes that CROs equip consumers to enter helping and leadership roles are also reported in a qualitative study by Ochocka et al. (2006):

> CSIs (Consumer/Survivor initiatives) not only offered people an alternative worldview, but equipped members to provide support to others. This important shift in providing support, from passive receiving to active contributing, was crucial for people's sense of empowerment, self-confidence, and self-worth (Ochocka et al. 2006, p. 280).

5.2.8 Knowledge and skills for articulating key values and navigating dilemmas

Felton's (2005) ethnographic analysis of key narratives used in one organisation indicate that the skills to articulate a vision of recovery and the unique values of an organisation as different to those required in public mental health services. Narratives used by peer management and staff, communicate commitment in the consumer movement, the pride of offering peer run alternatives and describing the service as the 'most understanding place' (p 382). This takes place in the context of a critique of the disempowering aspects of the mental health system. The narratives of the social life of the agency as a type of family was also noted. Felton (2005) argues that it is critical that leaders can articulate ways of working that resolve a potential conflict between consumer values and being responsible providers. Levels of accountability operate towards peers, mental health services and funders.

The nature of dilemmas experienced by leaders is a feature of a study by Nelson et al. (2008). The authors analysis finds that leaders of CROs need to negotiate a set of common dilemmas in their relationships with peers, the sector and government. These include 1) the need to respect the diversity or personal perspectives and recovery goals of individuals while also defining collective goals and aspirations, 2) the gaps between promoting self-help while advocating the benefits of peer support via paid staff or volunteers, 3) deciding agency focus between caring and support roles with emancipatory, advocacy based work and 4) maintaining agency autonomy and independence as against seeking government funding and meeting obligations. These issues become areas of discussion and decision making at board and executive levels and represent a significant skill set.

Further observations are made by Rose and colleagues in their ethnographic analysis of five consumer led organisations in the UK. A dominant theme is the need for articulating and maintaining organisational autonomy while also highlighting the importance of relationships of influence with policy stakeholders and NHS trust managers. However, the theme of complexity was also apparent. Leaders need to negotiate a complex context of policy directions and relationships, emancipatory interests, institutional discourse and corporate behaviour to succeed. They noted that 'the different places where service users might intervene, and influence are now immense and diverse. They are also confusing in terms of where efforts might be best paced to effect change in a direction desired by service users' (Rose et al. 2016, p. 258). The authors here are noting the diverse places of policy development, legislation, funding and commissioning, standards and quality assurance, service level advocacy and research.

5.3 Organisational conditions and expectations for lived experience leadership

This section reports on studies which focus on the organisational conditions, experiences and expectations regarding lived experience leaders. It reports on general themes that run across the experience of lived experience consultants, advocates and peer workers working within mental health organisations. Much of the literature emphasises barriers and challenges involved in the experience of consumer representatives and peer workers, with the literature on peer worker integration and support being the most consistent in identifying themes.

5.3.1 Benefits of lived experience leadership to services, consumers, families and lived experience leaders

There were many studies which included a focus on benefits in exploring the nature of peer work and other change agent roles within the sector. In the Australian context, Scholz, Bocking and Happell (2017b) analysed the views of 14 consumer leaders and allies, reporting that leaders add value by embedding consumer perspectives within organisational settings in ways that span the silos of professional and organisational centred decision making. Lived experience leaders improve the legitimacy and reputations of services for understanding consumer needs and preferences. They also link the service with their consumer information networks (Scholz, Bocking & Happell 2017b). In a further qualitative analysis, Scholz, Bocking and Happell (2018) report that consumer leaders communicate the positive, inherent value of recovery from the experience of ill health, in terms of sharing knowledge and skills gained, which through involvement can transfer to the culture of services, and embed a vision of recovery. Consumer leaders identify key improvement for planning services, encouraging a view towards positive consumer experience. In peer support work roles, Scholz reports that leaders share knowledge that benefits others, in a way where power relationship are reduced, promoting safe services from the consumer perspective. Peer support workers offer hope, and assist people moving beyond negative stereotypes of stigma (Scholz, Bocking & Happell 2018).

A number of other authors focus on the unique relationship that peer support work offers. Asad and Chreim (2016) and Gillard et al. (2013b) both report on the theme that peer support offers safe and relaxed engagement for consumers in their qualitative analysis. This is enabled through offering more equal relationships and the nature of having shared experience. Trust is a key outcome of these relationships (Hurley et al. 2018). In a further Australian study, Byrne et al. (2018b) analysed the perspective of 29 managers (including 10 peer designated managers) and found a number of key perceived benefits. These were the value of unique skills and perspectives that peers bring, more equitable relationships, improved opportunities for building involvement, peers are living examples of recovery and hope, and peers can offer deep empathy. For organisations and clinicians, peer leaders drive change towards recovery, bridge language between clinical perspectives, ordinary language and recovery, and provide deep insight into the experience of stigma (Byrne et al. 2018). A number of other authors focus on the unique engagement that peer support work offers. Asad and Chreim (2016) and Gillard et al. (2013a) both report on the theme that peer support offers safe and relaxed engagement for consumers in their qualitative analysis. This is enabled through offering more equal relationships and the nature of having shared experience. Trust is a key outcome of these relationships (Hurley et al. 2018). In a further Australian study, Byrne et al. (2018b) analysed the perspective of 29 managers (including 10 peer designated managers) and found a number of key perceived benefits. These were the value of unique skills and perspectives that peers bring, more equitable relationships, improved opportunities for building engagement, peers are living examples of recovery and hope, and peers can offer deep empathy. For organisations and clinicians, peer leaders drive change towards recovery, bridge language between clinical perspectives, ordinary language and recovery, and provide deep insight into the experience of stigma (Byrne et al. 2018). Hurley et al. (2018); Mulvale et al. (2019) and Gillard et al. (2014) emphasise similar themes on the contribution to team learning and culture within public mental health services. The advocacy role and systems change perspective is significant here.

In terms of the personal impacts for those working in peer worker roles, an Australian analysis of the views of 24 consumer workers concluded that consumer perspective work was viewed as enriching for the workers, and that they saw their work as part of the broader movement and cause. Workers valued opportunities to contribute to bigger picture change and challenge stigma and discrimination. There was a sense that consumer work enabled ‘real lives and real jobs’ and felt that roles needed recognition through proper remuneration (Bennetts et al. 2013, p. 318). Both Mulvale et al. (2019) and Franke, Paton and Gassner (2010) report in their studies that peer worker incumbents felt that peer work was a feature of their recovery, although that the challenges of work and participation in clinical organisations could lead to distress.

5.3.2 Issues of recognition, respect and power

Many studies identified a cluster of issues that affect the success and experience of lived experience leaders working within clinically orientated mental health services. With a focus on exploring leadership across the roles of peer work, consultants, representatives and educators, it is possible to see the overlap and prevalence of these issues.

5.3.3 Stigma and discriminatory attitudes

The first of these is the presence and impact of stigma among mental health service cultures and in the interactions between leaders and non-lived experience team members. Many of the papers focus on peer worker implementation highlight participant experiences of stigma as affecting the recognition and respect of their work. They suggest that stigma may be experienced in various ways, in the form of worries about risk, paternal attitudes about wellbeing, and prejudice about lived experience knowledge and capacity (Byrne et al. 2019b; Clossey et al. 2016; Franke, Paton & Gassner 2010; Gates, Mandiberg & Akabas 2010; Moran et al. 2013; Scholz, Bocking & Happell 2018; Shepardson et al. 2019). Negative and deficit based assumptions are also experienced in the advocacy and representative space, where stigma can affect how consumer views are heard and expressed around committee tables (Gee, McGarty &

Banfield 2016; McDaid 2009; Scholz, Bocking & Happell 2018) and in resistant professionals who do not value consumer involvement (Bennetts, Cross & Bloomer 2011; Gee, McGarty & Banfield 2016; Middleton, Stanton & Renouf 2004). It is also a theme of experience where consumers have become engaged in research activities, working alongside clinician-based researchers (Patterson, Trite & Weaver 2014) or are seeking funding opportunities (Russo 2012).

5.3.4 Representativeness and preferred knowledge

A longstanding theme that features in advocacy and representative leadership is where clinical and service leaders question the representativeness of consumer representatives and their perspectives. This plays out in different ways. One way is roles are titled as consumer representatives, where the leaders are expected to canvas and represent views not unlike a formal political or industrial role in decision making. Another is where roles use this title but expectations around action remain unclear to the incumbent leaders and others. A further way is when leaders are expected symbolically to represent the average consumer using services, in terms of the perspectives they put forward or their use of personal stories (Middleton, Stanton & Renouf 2004; Scholz et al. 2019; Stewart et al. 2019).

These points are examined in critical papers by Happell and Roper (2006) and Scholz et al. (2019). These authors argue that questioning the representativeness of leaders undermines their presence and leads to disempowerment. In many cases, leaders are not supported or resourced to be able to consult and canvas views with consumer networks, and that most clinicians or other professionals sitting on committees are not required to do this role. It becomes discriminatory as the lived experience leader's knowledge is not valued in the same way as other role experts. The other critical argument is that this role expectation also undermines the need for services to organise consultation as a part of its consumer experience and evaluation strategies (Scholz et al. 2019). Rose et al. (2016) add the finding that other consumers can also question the representativeness of leaders, where leaders become seen as different due to the skills and sector knowledge they develop in being experts, or the way they develop working relationships with clinical leaders.

This point about sector level expertise highlights that leaders need access to knowledge and resources in order to navigate systems and engage in policy and planning discussions with influence. McDaid reports on this in terms of critiquing the nature of participation and involvement within mental health services. He observed that consumer leaders were at a disadvantage on many levels as the conditions of credible knowledge are skewed toward professional perspectives and knowledge bases. Consumer participants come to the table without the developed policy knowledge of others or understanding the 'rules of the game' concerning planning within the sector. They also need to navigate complex language and jargon. This has an implicit action in devaluing lived experience knowledge and its recognition (McDaid 2009).

The theme of undervaluing lived experience knowledge also plays out in dynamics regarding the acceptance of peer support work roles and recovery principles within clinically oriented teams. This is reported as the dominance of the medical or psychiatric model in clinical decision making, and the impacts of this for peers working with consumers and families via recovery values. Peer worker participants in studies by Clossey et al. (2016) and Moran et al. (2013) report the medical model as a key barrier, which is demonstrated when teams and colleagues do not understand the recovery approach and thereby the role of the peer worker. The theme is echoed by consumer consultants seeking change in the planning of services. Recovery seeks a broad approach to care and places consumer preferences and autonomy at the centre of shared decision making. Consultants advocating for change in Middleton, Stanton and Renouf (2004) were frustrated by the narrow range of medical understanding and how it continues to shape decision making. In the study by Bennetts, Cross and Bloomer (2011) looking at the views of seven service managers, there was an acknowledgment that significant power is invested in medical decision making, and that those working from a traditional medical perspective, are likely to find the idea of empowered consumers a challenging one. These authors observed that managers often framed consumer consultants as the key persons for achieving good quality involvement, rather than seeing it as an organisational wide responsibility and activity. The authors note a range of complex dynamics regarding power and change in mental health services, and how ‘consumer knowledge’ and ‘therapeutic knowledge’ are recognised in different ways (Bennetts, Cross & Bloomer 2011).

5.3.5 Structural positioning and presence

There were a range of barriers reported across the studies that are related to the emergent nature of peer support work and consumer and carer involvement within mental health services, and the ways structures and positions are defined and resourced.

Role clarity and boundary issues are reported by many of the peer worker integration studies, whereby peers, managers and sector leaders report difficulties regarding relationships and acceptance within clinical teams, based on misunderstandings and conflicts on the preferred peer support roles (Byrne et al. 2018; Clossey et al. 2016; Gates, Mandiberg & Akabas 2010; Gillard et al. 2013; Moran et al. 2013; Shepardson et al. 2019). ‘…lack of consensus around what constituents peer practice can result in feelings for peer workers of inequality, disempowerment, uncertainty about identity and of being under supported’ (Gillard et al. 2013, p.1)

Hurley et al. (2018) describe how peers often needed to shape their role once in the positions, including negotiating relationships and finding ways of managing identity shifts from being a person with lived experience as well as a worker. A study by Asad and Chreim (2016) reported similar themes with peers needing to build credible relationships with both clinicians and consumers, educating both themselves and others on the preferred peer support work approaches and roles. Often this occurs in the context where roles remain ambiguous or where peers are assigned roles which do not align with peer work values (e.g. giving medicine) or which are menial support roles (providing transport) (Clossey et al. 2016).

Another feature of roles and acceptance in peer work is the use of boundaries and personal disclosure, and how well these aspects are understood and performed by peers as well as understood by others in the workplace. Most studies relating to peer support implementation highlighted the need for incumbents and other team members to have a consistent approach and understanding of these as essential skills (Asad & Chreim 2016; Gates, Mandiberg & Akabas 2010; Gillard et al. 2014; Gillard et al. 2013; Moran et al. 2013).

An Australian study by Scholz et al. (2017b) focusses on consumer leaders within organisational hierarchies and found three key issues relating to structure and presence. These were that organisational structure and roles were not well defined in terms of purpose and scope, that organisations lack authentic commitment and support for enabling effective involvement and partnerships, and a lack of acceptance of consumers within existing positions. The authors highlight the glass ceiling aspect, whereby higher-level leadership roles are mostly non-existent. This can contribute to the lack of strong organisational commitment and leadership to address the issues of defining roles, structure and funding (Scholz, Bocking & Happell 2017b). Similar findings regarding lack of organisational structures and role clarity were reported in an earlier Australian study by Stewart et al. (2008), indicating that gaps in training for consumer consultants and representatives compounded issues of role ambiguity and misunderstandings across organisations.

Apart from definition of roles, a key issue around presence relates to numbers of consumer leaders within organisations. Isolation can be a feature of involvement and work roles. Peer support workers can be isolated when they are in low numbers within clinical teams (Moran et al. 2013). Advocates and representatives can also experience isolation in committees, where they are frequently alone or outnumbered by professional perspectives (McDaid 2009). Similar experiences can occur in research settings for advisory meetings (Happell et al. 2018a) and education where single positions are created. In their study on consumer leader power and presence within research Happell et al. (2018a) point to the importance of strategies which encourage critical mass of consumer perspectives for overcoming power imbalances and generating authentic presence and collaboration.

A further aspect of the power and presence of lived experience leaders relates to not having budgets, discretionary spending and financial decision-making authority to support lived experience initiatives. This is reported by participants in Australian studies by Middleton, Stanton and Renouf (2004) and Scholz, Bocking and Happell (2017b).

5.3.6 Access to training and supports

A number of studies contain findings referring to the importance of effective training and support for people in leadership roles (Bennetts, Cross & Bloomer 2011; Dent 2011; Stewart et al. 2008). In their study on advisor and consultant experiences, Stewart et al (2008) found that 30 per cent of participants had not received training for their positions. However, in a more recent study, participant consumer leaders felt that mental health organisations offered productive training which helped to develop leadership skills and capacities. This range of training often included induction programs and workshop programs on areas including governance, meeting facilitation, advocacy and representative roles, peer education, mentoring and co-facilitating educational programs (Scholz, Bocking & Happell 2017a). In another paper focus on consumer representation, Scholz and colleague’s critique the ways representative training can be provided, arguing that training which allocates the representative and consultation functions as a consumer responsibility can be disempowering. Rather the training should be advocacy focused, encouraging consumers to ask what the organisation is doing in its consultation and involvement with consumers and families (Scholz et al. 2019).

In the peer support implementation literature, there were several nuanced issues around the provision and needs for training peers in support roles. Franke, Paton and Gassner et al. (2010) reported that while peers were well prepared with formal vocational qualification in peer support, incumbents starting work in organisations often lacked training in workplace policies, human resources requirements, and specific job responsibilities. Support structures and supervision are required to assist people to settle in and develop their roles. Organisational development in order to provide support and recognition of the peer support roles is essential, including challenging stigma.

Gillard et al. (2014) note in the English context that the availability of support and training to assist role development was uneven, with best practice examples seen in the community service context, compared to the NHS services, where there were more challenges in introducing peer roles to the culture and structures of clinical services. A key area of support required was assisting both peers and non-designated providers to understand the nature of using lived experience and personally defined boundaries rather than professionally defined. In an earlier paper Gillard et al. (2013) highlighted the importance of training and support which helps the peer support worker maintain role fidelity, identity and boundaries, as generic training and supervision can undermine roles defined by the movement's values. These authors also noted that peer support workers who lacked clinical knowledge often found it hard to fully participate in clinical team meetings, which suggested that organisations can reflect on language used in team discussions, as well as peer worker training needs.

Moran et al. (2013) interviewed thirty-one peer support workers in the USA context, and reported that issues regarding organisational pathways, learning and supports were key barriers. This included insufficient skills and knowledge and misalignment between training and the requirements of peer support roles. Peers also reported difficulties of the uneven spread of qualifications across peer workforces.

An Australian study by Byrne et al. (2018b), which explored the views and experience of peers and managers, had significant findings on supervision approaches. In this study, both formal and informal approaches were found effective, with a need to ensure opportunities for debriefing and assisting peers with challenging experiences and dilemmas. Participants reported that supervisors needed to be well grounded in recovery values, have well developed empathy, understanding of peer work roles and values, and a good working knowledge of organisational policy and process. Some participants felt peer-based supervision as essential, given the need to use lived experience effectively. This has also been enabled and valued in organisations which have created peer management positions (Byrne et al. 2019a). Byrne et al. (2018) also noted that successful support is provided in the context of offering reasonable adjustments to work hours and other flexible arrangements to enable self-care (see also Gillard et al. 2014).

Access to training is also discussed in the context of research and teaching work. The development of key standards for Experts by Experience teachers by Horgan et al. (2020) identifies training requirements in using personal stories effectively as well as ways of delivering lectures and tutorials and using libraries to identify teaching resources. Supports identified in the teaching space include, induction and orientation, external supervision by lived experience academics, emotional and practical preparation for teaching, peer-based sharing, shared mentorship between lived experience and clinical based academics, and pre and post session support.

The research orientated literature reports on the need for specific research training and capacity building for lived experience participants to understand the common elements of the research process, i.e. the processes of planning, research questions, recruitment, implementation, analysis, reporting and translation, as well as skills that enable consumer led initiatives (Banfield et al. 2018). As lived experience research has a specific paradigm and values base, Russo (2012) argues that training needs to occur in this context. The UK survey study by Patterson, Trite and Weaver (2014) identified a range of supports which assists lived experience researchers to be successful. These include support and mentoring to navigate university environments, membership of consumer/user research networks, use of peer networks for practical advice and peer review functions, being involved in projects which aligned with peer values and where requirements matched skills and capacity, and flexibility arrangement for managing workloads (Patterson, Trite & Weaver 2014).

5.3.7 Personal impacts

Training and supports are generally seen as critical to the success of roles and to support the wellbeing of people across leadership positions and roles. Gee, McGarty and Banfield (2016) list personal impacts for advocates as being stress, fatigue and uncertainty about the directions and processes of change, high workload requirements, and poor committee practices such as not getting reading material well in advance (see also Middleton, Stanton & Renouf 2004). McDaid (2009) found that consumer leaders in his study could experience committee work as stressful at times, leading to fatigue for advocates and representatives. Some participants reported that policy development was a challenging role and required energy, time and concentration to absorb, process and work with complex information. The study argues that meeting processes require accommodations to support and recognise the needs of emerging leaders in working with information and having successful influence. Emotional supports should also be provided. Involvement should strengthen wellbeing, not generate additional life stresses for people with lived experience.

Among the peer support work literature, personal impacts are varied. Franke, Paton and Gassner (2010) start with the acknowledgement that peers need to balance the demands and challenges of peer support with their own wellbeing needs, within a role that directly connects wellbeing, sharing and positive change. Challenges to wellbeing can occur through issues of boundary setting, being triggered by consumer situations and trauma (Moran et al. 2013), working with consumers in crisis or not ready for recovery (Clossey et al. 2016), or previously mentioned issues on role conflict, identity, acceptance and not being valued by others in the organisation (Clossey et al. 2016; Gillard et al. 2013; Shepardson et al. 2019). High workloads (Clossey et al. 2016) and poor rates of pay (Asad & Chreim 2016; Gillard et al. 2013) can also have negative impacts for peers.

5.3.8 The role of allies in lived experience work

A theme on organisational conditions through the review has been the impact of relationships of recognition and support. The concept of non-lived experience workers as allies to the lived experience movement has been studied within mental health service and research contexts. Happell and Scholz (2018) discuss the role of allies with reference to how the term has emerged within LGBTIQ+ activism and empowerment, where people have supported and recognised the experience and struggles of specific identity groups. An important aspect of an ally is recognising and using privilege and access to resources to assist the advocacy goals of less powerful groups. In their discursive paper, Happell and Scholz (2018) characterise mental health allies as workers and leaders who encourage effective valued involvement and inclusion: 'nothing about us, without us', who encourage consumers and carers to 'tell it as it is', and who acknowledge and respect consumer knowledge. Allyship also involves staying in a non-peer space and not speaking for lived experience. The other quality highlighted is the need to respect diversity of lived experience and encourage participation of advisors whose lived experience aligns with the topics under discussion.

These themes were also found with a small qualitative research project exploring allyship with nine participants (Juntanamalaga et al. 2019). In this study, there was an emphasis on allies as workers with access to decision making and resources which can be used to support advocacy goals for systemic and organisational change. Findings also included a focus on ways in which allies can thwart recognition and progress. These are dynamics where allies do not have a well-developed and principled approach to empowerment, where they have hidden agendas, or where they speak for consumer interests. The authors note that allies can include people working within services and beyond, and can include, social workers, medical practitioners, nurses, occupational therapists, policy makers and politicians (Juntanamalaga et al. 2019).

Byrne, Happell and Reid-Searl (2017) have studied the specific role of mental health nurses as allies, from the perspective of thirteen lived experience participants. The study pointed out the capacity of nurses to be 'natural allies' given the large size of the mental health nursing workforce, the impact of nursing attitudes and culture on involvement and the lived experience workforce. Two key features of allyship are described. One relates to direct action whereby nurses support and create space for consumer advocacy, ensuring inclusion in key meetings and forums. The other feature is in role modelling allyship. This enables other professionals to observe actions and impacts which align with recovery goals and reduce risk averse thinking (Byrne, Happell & Reid-Searl 2017).

The focus on allyship is examined in the mental health research context by Happell et al. (2018b), who interviewed eleven researchers about the role. This study found that allies assist lived experience researchers in multiple ways. These include working to establish and support specific researcher roles in academic settings, corralling resources and funding for projects and guiding navigation of university systems and organisational process for payment, reimbursement and ethics applications. A further key activity was advocating at multiple levels for lived experience research; within the university, at the services level and the policy level. Support can be also provided by a consistent aspiration for co-produced or consumer led research, desiring to increase the opportunities and capacities for projects, and linking consumer researchers with new networks and partnerships so as to avoid isolation (Happell et al. 2018b).

5.4 Enablers for recognition and empowerment at organisational and systems levels

5.4.1 Systems and organisational leadership for valuing peer workforce

The following findings were related to studies which had focused on organisational change strategies for the integration of peer worker roles or those which had identified enablers for recognition through participant interviews. Studies by Mulvale et al. (2019), Gates, Mandiberg and Akabas (2010) and Shepardson et al. (2019) provide the basis for this section as they provide the higher levels of structure and evidence. These studies also offer an organisational wide focus, which identify strategies concerning executive leadership, program administration, staff relationship, workforce development and research/evaluation to be seen within the overall scope of change.

Regarding executive leadership, Mulvale et al. (2019) found that successful implementation of peer support roles occurs where organisational leaders recognise, promote and support peer support as an organisational priority. Adoption and change can then be released through a process of continuous improvement and problem solving across the organisation, which is based on exchange of learning and knowledge across teams and organisations (Mulvale et al. 2019; see also Byrne, Stratford & Davidson 2018). Shepardson et al. (2019) report that diverse stakeholder buy-in and commitment is required, and that this extends beyond organisations with the need to include policy makers on a national level. This is needed to ensure funding and recognition by policy makers and professional bodies. These authors also describe the importance of lifting the visibility of roles, availability, achievements and goals of lived experience workers. One key way of lifting visibility is through good quality evaluation of service data regarding consumer and families experience, peer worker impact and outcome effectiveness (Mulvale et al. 2019; Shepardson et al. 2019). In some settings, visibility and understanding has been assisted by generating community information brochures about peer support work to inform consumers and families, and staff (Gates, Mandiberg & Akabas 2010). A further important commitment is to ensure increased funding for positions in terms of payment and numbers of positions (Shepardson et al. 2019) (see also Clossey et al. 2016).

Executive leaders and organisational managers should base implementation of peer support roles on sound program and administrative planning. Well defined program functions, including objectives, scope, key actions, referral pathways, workflows and feedback loops have been seen as essential developmental processes within teams and across services (Shepardson et al. 2019). Studies have also found that well defined recruitment processes and job descriptions are important for role clarity and selection of skilled incumbents (Gates, Mandiberg & Akabas 2010; Moran et al. 2013; Shepardson et al. 2019). In the process of working up job descriptions and support structures, authors observe that the autonomy and uniqueness of peer support practice should be protected (Shepardson et al. 2019) (see also Gillard et al. 2013). Effective supports for the peer support workforce have been reported to include flexible work arrangements which offer adjustments for self-care needs and support and recognition for preferred self-care practices (Shepardson et al. 2019) (see also Byrne 2019a). Flexible lived experience-based supervision arrangements are also preferred for recognition and role fidelity (Byrne et al 2019a). Administrative supports and appropriate infrastructure, including suitable rates of pay, office space and facilities are essential (Gates, Mandiberg & Akabas 2010; Shepardson et al. 2019).

The organisational change studies above also reported on the need for staff development and education. This included a focus on both peer support workers and non-designated lived experience workers. For incumbents, areas of skill development identified are advanced communication skills (Byrne et al. 2018), the abilities to navigate complex relationships (Gates, Mandiberg & Akabas 2010), and skills to enable the effective use of disclosure, boundaries, stories and consumer perspective (Gates, Mandiberg & Akabas 2010; Moran et al. 2013). Also listed is knowledge development on the policies of services, systems and administration (Franke, Paton & Gassner 2010; Gates, Mandiberg & Akabas 2010). Authors point out the importance of facilitating access to formal peer work certification for quality and consistency of practice (Mulvale et al. 2019) and how confidence and credibility is enhanced through skills development (Clossey et al. 2016).

For non-lived experience workforces, effective strategies include education that challenges stigma and deficit based assumptions about people living with illness (Gates, Mandiberg & Akabas 2010; Mulvale et al. 2019) and which workshops the peer support role so that workers are clear about the unique contribution, practice and directions of peer support (Shepardson et al. 2019). Mulvale et al. (2014) note that organisations should identify and focus on groups of staff that are resistant to change and assist them to recognise and process discomfort. A further approach is to highlight the links between peer support and achieving organisational wide visions of recovery and person-centred care (Mulvale et al. 2019).

5.4.2 Systems and organisational leadership for valuing lived experience

The evidence for improving recognition and effective influence of other consumer leadership positions is identified by qualitative studies on participant views and experiences while operating within mental health services. Authors report that promoting the presence of consumer leaders within organisational hierarchies, and having positional power is an essential strategy for change, and that this should include well defined structures and positions, supported by clear principles and values and authentic commitment (Byrne et al. 2019a; Scholz, Bocking & Happell 2017b). This would enable the contributions, networks and value brought by lived experience leaders to services to be recognised within management hierarchies. Organisations should explore structural ways that leaders can have more influence on financial decision making and contracting (Scholz, Bocking & Happell 2017b), including having control of these functions.

There is also evidence that organisations and the sector should work to carefully develop clear definitions of lived experience leadership, to ensure that definitions are not only limited to particular roles, and that these account for incongruent perceptions around required capacity, perspective (Stewart et al. 2019) and representation of interests and experience (Happell & Roper 2006; Scholz et al. 2019). There is further evidence from the experience of leaders that the role of allies should be promoted for non-designated lived experience actors within mental health organisations and also those operating on systems and sector levels (Byrne, Happell & Reid-Searl 2017; Happell & Scholz 2018; Juntanamalaga et al. 2019). Throughout mental health organisations, recognition and valuing of lived experience leaders is enhanced by good quality committee and communication practices which enable involvement at different levels of the organisation (Middleton, Stanton & Renouf 2004), and proactively address cultural and knowledge barriers which disadvantage lived experience participants (McDaid 2009). As in the above section, staff training in effective lived experience involvement practices, benefits and processes is a strategy for change, one that can be co-produced and delivered by consumer and carer leaders (Bennetts, Cross & Bloomer 2011).

Consumer leaders in Dent's UK study identified that approaches to recovery used by mental health services should be defined by consumer leaders to avoid distortions of meaning, and that recovery groups should be co-facilitated by peer leaders. Strengthening leadership in organisational structures can occur via continued presence of leaders in recruitment of staff, creating more positions within the organisation, and development of a sector wide consumer engagement framework to promote shared commitment and understanding (Dent 2011).

Universities as well as mental health services are important sites for organisational leadership. This occurs in the context of lived experience, Experts by Experience education of mental health professionals and co-produced research activities. As detailed in recent sections, there are a range of essential supports that enable effective involvement and employment of lived experience educators (Horgan et al. 2020), researchers and academics in university-based work (Happell et al. 2018a; Happell & Roper 2009; Happell et al. 2018b). The role of academic allies is prominent in this arena.

6 Discussion

The above findings depict a diverse range of studies and conceptual arguments regarding lived experience leadership and organisational conditions which support or hinder the realisation of changes towards more recovery-based care, or peer-based activity and services. Findings and observations indicate a wide range of qualities, knowledge and skills are required by, or expected of lived experience leaders.

6.1 Concepts of lived experience leadership

The review indicates that lived experience leadership is an emergent and complex concept as it can be defined from different perspectives and positions, contexts, service settings and levels of formal and informal roles. It is also based on concepts of lived experience which can vary, having different ideas and influences that are themselves contested. Stewart et al. (2019) depict some of these complexities and why a definition is yet to be established.

One of the key observations is that lived experience leadership is defined by the movement rather than from a service or professional perspective. This is clear in the paper by O'Hagan (2009) and another by Gordon (2005). It is apparent that leadership identity occurs informally, is driven by personal and collective values, is beyond specific roles within mental health services, yet operates across them. Formally, leadership occurs within a range of roles crafted within consumer and carer organisations, public services, non-government organisations, universities, policy work and systems advocacy. As leadership emerges from peers, it is also an implicit feature in peer support work as recovery leaders (Byrne, Stratford & Davidson 2018). These features of the concept are challenging, but important to clarify as a clear concept assists recognition by the broader community, service managers and funders. Appendix 1 offers a concept map which depicts the contexts of the movement, services and academia, and positions leadership roles as occurring in relationship with these settings, sector leaders and allies.

The concept is also made complex due to definitional issues on carer inclusion. While most of the papers centred on user and consumer leadership, there were some which included carers as study participants and saw consultancy roles and peer support/specialist roles as being undertaking in carer as well as consumer spaces, and thus a part of a broader idea of lived experience leadership. This is an area which needs better clarity and work within research design, so that papers are clear on the areas of carer leadership and do not conflate both identities and sets of interests. There were no specific papers solely focusing on carer leadership as a concept.

A further observation is that the studies did not have a focus on how diversity and intersectionality is understood within peer roles or leadership activity. This was almost entirely absent, beyond the work of defining allyship in the LGBTIQ+ advocacy context, i.e. Gillard et al. (2014), which identified peer support for black and ethnic minorities in England. Additionally, there weren't any eligible papers centred on young people's leadership, older persons mental health, or carer leadership in the children's services arena. There were numerous Australian papers in the review, but the involvement of Aboriginal and Torres Strait Islanders in leadership or engagement practices were not featured. The connection to leadership in suicide prevention work was also missing, which shows a disconnect with research activity and peer led programs such as Alternatives to Suicide (Western Massachusetts Recovery Learning Community 2020).

In the LGBTIQ+ context, Pandya (2014) notes peers have created recognition and service responses by entering the mental health professions, but that there is a less overt connection between LGBTIQ+ movements and mental health advocacy. Local LGBTIQ+ advocates may experience barriers in raising the mental health needs of groups due to the legacy of pathologising diverse sexual orientation and gender identity. However, this is challenged by the observation that peer-based approaches are well known as ways of supporting the wellbeing and mental health of LGBTIQ+ communities. This has occurred with peer-based education for young people (Amodeo et al. 2018), peer phone lines (Almeida et al. 2014) and peer worker training (Willging et al. 2018). It is likely that this range of peer-based activity is yet to be recognised and discussed in the general research on leadership.

In terms of cultural diversity, there have been efforts to describe involvement strategies and projects involving culturally diverse participants, and communities. The literature in this area tends to be at industry level e.g. (Kalathil 2008; Romios, McBride & Mansourian 2007) and often focuses on barriers to involvement and consultation processes. The work by the UK National Survivor User Network identified a range of ways that the user movement could strengthen involvement and leadership of black and minority ethnic communities, building on emerging networks and broadening connections with other representative groups (Kalathil 2008). There are questions about the cultural competency of existing peer support groups (Jonikas et al. 2010) and the need to establish culturally diverse peer support (Gillard et al. 2014). The peer reviewed literature does not feature a connection with Indigenous peoples' health leadership, within the USA, Canadian, New Zealand or Australian context. Other areas of disability are also invisible.

One of the important dimensions of lived experience leadership, which appears more developed in the USA than Australia, is that formal leadership includes positional power as board members, directors and managers as well as staff within services. This occurs in the consumer run organisational sector in the USA, which from literature, numbers over one thousand organisations (Allen, Radke & Parks 2010). This is recognition that leaders create and operate effective peer-based mental health collectives and organisations, including drop in, recovery work, social inclusion and advocacy operations. Such leadership creates opportunities for consumers entering these services to be active in assisting themselves and others. This is another key message to be communicated about the potential and capacity of lived experience leadership, that service responses can be generated from the foundation of the collective experience of recovery (Byrne & Wykes 2020). CROs enable leaders to play a central role in planning, funding and delivering services (Gordon 2005), as well as being an expression of citizenship (Tanenbaum 2011). The understanding of the purpose, dynamics, and relationships surrounding consumer leadership is more developed in the CRO context than it is in public or NGO mental health services. Here, Scholz et al (2017c) concluded: 'The lack of research on consumer leadership in mainstream organisations (relative to CROs) might suggest ongoing reservations about such leadership within traditional settings' (p. 29).

A final observation on concepts of leadership is that reviewed papers rarely make a connection with the sociological literature on social movement leadership, despite lived experience being widely understood as a movement There is likely to be significant value in connecting with literature on embodied health movements, and identity based social movements for the way in which leaders develop networks, engage state representatives, harness academia and seek influence (Brown et al. 2004; Krinsky & Crossley 2014). In this field, there is an understanding that leadership and influence occurs both informally and formally, and that leadership is often distributed across groups and levels of activity. An important role for social movement leaders is connecting with smaller, dispersed constituent groups and engaging people with local influence (Krinsky & Crossley 2014). Within embodied health movements (e.g. Environmental Breast Cancer Movement), Brown et al. (2004), notes that leaders operate in disrupting boundaries between lay and expert knowledges, where lived experience is used to challenge as well as reorientate inadequate scientific perspectives. There is also relevance in the role of leaders in framing public narratives about difficulties, demands, urgency and the vision for change, and how they inspire, mobilise and guide strategic action. Connecting local stories within a wider narrative for change is a key process that leaders enable (Bate, Bevan & Robert 2004). Engaging with this level of analysis would also enable the mental health area to see how other social movements have articulated intersectionality in policy and practice. Campbell (2020) encourages an analysis in the user movement (UK) which highlights how 'bonding' networks can be developed within specific communities, how 'bridging' networks can form across different marginalised communities and how these groups can be 'linked' to allies with access to resources and influence. The author argues that these three levels of networking have not been successfully generated despite ongoing efforts of user activists (Campbell 2020). Local network development has also been considered from the concept of Adaptive Leadership, which offers key principles of empowering local people to undertake action on challenging social issues (Klau & Hufnagel 2016).

6.2 Knowledge and skills and pathways to development

Different studies contributed to being able to identify a range of knowledge and skills that support leaders with lived experience operating in diverse roles and activities. These include knowledge bases for peer support roles, group work, representation and systems advocacy, training and education of professions such as nursing, and managing organisations. Most of these are identified through studies of views and perspectives rather than evaluated learning programs. Collectively they offer an emerging basis to consider content of leadership programs.

While not a strong feature of the literature, it is possible to discern several pathways where people gain knowledge and skills as emerging leaders. This includes people undertaking peer worker education through their own experience of peer-based services and groups, and the motivations and inspiration that comes from transformational recovery and citizenship experiences.

Another pathway comes through the advocacy role and service design area, whereby people become active in joining advocacy training delivered by peer organisations, or where they are recruited within public or NGOs through consumer and carer involvement roles and training. Both pathways operate in Australia through the work of peak consumer and carer bodies and public health services operating under Standard 2 of the National Standards for Quality and Safety (ACSQHC 2020). A theme arising from some of the USA material on consumer organisations, empowerment and training, is the importance in creating training programs as leadership programs, rather than them being named relative to roles that people fulfil such as consumer advocacy, representation or community speaking (Dziadkowiec et al. 2010). A further question is how systems can create career pathways for leaders within public services, seeing the activities in advocacy, education, and peer support work as steppingstones for service and policy leader positions (Grey & O'Hagan 2015). In this regard, there is promising development in the peer support leadership space where organisations are creating team leader and management roles (Byrne et al. 2019a; Fletcher, Barroso & Croft 2020).

One key theme from the literature in this space was in leaders needing to have developed narratives and responses for managing some of the dilemmas and complexities involved in the movement, and in relationships with service providers and the broader community. This points to areas where leadership programs can have a specific focus on clarifying key narratives about inclusion, collective action, diverse advocacy targets and audiences. Understanding the diversity of advocacy targets and interests is a significant issue impacting on the lived experience movement. Consumers have differing views on psychiatric treatment, diagnosis, preferred language around experience, and the inclusion of carers. These are fundamental experiences which shape advocacy aspirations and policy makers must enable space to hear this diversity (Daya, Hamilton & Roper 2019). This is part of an authentic recognition process and needs to be managed by the lived experience movement internally and externally.

A further discussion is recognising that leaders have skills and qualities that are from a broad experiential basis: from recovery, from being in the movement, from engaging as leaders, as well as those from other life, work and study areas. The skills and capacities of leaders are not about being different from the typical person living with distress, which itself is a stereotypical assumption, but that lived experience leaders are part of a social movement, with a collective perspective on recovery and citizenship, and at times, a critical perspective on medicalised responses to distress.

6.3 Organisational conditions supporting leadership in mental health services.

Studies informing the third research question revealed a range of key organisational issues affecting the experience and performance of lived experience leaders operating in mental health services. Overall, the barriers of stigma, issues with acceptance and valuing, isolation, lack of suitable training and supports, role confusion and disempowering structures and inappropriate pay rates were commonly reported by studies. These were clearly detailed in many studies of peer support worker implementation, as well generalised studies of leadership within service decision making, and research activities. Systematic reviews on peer worker implementation consolidate our knowledge that these barriers are common in the context of clinical settings (Vandewalle et al. 2016; Walker 2013). Similarly, reviews on consumer involvement in health point to barriers surrounding cultures of inclusion, sound committee practice and accountability in health service decision making (Sarrami Foroushani et al. 2012). Themes of stigma and acceptance, questions over representativeness, role uncertainty, and professional defensiveness also occur within lived experience led education (Happell et al. 2014).

Numerous studies identified organisational strategies that support recognition of leaders and peer informed programs and services. These can be seen within a systems and organisational context as sites or opportunities for influence and change and call on the commitment of executive leaders and allies. These can be considered in four categories:

Organisational leadership

- Making the development of the lived experience leadership, planning and peer work delivery an organisational priority and adopting a change management process;
- Ensuring proactive recognition, promotion and commitment from executive leaders on lived experience leadership, values and autonomy;
- Ensuring buy in and commitment from range of organisational and national level stakeholders;
- Lifting visibility of roles, availability, achievements and goals of lived experience workers and leaders;
- Promoting presence of consumer leaders within organisational hierarchies via management positions;
- Enabling leaders to have access to financial decision making and contracting; and

- Recognising the external networks and culture that leaders bring to services and supporting these.

Roles, programs and administration

- Appropriately funded roles and infrastructure, including rates of pay, office space and facilities; and
- Developing well defined programs on peer support work and consumer leadership/involvement, which cover recruitment, objectives, scope of roles, key actions position descriptions, referral pathways, workflows, supervision, support and self-care options.

Culture and training

- Promoting the role of allies and champions within teams, organisations and sectors;
- Ensuring education programs which challenge stigma and deficit assumptions within organisations;
- Identifying and engaging resistant groups – helping to create narratives which overcome defensiveness and promote collaboration; and
- Integrating the benefits of leadership through narratives of recovery and person-centred service responses.

Knowledge and research

- Facilitating shared learning and knowledge exchange within organisations and sectors;
- Ensuring service data and consumer experience enables evaluation of peer/leader impact and outcome effectiveness; and
- Strengthening the presence of lived experience researchers and activity across academic, service and community contexts.

Organisational commitment and leadership are commonly seen as the foundation for change, whereby many of the strategies indicated above can be facilitated and funded. In this regard, Cleary et al. (2016) argue that recovery transformation within public services requires shared vision and collaborative action by clinical leaders, lived experience leaders and academics (see also Byrne, Happell & Reid-Searl 2017). They call on mental health nurses as a key ally in the transformation, ensuring both top down and bottom up approach, within services and within teaching and academia. Nurses can also promote recovery perspectives to the wider community. Organisational commitment and leadership are commonly seen as foundation for change, whereby many of the strategies indicated above can be facilitated and funded. In this regard, Cleary et al. (2016) argue that recovery transformation within public services requires shared vision and collaborative activity by clinical leaders, lived experience leaders and academics (see also Byrne, Happell & Reid-Searl 2017). They call on mental health nurses as a key ally in the transformation, ensuring both top down and bottom up approach, within services and within teaching and academia. Nurses can also promote recovery perspectives to the wider community.

6.3.1 Enabling leadership at the systems level

Grey and O'Hagan (2015) make the point that the commitment of allyship should not be limited to service level leaders but also funders, policy makers and organisations supporting standalone lived experience initiatives. They also point out, as found in this review, that different structural contexts need consideration, including change processes within statutory public mental health services, existing non-government services, and CROs. Strategic consideration needs to be given across multiple service areas, including both the transformation of public mental health services as well as generating new streams of funding for consumer run initiatives and alternatives. This can occur via a broad perspective which acknowledges that peer leaders working within clinically orientated services require significant energy and leadership support in overcoming barriers compared to those operating under peer philosophies (Gillard et al. 2013).

Legislative provisions are a key structural influence which establishes authority in public and non-government mental health services. One of the observations of the USA context is that legislation can be used to identify services and the requirements for funding. An example is the recent naming of peer provider funding in the *Substance Use-Disorder Prevention that Promotes Opioid Recovery and Treatment for Patients and Communities Act* (US Government 2018). This Act provides for peer support enhancement and evaluation, promotes Medicaid insurance coverage for peer support workers, and identifies peer services within the Communities of Recovery Program. It also names the role of centres of training and technical support. The federal Substance Abuse and Mental Health Services Administration (SAMHSA) is subsequently administering funding for these programs.

A further possibility for leadership and commitment is to fund state-wide, peak organisations. These organisations were evident across the context of several studies. SAMHSA has a long established funding stream for state-wide consumer networks. The role of these networks appears to be variable across states, but plays key functions in representation, organisation and partnerships, including liaison with state planning councils on policy decisions. In some states, the networks have a commissioning function to fund consumer run services, and also have direct reach with communities through information provision, use of web-based resources and promoting self-help approaches (Miller & Moore 2009). The role of state-wide lead organisations, including lived experience peak bodies, provides independence and recognition of consumer voice in ways that connect diverse local groups and create opportunities for national level advocacy (Fisher & Spiro 2010).

6.4 Research and knowledge mapping

As a scoping review, there are several observations to make about the research within the selected papers, and how this literature engages with research about outcomes of work led or delivered by lived experience leaders. There was a distinct grouping of types of research, as noted in Appendix 2. The first of these were mainly Australian qualitative studies focusing on the aspirational and experiential views of lived experience participants, consultants, advocates and managers about leadership and involvement within the mental health sector. This group of papers identifies key barriers, benefits and other organisational conditions enabling and hindering the roles established to promote change within existing organisations. As this field is about aspirations, meaning and identifying important experiences, qualitative approaches for research were appropriate. An opportunity exists to undertake a narrower, qualitative synthesis on these studies.

Another group of papers were qualitative studies on the experience of peer support workers and managers regarding the implementation of the role. These studies again were based on views, experiences and evaluations of individuals working in the sector and identified key barriers and enablers. We are aware a significant number of papers exist in the literature with this focus and there is a qualitative synthesis on key barriers (Vandewalle et al. 2016), as well as other reviews which include a focus on implementation as well as outcomes of the roles for consumers (Miyamoto & Sono 2012; Walker 2013). Further work in this area is needed on evaluating organisational change strategies to improve acceptance, and educational approaches which help non-lived experience staff to overcome defensive responses.

The papers describing consumer leadership in research and education reflect another body of literature, which has a reasonable level of development. There are a number of systematic reviews focusing on the outcomes for health student learning from lived experience education (Arblaster, Mackenzie & Willis 2015; Happell et al. 2014; Perry et al. 2013). These show promising areas of learning, but there is a need to update given teaching research in recent years. There is a need for a specific review on the outcomes of consumer or carer led research which has grown in recent years.

A further group of papers were descriptive studies on leadership structures, characteristics and participants of CROs. And from this another group of quantitative studies seeking to measure impacts on personal and social empowerment over time. These were the most developed projects, and showed promising empowerment-based outcomes from people's participation and social interaction within CROs. One of the key challenges in this field is showing a beneficial connection between leadership, involvement or co-production with recovery-based outcomes for participants. The studies on CROs attempt to do this, and use a paradigm of empowerment and recovery, rather than traditional symptom reduction outcomes. This is an important point in the evaluation of lived experience initiatives, as study paradigms and methods need to understand how peer support generates individualised outcomes, which are difficult to measure in standardised ways (Grey & O'Hagan 2015). The tailored approach to evaluation in the UK Hearing Voices Networks (Longden, Read & Dillon 2018; Oakland & Berry 2015), is an example of how research can identify effectiveness in terms of aims, outcomes and processes which reflect the values guiding consumer/user run initiatives.

While it hasn't been the focus of this review, there is a significant array of promising yet lower quality research about the outcomes of CROs for recovery (Grey & O'Hagan 2015; SAMHSA 2011). There appears to be only one well developed controlled trial on these outcomes, which was called the Consumer Operated Services Programs Multisite Research Initiative (Rogers et al. 2007). This study depicts the sophistication required to measure wellbeing and empowerment where participants are accessing CROs alone or as an adjunct to care from clinical services.

The peer support worker evidence base has further developed, as there have been numerous RCT level studies involving the mental health outcomes of consumer's accessing peer specific programs in mental health services or clinical teams where peer support is integrated in the service. There have been four systematic reviews on these outcomes according to Bellamy, Schmutte & Davidson 2017. The recently published update by Bellamy, Schmutte and Davidson (2017) reports that the levels of evidence vary, but there is positive evidence that peer support services achieve the same outcomes as clinically based care in reducing symptom severity and hospital admission rates. In assessing recent studies, they indicate that peer support services may have better outcomes on levels of hope, quality of life and empowerment. One reflection from this review is that the issues around role clarity, support and acceptance of peer support workers in public services may impact on performance and quality of outcomes. Has the wide prevalence of these issues hindered the potential of peer support and outcomes for consumers using public mental health services?

A similar question can be asked about the outcomes from the involvement of consumers and carers in decision making and planning forums of mental health services and programs. While there are mixed experiences around inclusion and recognition, and issues around acceptance, token involvement and lack of authentic support, there are questions about whether coproduced services can realistically occur. There is a need for research which documents the links between good quality partnerships/co-production, innovative service programs, and their outcomes. This is a challenging research quest, as a range of descriptive, evaluative and outcome study designs are needed. There are examples of outcome evaluation of co-produced services, but robust studies in this area are only just emerging. An example is by Pocobello et al. (2020) who compared a co-produced mental health centre with traditional day centres in a cross-sectional study to measure hospitalisation rates and use of psychotropic medicines. While using quantitative measures for these aspects, qualitative focus group interviews were also used to identify consumer experiences and perspectives about using the centre. A review on leadership and co-production outcomes would benefit the sector.

7 Limitations

The nature of the leadership concept within the lived experience space has played out in various ways to shape the design of the review, decisions on eligibility criteria of papers and understanding of findings. There were several definitional challenges and overlaps between the concepts of leadership and involvement which meant there was ongoing ambiguity in identifying the distinct elements of lived experience leadership, and the description of study participants as leaders. It also meant careful consideration of each paper, ensuring that papers were chosen which focused on the higher levels of consumer and carer involvement, where leadership was likely to be better recognised as such.

A key limitation in undertaking a single search across diverse pockets of research is that there are limits to the number of papers in each field that may have been reached by the search. Each of peer work, lived experience research, academic education and consumer involvement have their own narrower specialist fields of literature. There will be papers that we haven't identified due to the search design and resources needed for handsearching. This has been a limitation in order to meet the overall aim of understanding leadership as occurring across roles and fields and identifying common as well as diverse aspects of identity, conditions and supports which enable recognition and change across systems. This limitation is also seen methodologically in many of the included studies, where participants are operating in diverse settings and roles, but defined as being suitable for study inclusion as they are seen as leaders.

A further consideration is that the review has been centred on mental health lived experience leadership in the sector. There are external bodies of knowledge about and from other social movements, advocacy, diversity and leadership, transformation and organisational change which are relevant to this area and to which the mental health lived experience movement should engage with.

8 Conclusion

This review has explored the concept of lived experience leadership in the context of common activities and roles, and the organisational condition and expectations which support consumers and carers to seek change in the design of services and share a vision of recovery and inclusion with others. It has found that lived experience leadership is an emergent and complex concept, given the different settings where leadership is expressed, or facilitated, and the diverse methods and goals for action. The review indicates that lived experience leadership is best understood in the context of consumer experience, recovery and empowerment, with research showing the key meanings of peer-based leadership are enacted in CROs where leaders can express the values of the movement. Leadership has its basis in informal and formal spaces of peer networks as well as in various roles that are created in consumer run initiatives and in mental health services.

To be successful in these roles, people need a range of general and specific skill sets, and a significant knowledge base about mental health and illness, diversity, peer support, education, psychiatry, empowerment and advocacy. Leaders need skills to engage with change processes on relational, organisational and system levels in ways that clinical leaders may not have to consider, given the various barriers and forms of othering that active consumers and carers may experience.

In mental health services and the policy sector, leadership experience and success are shaped by various expectations, the support of allies and organisational leaders, and the provision of funding. It also requires well defined positions, relationships and supports. Authentic recognition and commitment by sector and service leaders is required to transform a range of common barriers which hinder existing positions, as well as create pathways for improved structural leadership and service management. This is required in peer support work programs as well as in co-production and service decision making. Similar requirements are evident for leadership within the academic settings of research and teaching,

An important aspect of lived experience leadership is shaping narratives about change, recovery, and membership. Leaders need to articulate and guide efforts toward collective recognition, advocacy goals and autonomy, and have effective responses to the tensions and dilemmas of the movement. Leaders also need to influence relationships with the professions and policy makers.

On the larger systems level, many of these themes apply. Recognition on the systems level is about seeing leadership in terms of systems advocacy, community education, promoting empowerment and citizenship, and seeking to shift understandings about the management, planning and delivery of services. Key goals are about seeking preferred service responses and peer-based alternatives. Key actions are about making this happen.

One of the main challenges for the lived experience movement in mental health is to consider how it understands and is inclusive of intersectionality. The literature in the area does not reflect diverse experiences and identities and how peer leadership, allyship and support in LGBTIQ+, CALD and Indigenous communities are also focused on mental health and responses to distress and/or injustice.

The research basis of lived experience is emerging, and the evidence is limited due to the nature of studies that have occurred in the area. The research base includes pockets of research across the lived experience workforce, local service advocacy, consultancy, research, education and peer support. The strongest research base is focused on CROs and leadership in the USA and Canadian contexts. Having a system focus enables reconsideration of how the learning and successes of lived experience leadership can reorientate mental health ecosystems. This is the promise of conceiving, directing, delivering and evaluating a system of service responses which are centred in lived experience principles and values.

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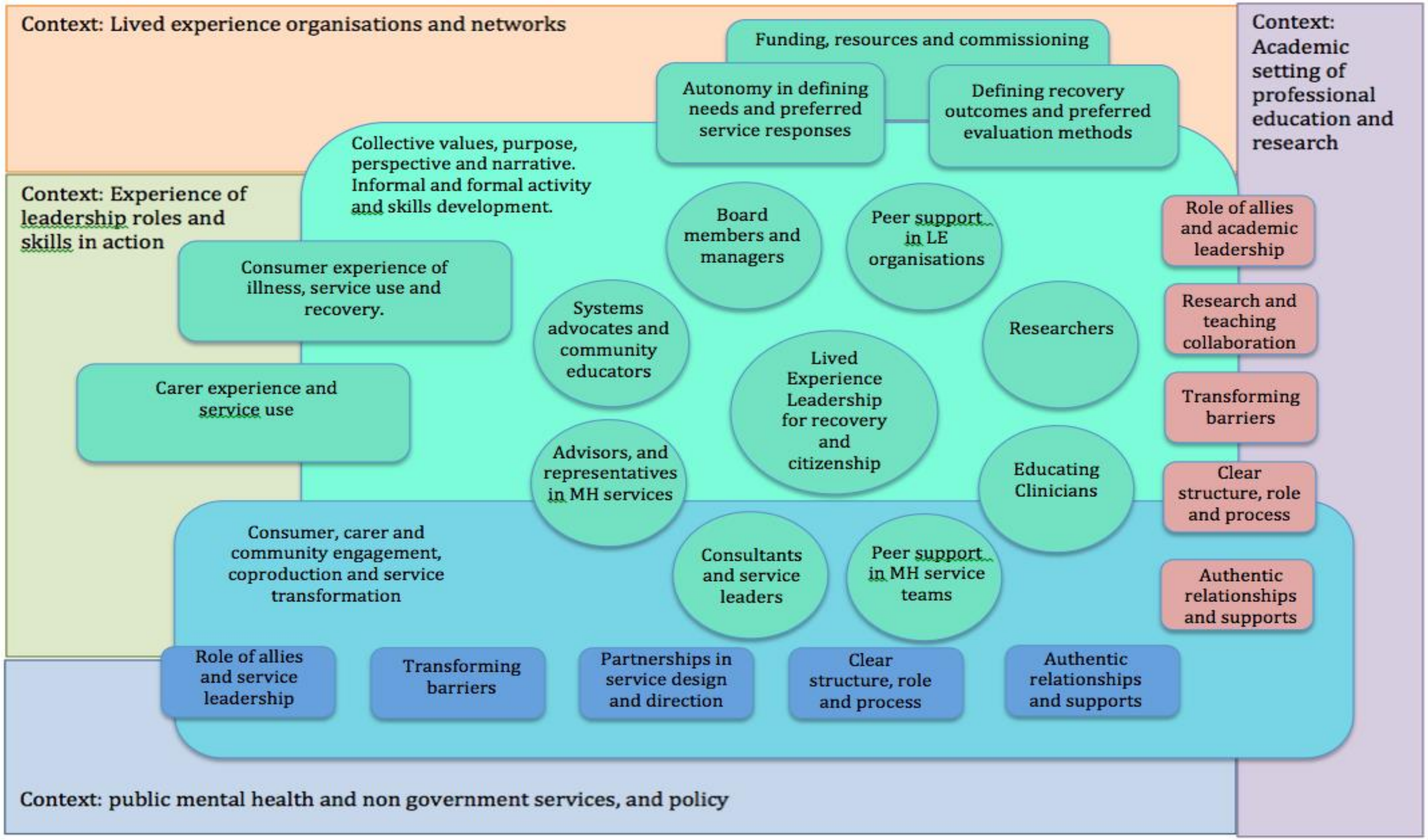
Appendix 1: Concept map of lived experience leadership: role, skills and organisational experience



Appendix 2: Focus of research methods and knowledge about lived experience leadership

Research focus	Study designs and JBI meaningfulness level	Included studies
Lived experience leadership roles, positions and organisational conditions	Descriptive, reflective or discursive papers on service level roles (JBI level 5 meaningfulness)	Cleary, Walter and Escott (2006); Gordon (2005); Happell and Roper (2006); Happell and Scholz (2018); O'Hagan (2009); Stratford et al. (2019)
	Descriptive, reflective or discursive papers academic level roles (JBI level 5 meaningfulness)	Banfield et al. (2018); Happell and Roper (2009); Patterson, Trite and Weaver (2014); Russo (2012)
	Qualitative studies of views of lived experience leaders, advocates and consultants and/ or managers	Barkway et al. (2012); Bennetts, Cross and Bloomer (2011); Bennetts et al. (2013); Byrne, Happell and Reid-Searl (2017); Byrne et al. (2019b); Gee, McGarty and Banfield (2015); Gee, McGarty and Banfield (2016); Juntanamalaga et al. (2019); McDaid (2009); Piat, Sabetti and Padgett (2018); Scholz, Bocking and Happell (2017a); Scholz, Bocking and Happell (2017b); Scholz, Bocking and Happell (2018); Scholz et al. (2019); Stewart et al. (2019); Stewart et al. (2008)
	Qualitative studies of views of peer support leaders and/or managers	Asad and Chreim (2016); Byrne et al. (2018b); Byrne et al. (2019a); Clossey et al. (2016); (Gillard et al. 2014); Gillard et al. (2013a); Hurley et al. (2018); Moran et al. (2013); Shepardson et al. (2019)
	Qualitative studies of views in academic contexts (JBI level 3 meaningfulness)	Bocking et al. (2019); Happell et al. (2019); Happell et al. (2018a); Happell et al. (2018b); Horgan et al. (2020)
	Qualitative/ mixed-methods on peer support work role implementation (JBI level 3 meaningfulness, level 4 effectiveness)	Gates, Mandiberg and Akabas (2010); Mulvale et al. (2019)
	Evaluation level reports on consumer leaders, consultants and advocates (JBI level 5 meaningfulness)	Dent (2011); Franke, Paton and Gassner (2010); Middleton, Stanton and Renouf (2004); O'Hagan (2009)

Research focus	Study designs and JBI meaningfulness level	Included studies
Lived experience qualities, knowledge and skills	Project descriptions and discursive papers (JBI level 5 meaningfulness)	Nelson et al. (2008); Newton et al. (2013); O'Hagan (2009); Stringfellow and Muscari (2003)
	Qualitative projects exploring experience, skills and use of narratives. Ethnographic or Participatory Action Research designs (JBI level 3 meaningfulness)	Felton (2005); Fieldhouse et al. (2017); Rose et al. (2016)
	Training or project evaluations (JBI level 5 meaningfulness)	Franke, Paton and Gassner (2010)
Consumer run organisations	Descriptive studies on organisational structures, including leadership characteristics (JBI level 4 effectiveness)	Brown et al. (2007); Mowbray, Robinson and Holter (2002); Ostrow and Hayes (2015); Tanenbaum (2011); Wituk et al. (2008)
	Mixed-methods studies on organisation leadership roles (JBI level 3 e, 4 effectiveness)	Janzen et al. (2006)
	Descriptive studies on benefits and changes through participation in social and leadership levels (JBI level 4 effectiveness)	Brown (2009a)
	Qualitative studies on benefits and changes through participation in social and leadership levels (JBI level 3 meaningfulness)	Brown (2009b); Ochocka et al. (2006)
	Quantitative studies – within subjects and on empowerment and recovery type outcomes from participation levels (JBI level 3 e, effectiveness)	Brown et al. (2008); Brown and Townley (2015); Segal, Silverman and Temkin (2013)

Appendix 3: Search strategy

#	Searches	Results
1	Patients/	20293
2	Caregivers/	34464
3	(consumer* or mental health consumer or prosumer* or client* or patient* or carer or caregiver or advocate or service user).ab,ti. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	6561610
4	1 or 2 or 3	6580376
5	"Power (Psychology)"/	12564
6	Capacity Building/	2341
7	Consumer Advocacy/	3349
8	Consultants/	6636
9	Leadership/	39898
10	Patient Participation/	24824
11	Intersectoral Collaboration/	1699
12	Consumer Organizations/	1257
13	Community Participation/ [Psych]	16745
14	Mentors/	10450
15	Mentoring/	1375

16	Preceptorship/	4979
17	(empower* or build* capacity or capacity build* or consumer advocacy or consultant or consumer consultant or leader* or patient participation or consumer participation or collaboration or lived experience or leadership or consumer leader* or consumer representation or consumer involvement or consumer movement or ally or management or advocacy or community leader* or peer leader* or health consumer leader* or consumer organization or community participation or mentor* or preceptor* or support).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	10529813
18	5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17	10537888
19	Mental Health Services/	32673
20	Community Mental Health Services/	18317
21	Emergency Services, Psychiatric/	2411
22	Social Work/	15016
23	Social Work, Psychiatric/	2679
24	Mental Health/	35749
25	(mental health service* or community mental health service* or emergency service* or social work or mental health).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	267506
26	19 or 20 or 21 or 22 or 23 or 24 or 25	267506
27	4 and 18 and 26	53921
28	Social Change/	16816

29	Policy Making/	15964
30	Public Policy/	31009
31	Health Policy/	64437
32	(social change or social power or social movement or policy mak* or public policy or health policy).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	159514
33	28 or 29 or 30 or 31 or 32	159514
34	27 and 33	1399

Appendix 4: Data chart of selected papers

Citation	Study design	Setting	Participants	Data & analysis	Relevant findings
Asad, S & Chreim, S 2016, 'Peer support providers' role experiences on interprofessional mental health care teams: A qualitative study', *Community Mental Health Journal*, vol. 52, no. 7, pp. 767-74.	Qualitative	Canada: Peer work boundaries and integration in assertive community treatment team and a non-standard team	n=12 participants peer support workers	Semi- structured interviews and qualitative coding and analysis	Key findings • Relationships with others: Theme of acceptance – gradually building with professionals – not understood, clients not understanding • Peer workers had to educate themselves, learning to manage disclosure about themselves and clients to clinicians. Workers also need to learn to • build relationships by setting boundaries which reflects the unique engagement that peer support work offers. Role ambiguity includes positives and negative implications. Remuneration issues (low payments) are experienced.
Banfield, M, Randall, R, O'Brien, M, Hope, S, Gulliver, A, Forbes, O, Morse, AR & Griffiths, K 2018, 'Lived experience researchers partnering with consumers and carers to improve mental health research: Reflections from an Australian initiative', *International Journal of Mental Health Nursing*,	Reflective paper	ACT, Aust: Describes work of ACACIA: The ACT Consumer and Carer Mental Health Research Unit	N/A	N/A	ACACIA enables consumers and carers in the ACT to take an active role in relevant, high-quality mental health research. ACACIA has five primary objectives: 1) consumer and carer involvement in setting the research agenda; 2) consumer and carer involvement in developing effective involvement methods; 3) research training and capacity-building for consumer- and carer-led research; 4) lived experience research dissemination; and 5) using the results of the first four objectives to influence ACT policy and practice. Describes the process for ACACIA's Consumer and Carer Advisory Group and a research priority-setting forum.

vol. 27, no. 4, pp. 1219-29. (LE[2])					Developing methods for involvement. consumers and carers provide input into specific methods for their meaningful involvement in the research process Key strategies of engagement include: - Work with community orgs already undertaking research- increase recognition; - Conduct skill-building workshops to facilitate greater involvement of consumers and carers in the research process; - Focus on specific tasks to which consumers and carers can easily contribute; and - Recruit and engage participants in ways that work best for them.
Barkway, P, Mosel, K, Simpson, A, Oster, C & Muir-Cochrane, E 2012, 'Consumer and carer consultants in mental health: The formation of their role identity', *Advances in Mental Health,* vol. 10, no. 2, pp. 157-168.	Qualitative interviews	South Australia: Metropolitan mental health service	n=5 (3 consumer and 2 carer consultants)	Individual semi-structured interviews (13 prompt questions)	The findings are focused on the ways in which the respondents formed their identity in relation to the consumer or carer consultant role. 4 Themes: - identified role motivation: passion to seek change and shared learning from recovery; - role preparation; learning skills and knowledge; - role practice/focus; and

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[2] Papers with known lived experience authorship are signified by (LE) after the citation

					- role ambiguity/conflict, in relationship with other team members.
Basset, T, Newton, A, Beales, A & Collins, DA, 2013. ‘Service user leadership: training and development for service users to take the lead’, *The Journal of Mental Health Training, Education and Practice,* vol. 8, No. 3, pp.134-140. (LE)	Descriptive paper	UK: This paper outlines the concept of service user leadership and both describes and reflects on an accredited training program.	N/A	Describes evaluation data from training program: “Voices Together: service user leadership and peer support”	The programme is comprised of 12 training days that focus on a broad range of themes and topics, from equality and diversity to stigma and discrimination, self-esteem and confidence to emotional literacy, meeting skills to presentations and the service user movement. The doors that the training has opened to participants are numerous, with people: speaking at AGMs, Universities, conferences, county council meetings; taking on leadership roles, in relation to the service they attend, becoming co-facilitators on subsequent training programmes; taking on the role of chair, treasurer or becoming a member of the board in both national and local voluntary organisations; completing other training courses; changing jobs to something more suitable and rewarding; lobbying, campaigning and advocating; and taking on voluntary work.
Bennetts, W, Cross, W & Bloomer, M 2011, 'Understanding consumer participation in mental health: Issues of power and change', *International Journal of Mental Health Nursing,* vol. 20, no. 3, pp. 155-164. (LE)	Qualitative study	Victoria, Australia: Several mental health services	n=7 Managers	Individual semi-structured interviews and thematic analysis	Two major themes: ‘change’ and ‘power’. All participants implied that consumer consultants were somehow different to other consumers of services, who managers in this project saw overwhelmingly as not identifying with consumer participation, a view that most likely contradicts how consumer consultants see themselves. The study also found that service providers did not believe that consumer consultants were representative of consumers of service generally. The participants identified nurses and psychiatrists as those with the most negative attitudes towards consumer participation. Training and education emerged as a theme

					and seemed to be recognised as an appropriate place for consumer participation, a view consistent with other literature.
Bennetts, W, Pinches, A, Paluch, T & Fossey, E 2013, 'Real lives, real jobs: Sustaining consumer perspective work in the mental health sector', *Advances in Mental Health,* vol. 11, no. 3, pp. 313-326. (LE)	Qualitative and thematic analysis (by consumer reference group)	Victoria, Australia: Members of Victoria Mental Illness Awareness Council	n=24 consumer workers	Focus groups or in-depth interviews	That consumer perspective work was viewed as enriching, challenging, and enables individuals to contribute their expertise by experience to a broader movement and cause, but educational and peer supervision options were limited and underdeveloped.
Bocking, J, Happell, B, Scholz, B, Horgan, A, Goodwin, J, Lahti, M, Platania-Phung, C, MacGabhann, L, Greaney, S, Granerud, A, Griffin, M, Russell, S, Bjornsson, E, van der Vaart, KJ, Ellilä, H, Hals, E, Doody, R, Vatula, A, Pulli, J, Manning, F, Allon, J & Biering, P 2019, 'It is meant to be heart rather than	Qualitative	Iceland, Ireland (2 sites), Norway, Finland, the Netherlands and Australia. Mental Health Nursing Education sites as part of the COMMUNE project	n=9 experts by experience (teachers)	Semi-structured interviews Thematic analysis using Braun and Clarkes approach, Critical Social Theory	Theme one: there wasn't a barrier. The first reported how the EbEs[3] unique approach of using personal narratives in their teaching resulted in increased relational learning between EbEs and nursing students EbEs reported to develop a classroom environment that was authentic and allowed for discussions on power imbalances to be facilitated. EbE teaching appeared to add an emancipatory element to mental health nursing education and provided opportunity for students to develop a broader critical consciousness than available through traditional methods alone. Theme two: made the human being visible

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[3] EbEs = Expert by experience

head'; International perspectives of teaching from lived experience in mental health nursing programs', *International Journal of Mental Health Nursing*, vol. 28, no. 6, pp. 1288-95. (LE)					EbEs reported that the use of personal narratives in their teaching offered both an unheard perspective and contextual information. Use of story provided details on the lead up to seeking mental health treatment, the personal impact of that treatment, and the multifaceted recovery process beyond hospital admission , a more complete picture of an individual as opposed to a diagnostic category often used to describe people in the mental health system. The scope of the EbE teaching included the various socio-political factors of their distress (e.g. poverty, racism, isolation, abuse). Also benefits in teaching recovery and stigma experiences.
Brown, LD 2009, 'How people can benefit from mental health consumer-run organisations', *American Journal of Community Psychology*, vol. 43, no. 3-4, pp. 177-188.	Descriptive survey	USA: Explored how CROs engage consumers in meaningful roles and build social networks	n=194 consumer participants from 20 CROs	Descriptive survey and coding analysis	Data analysis led to the identification of 18 personal change categories and 7 experiences that led to change. Top 5 personal change categories: • Self-esteem—feeling more valued, more confident, more pride; • Social skills—relationship skills, such as listening or communication; • Increased activity—becoming more active, spending less time at home; • Coping and problem solving—averting crises and reducing stress; an • Outgoing—increased interest in and enjoyment of social interactions Conceptualisation of change where individuals' characteristics of CRO participants interact with the organisational context to determine the course of role and relationship development. Changes occurs on different

					levels via development of friendship and leadership roles. Both are helper roles. CRO participants can obtain a variety of benefits when such helper roles are established e.g. emotional and information resources, positive self-appraisal. Through practice, CRO participants can meet their friendship and leadership role expectations. Coping skills, social skills, and job skills develop, thereby enabling a mastery of role expectations. With new roles and accompanying skills established, people experience identity transformations and alter their self-descriptions. They may begin to see themselves as more independent, outgoing, and conscientious.
Brown, LD 2009, 'Making it sane: Using narrative to explore theory in a mental health consumer-run organisation', *Qualitative Health Research,* vol. 19, no. 2, pp. 243-257.	Narrative study – life histories	USA: Conceptual framework for understanding benefits of participation in CROs	n=7 consumer participants	Participant observation and qualitative interviews, narrative analysis	Through participation in a welcoming setting, informants developed friendship and leadership roles. In these helper roles, participants exchanged social sup- port and contributed to organisational functioning. Success in meeting helper role expectations enabled the attainment of positive appraisals from both self and others. These positive appraisals promoted emotional well-being and self-esteem. However, informants often had to build new skills to be successful. The challenges and triumphs of these new roles frequently led to identity transformations such as an increased sense of independence. No longer trapped in dependency roles, participants began “making it sane” as independent citizens valued by others.
Brown, LD, Shepherd, MD, Merkle, EC, Wituk, SA & Meissen, G 2008, 'Understanding how participation in a consumer-run	Quantitative	Kansas, USA: Explores benefits from participation in terms of social	n=250 CRO participants of 20 CROs	Variety of 5 modified empower-ment scales to measure change in mutual learning, intimacy and sharing	An empowering participation experience refers to involvement in leadership roles and contribution to organisational functioning. A socially supportive participation experience refers to social involvement in mutually supportive friendships with intimacy and sharing. Results indicate that both types of participation are

organisation relates to recovery', *American Journal of Community Psychology,* vol. 42, no. 1-2, pp. 167-178.		relationships and empowerment in terms of leadership and organisational roles		and consumer satisfaction,	associated with recovery, although a socially supportive participation experience maintains a stronger relationship with recovery than an empowering participation experience. Findings are consistent with the idea that CROs should encourage both types of participation. The study discusses organisational strategies commonly used by CROs to engage participants in organisational activities and leadership and promote empowering environment: basic volunteering opportunities; organisational decision making; planning and organising activities; formal leadership positions; prevent and resolve conflict with a code of conduct; recognise member accomplishments; organise a variety of interesting activities; develop self-help groups and/or peer counsellors.
Brown, LD, Shepherd, MD, Wituk, SA & Meissen, G 2007, 'How settings change people: Applying behavior setting theory to consumer-run organisations', *Journal of Community Psychology,* vol. 35, no. 3, pp. 399-416.	Mixed-methods: document analysis, organisational characteristics survey, questionaries for individual consumers	USA: Explores benefits of CROs for people participating	n=250 consumer participants, n=20 CROs	Scale: Consumer satisfaction survey MHSIP Document analysis. Correlation matrix and analysis of study variables	Results suggest that as CROs become larger, there is a decline in the percentage of members contributing to organisational planning and management. According to behaviour setting theory, this is because it becomes increasingly competitive to get involved in these leadership roles How does participation lead to member benefit: it does not appear that participation in a leadership role is the primary force contributing to member benefit. Instead, it may be the benefits derived from the formation of mutually supportive relationships that are most important.
Brown, LD & Townley, G 2015, 'Determinants of engagement in mental health consumer-run	Quantitative: mixed scales	Kansas, USA: Explores the individuals and organisational	n=250 consumer participant respondents across 20 CROs	Scales: CRO engagement used Group Environment Scale.	Study outcomes show that perceived sense of community was the only characteristic that predicted attendance as well as leadership involvement and socially supportive involvement. Perceived organisational empowerment, shared leadership, peer counselling, and several

organisations', *Psychiatric Services,* vol. 66, no. 4, pp. 411-417.		characteristics which indicate three types of engagement in CROs—attendance, leadership involvement, and socially supportive involvement		Used multivariate, regression analysis	demographic characteristics also predicted some measures of engagement.
Byrne, L, Happell, B & Reid-Searl, K 2017, 'Risky business: Lived experience mental health practice, nurses as potential allies', *International Journal of Mental Health Nursing,* vol. 26, no. 3, pp. 285-292. (LE)	Qualitative	Australia: Involved lived experience paid workforce from variety of roles and positions	n=13 lived experience practitioners	Semi-structured individual interviews	Findings: Size of nursing workforce positions them as natural key allies. Nurses as allies can be instrumental at two levels. Firstly, providing support to LEP, valuing and promoting the contribution they make, advocating for their voice to be heard and ensuring they are included in key meetings and activities. Secondly, nurses can role model effective working relationships with LEP and provide advice to other health professionals about how risks have been reduced or overcome.
Byrne, L, Roennfeldt, H, Wang, Y & O'Shea, P 2019a, 'You don't know what you don't know': The essential role of management exposure, understanding and commitment in peer workforce	Qualitative	Queensland, Australia	n=29 participants from a range of organisations n=16 in non-government n= 13 in public health services. n= 19 non-designated peer	24 in-depth, semi-structured interviews and One focus group. Analysis via ground method approach	Findings of this study: management exposure to and understanding of peer work are essential to the development of an effective peer workforce.; leads to greater acceptance and commitment from management. Themes include the role of championing and acceptance within organisational culture including designated 'peer management' positions. Development of peer management positions is suggested as an effective means of improving the impact of peer perspectives, advocating for peer work

development', *International Journal of Mental Health Nursing*, vol. 28, no. 2, pp. 572-81. (LE)			positions n= 8 in peer positions n=2 in carer positions		and providing ongoing and timely supervision. Management staff require training and information on the unique function, purpose and value of peer roles; and the development of networks, including mentoring opportunities, for organisations with limited experience to gain support and advice from those with greater experience developing peer roles.
Byrne, L, Roper, C, Happell, B & Reid-Searl, K 2019b, 'The stigma of identifying as having a lived experience runs before me: Challenges for lived experience roles', *Journal of Mental Health*, vol. 28, no. 3, pp. 260-66. (LE)	Qualitative	Study of views of lived experience practitioners from different services	n=13 lived experience practitioners.	Semi-structured interviews and grounded theory framed analysis Strauss and Corbin	Issues of stigma and discrimination were identified as a core category of this study. Participants described stigma and discrimination so prevalent as to be considered a ‘‘normal’’ part of their working life. Professional isolation and attitudinal barriers from colleagues were seen to inhibit the effectiveness of lived experience roles. The experience of discrimination from some staff and professional isolation was a theme
Byrne, L, Roennfeldt, H, O’Shea, P & Macdonald, F 2018. ‘Taking a gamble for high rewards? Management perspectives on the value of mental health peer workers’, *International Journal of Environmental Research and Public*	Qualitative	Queensland, Australia: Study of managers perceptions of peer work roles and value. Recruiting across pubic mental health	n=29 participants from 24 organisations n=16 non-for-profit and n=13 public MH n=19 non-peer designated n=10 designated peer exec or carer exec	25 semi- structured interviews and one focus group n=6	Benefits – unique skills and perspectives, more equitable relationships with consumers of services, lived experience provided credibility and positive opportunities for building rapport. Living examples of recovery and hope, deep empathy, peer workers drive positive change for recovery practice, bridge language between clinical perspectives and ordinary language, deeper understanding of stigma. Limitations of peer work: role can be diminished by limitations. The emergent nature of peer work, lack of understanding from colleagues, people in peer roles may be unreliable or become unwell as a barrier to engaging peers.

Health, vol. 15, no. 4, p.746. (LE)		and NGO settings			Negative experience from peers: poor use of personal stories. Importance of practical strategies and supportive measures to maximise the effectiveness and consequently the benefits of peer roles: Strategies included well-planned recruitment, ongoing and appropriate supervision, reasonable adjustments/flexible work arrangements and self-care. Recruitment should identify 'soft skills' including advanced communication and the ability to navigate complicated situation important. Learning curve of the role: adequate and appropriate supervision as key to management of peers. Variety of supervision approaches including formal and informal supervision, with an emphasis on ensuring timely debriefing and support.
Cleary, M, Walter, G & Escott, P 2006, '"Consumer consultant": Expanding the role of consumers in modern mental health services', *International Journal of Mental Health Nursing,* vol. 15, no. 1, pp. 29-34.		Australia: Area Mental Health Service	N/A	N/A	Focus on education and training, advocacy and policy and program development consistency in training job descriptions, pay rates selection. Roles engaging and organising care of other service user role in complex work involving collaboration. Advocacy on client level in services links to systemic advocacy. Education and training and support – being a student and learning and also delivering education to staff on the consumer perspective and the movement. Boundary issues – wellness, sick leave and supports. Strifeful work, clarity on reporting structures acceptable service – peer work boundaries. Discusses Involvement in research, training in ethics and design – research training needed.

Clossey, L, Gillen, J, Frankel, H & Hernandez, J 2016, 'The experience of certified peer specialists in mental health', *Social Work in Mental Health*, vol. 14, no. 4, pp. 408-27. (LE)	Qualitative study	USA: Study of certified peer specialists working in variety of mental health organisations	n=13 peer specialists, working in 8 different Mental Health organisations	Semi-structured interviews and focus groups (n=2) Grounded theory analysis	Roles in addition to peer mentoring, these workers coordinate between peers, providers and payers, handle client emergencies, and liaison between peers and ACT treatment staff. Some CPS[4] respond to peers in their home, some only in the office. Some worked primarily one on one, while others also facilitated recovery focused groups. All of the respondents spoke of trying to empower peers, establish recovery goals and implement them, and function as an advocate and a role model Job stressors, high caseload, and consumers who are not ready for recovery. The medical model as a barrier, working in systems that did not understand recovery or CPS; some felt they were not treated as an equal. The second largest barrier perceived by CPS was the sense that providers often did not take them seriously. Another aspect of feeling misunderstood by providers has to do with the CPS emphasis on partnership with providers. CPS feel that it is essential to recovery to educate peers about wellness and encourage discussion of medications. Other issues included being assigned work that is not perceived as legitimate to the CPS role and discrimination and stigma reported also due to provider attitudes. Facilitators include: Supportive organisations and having a CPS supervisor, funding, geographic region, reputation, helping alliance, rewarding work, patience, a good support system, effective training, effective work, helping alliances

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[4] CPS = Certified peer specialists

					with staff and the rewarding nature of the work. Organisational integration is essential.
Dent, N 2011. 'Taking a lead from the users of mental health care services', *International Journal of Leadership in Public Services, vol.* 7, no. 4, pp. 304-313.	Evaluation summary of user leader appreciative enquiry initiative	UK: Identifies strategies preferred by user leaders to engage with mental health services and promote recovery	n=12 service user interviewer participants n=46 service user interviewees	Analysis of interviews by user interviewers. Process of consensus meetings to identify themes and findings	Key strategies for preferred engagement: Employ more service users in services as peers; Increase use of co-facilitated collaborative groups which promote user perspectives to MHS staff; and recovery to users of services; Targeted engagement in defining recovery as used by mental health services, so definitions are user driven; Strengthen user leadership through more training provision; Mental health services to strengthen commitment to including user leaders in staff recruitment. Mental health services to develop strategies to engage diverse cultural groups and LGTBTIQ communities; and Develop a trust wide engagement strategy that defines user experience and includes roles in commissioning, primary care services and statutory Mental health services.
Felton, BJ 2005, 'Defining location in the mental health system: a case study of a consumer-run agency', *American Journal of Community Psychology,* vol. 36, no. 3-4, pp. 373-386.	Ethnography	USA: Explores narratives of CROs in terms of maintaining identity and cohesion and managing service tensions	n=1 CRO, n=14 peer staff	Participant observation, interviews with consumer leader, peer staff. Interpretive analysis	Findings – narrative themes: Mental illness can happen to anyone; Recovery is possible; full functioning in the form of employment is the criterion for recovery; The same system (mental health) that offers help—that ought to provide help poses its own problems; and Helping is the logical use of lived experience and use of the system. Consumer staff views of their agency:

					• gratification in helping; • agency pride; • agency as understanding (the most understanding place); and • agency as family – describing information social life of the organisation. The analysis indicates that the CROS were able to resolve positive and negative views of the mental health system and resolve potential conflict between consumer values and provider responsibility.
Fieldhouse, J, Parmenter, V, Lillywhite, R & Forsey, P 2017, 'What works for peer support groups: Learning from mental health and wellbeing groups in Bath and North East Somerset', *Mental Health and Social Inclusion*, vol. 21, no. 1, pp. 25-33.	Participatory Action Research Project	Bath and North East Somerset, UK: Explores what works in promoting successful consumer support groups	n=6 consumer peer groups with diverse functions n=17 participants in focus groups	2 focus groups plus 6 knowledge café workshops with broader attendance (figure not provided). Braun and Clarke 2006 thematic analysis	Successful groups have six characteristics: mutual support; a positive shared identity; opportunities for taking on roles; negotiated ground rules; skilled facilitation; and a conducive physical environment. Additionally, each group achieved a balance between the following areas of tension: needing ground rules but wanting to avoid bureaucracy; needing internal structure while also committing to group activities; balancing leadership with accountability; wanting peer leadership while acknowledging the burden of this responsibility; and lobbying for change in mental health services while acknowledging the need for support from them. 6 main themes: Mutuality among members; collective identity; opportunities for leadership; negotiating structures and respect; confidentiality; democracy; skilled facilitation; and accessible environments. Key challenges encountered by community groups: Rules vs. bureaucracy; structure vs. group activities; facilitation

					vs. accountability; peer leadership vs. burdening people; change vs. support.
Franke, CCD, Paton, BC & Gassner, L-AJ 2010, 'Implementing mental health peer support: A South Australian experience', Australian Journal of Primary Health, vol. 16, no. 2, pp. 179-86.	Results of survey – descriptive study, evaluation of training pathway 2007 SAHRU report s from 2007, 2008	South Australia: Describes development of peer support model and training		Survey with graduates n=50 Interviews n=25 with peer workers, managers and colleagues	Describes pathways of support, training for peer workers, support group introduction to peer work graduates and workplace mentoring Organisational development and support through consultancy to prepare their organisations, develop peer work roles, and establish effective support structure for peer work – employer tool kit Topics of knowledge and skills required for peer work: Topic social justice and recovery framework, mental health and mental health services, working within an organisation, peer support work roles. Workplace culture and communication Issues of confidentiality; Importance and variety of peer work roles, recovery-based principles; Issues and barriers in the communication process, recognising own triggers, warning signs and symptoms and personal and career opportunities. Skills for dealing with stigma and discrimination, promoting recovery and social inclusion and research and sharing information. Other skills include using resources for the benefit of consumers, working and participating in a team or group, setting boundaries and adhering to ethical guidelines, sharing own experience safely and professionally, assisting consumers to identify needs and set goals, active listening and communication self-

					management and strategies for maintaining wellness, goals setting, workplace mentoring and debriefing.
Gates, LB, Mandiberg, JM & Akabas, SH 2010, 'Building capacity in social service agencies to employ peer providers', *Psychiatric Rehabilitation Journal*, vol. 34, no. 2, pp. 145-52.	New York, USA: Organisational change PAR type study using goal setting and appraisal to develop successful workplace change Mixed-methods		n=71 peer, non-peer and supervisory staff participated from 6 agencies over a one-year period. n=23 peer staff, n=31 non-peer staff, and n=17 supervisors	Semi-structured interviews and team-based group consultation sessions, use of process logs to document change Use of goal attainment scale Thematic analysis and descriptive statistics	Key finding regarding implementation: Role definition and conflict; uncertainty of boundaries; confidentiality and disclosure expectations and diverse practice; and lack of on the job supports and orientation. Enabler actions: • information on peer roles to consumers of service; • responding to inconsistent Application of HR policies; • enhancing peer staff control over disclosure; • drafting written job descriptions to clarify who does what; • improving support to peer staff through training to learn their jobs and introduce them to workplace culture and policies; and • changing stigmatizing attitudes to- ward peers. Several Teams initiated unit-wide or agency-wide in-service training to introduce the role of peer providers and express commitment to their contribution to treatment teams.
Gee, A, McGarty, C & Banfield, M 2016, 'Barriers to genuine consumer and carer participation from the perspectives of Australian systemic	Qualitative – mixed-methods	Australian Capital Territory: Explores barriers identified by consumer	n=2 mental health systemic advocacy organisations – CROs and one Consumer carer group	Document analysis and semi-structured interviews. Thematic analysis	A number of individual-level barriers were described, however, advocates gave more focus to systemic barriers, for which five themes emerged. These reflected lack of awareness, limited participation opportunities, slow progress for change, policy issues and mental health culture including stigma.

mental health advocates', *Journal of Mental Health,* vol. 25, no. 3, pp. 231-237. (LE)		advocates groups to systematic change	n=9 interviews (n=5 consumers and n=4 consumer/ carers)		Individual-level barriers included fatigue and stressful workloads among representatives, high level of commitment and skills required to manage the workload, changes in life circumstances of representatives which requires attention, committees not providing material in advance of meetings, and uncertainty at times about purpose and direction. Organisation-level barriers included difficulty finding enough people for advocacy and representative work, heavy reliance on few people, staffing and membership changes delaying projects, and minimal opportunities for direct dialogue with government.
Gee, A, McGarty, C & Banfield, M 2015, 'What drives systemic mental health advocates? Goals, strategies, and values of Australian consumer and carer advocacy organisations', *SAGE Open,* vol. 5, no. 4, pp. 1-18. (LE)	Qualitative – mixed-methods	Australian Capital Territory: Works to identify major themes relating to goals, activities, and values driving advocates and their organisations	n=2 mental health systemic advocacy organisations – CROs and one Consumer/ carer group n=9 interviews (n=5 consumers and n=4 consumer/carers)	Document analysis and semi-structured interviews. Thematic analysis	Five major focus issues were identified: • Building consumer and carer participation. The advocates sought consumer and carer participation primarily through representation and lobbying, putting consumer and carer representatives on committees, producing submissions, and meeting with constituents, government departments, and ministers. They facilitated training for members (e.g., advocacy, media skills, communication, conflict resolution) and by providing mutual support (e.g. administrative support, debriefing, attending committees in pairs). • Voice and recognition for consumers and carers. Advocates aimed to present unity to contribute to better recognition of consumer and carer concerns and raise awareness of professional bodies, government, and the community.

					- Influencing and improving mental health systems. They worked to ensure that services and practices uphold the rights of people with mental disorders and are consistent with social justice values (human rights, equality, inclusion). - Effective collaboration and partnerships. Building collaborations with other community, government and non-government organisations, professionals, bureaucrats, and service staff was important, including reporting to stake- holders and constituents. - Building organisational strength. conducting membership reviews, promoted the organisation, undertake good business practices. Sustainability was also emphasised along with the need to build stronger organisational profile.
Gillard, S, Edwards, C, Gibson, S, Holley, J & Owen, K 2014, 'New ways of working in mental health services: a qualitative, comparative case study assessing and informing the emergence of new peer worker roles in mental health services in England', *Health*	Qualitative comparative case study design	UK: 10 contrasting cases comprising mental health NHS trusts, voluntary sector service providers and partnerships between the NHS and voluntary sector or	n=89 relatively equal proportion from peer workers, service users, non-peer co-workers, line managers, strategic managers and commissioners	Descriptive statistics regarding implementation and qualitative interviews. Interview data analysed using thematic and framework analysis approach	Reflects findings of other studies: Key findings report experiences and difficulties with pay, leadership, shared understanding of the role, training and management where good practice was uneven. Positive examples of good practice were evident in the voluntary sector, where peer worker roles had been established for longer and organisations were more flexible. In the NHS there were a range of challenges around introducing peer worker roles into existing structures and cultures of practice. Conclusions: Key barriers to, and facilitators of, peer worker role adoption were identified, including valuing the differential knowledge and practice that peer workers brought to the role (especially around maintaining

Services and Delivery Research, vol, 2, iss. 19.		social care providers			personally, rather than professionally defined boundaries); maintaining peer identity in a role of work; changing organisational structures to support peer workers to remain well in their work; and challenging organisational cultures to empower peer workers to use their lived experience.
Gillard, S, Edwards, C, Gibson, SL, Owen, K & Wright, C 2013a, 'Introducing peer worker roles into UK mental health service teams: a qualitative analysis of the organisational benefits and challenges', *BMC Health Services Research*, vol. 13, p. 188.	Qualitative	UK: Secondary analysis of broader study on peer worker integration in mental Health NHS trusts. Peer workers were involved in community education and support group services	N=41 Peer workers, managers, clinicians, and service users	Semi-structured interviews. Grounded theory approach to analysis	Peer workers were highly valued by mental health teams and service users. Non-peer team members and managers worked hard to introduce peer workers into teams. The study reports an evolutionary process: in the absence of formal recruitment processes for peer workers, differences in expectations of the peer worker role can emerge at the selection stage; flexible working arrangements for peer workers can have the unintended effect of perpetuating hierarchies within teams; the maintenance of protective practice boundaries through supervision and training can militate against the emergence of a distinctive body of peer practice; lack of consensus around what constitutes peer practice can result in feelings for peer workers of inequality, disempowerment, uncertainty about identity and of being under-supported. Keys findings: motivations of peer support workers; role seen as developmental opportunity and career pathway; issues in acceptance and team integration; some peer workers did not share the view that they were equals in the new team. Some staff identified resistance in the existing workforce to the introduction of peer workers into the team: It was recognised that the source of this resistance might lie in the training and background of existing staff; a sense that their roles and responsibilities might be threatened by a new peer worker role; peer workers experience a challenge of

					boundary setting, while also offering safe and unique form of engagement with service users.
Gordon, S 2005, 'The role of the consumer in the leadership and management of mental health services', *Australasian Psychiatry: Bulletin of Royal Australian and New Zealand College of Psychiatrists,* vol. 13, no. 4, pp. 362-365. (LE)	Descriptive paper	New Zealand: Mental health sector services and leadership	N/A	N/A - refers to consultation reports and policy	Paradigm shift from consumer participation to service user leadership on individual and systems level - for recovery-based care. Three critical dimensions: 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 Central involvement of service users in mental health advocacy, training, education and promotion.
Happell, B & Roper, C 2009, 'Promoting genuine consumer participation in mental health education: a consumer academic role', *Nurse Education Today,* vol. 29, no. 6, pp. 575-579. (LE)	Discourse paper Evaluation of consumer academic has not occurred yet.	Australia: Centre for Psychiatric Nursing	n=1 consumer academic	N/A	Describes the role of consumer academic and needs for influence, support and autonomy Key activities: • Education and training; • Research; and • Consultancy. Education: teaching critical reflection on statutory role and impact on consumers and ethics of restrictive practices and impact of trauma. Research: being a principal or co-investigator on applications for competitive funding, to being an investigator on a funded project. Consultancy: assisting research in industry level projects such as consumer engagement. The successful implementation of the consumer academic role was attributed to four primary

					factors: partnership and commitment; support; scope and autonomy
Happell, B & Roper, C 2006, 'The myth of representation: The case for consumer leadership', *Australian e-Journal for the Advancement of Mental Health),* vol. 5, no. 3, pp. 1-8. (LE)	Reflective/ discursive paper	Victoria, Aust	N/A	N/A	Key arguments: negative impacts of representation argument: View is damaging to the consumer participation movement and at worst blatantly discriminatory, specifically because it is a method to silence activism; undermines the legitimacy of consumer roles; and requires consumers to justify themselves in a way that mental health professionals are not, therefore discriminatory expectations. Consumer leadership should be valued rather than consumers as representatives. Mental health services need to evaluate the performance of services directly with consumers, not through representation. 'Within this model of consumer leadership, the issue of ensuring that the voice of all consumers is heard by mental health services becomes the responsibility of all leaders not merely that of those consumers who choose to participate' (p. 6).

Happell, B, Bocking, J, Scholz, B & Platania-Phung, C 2019, 'The tyranny of difference: exploring attitudes to the role of the consumer academic in teaching students of mental health nursing', *Journal of Mental Health*, pp. 1-7. (LE)	Qualitative	Australia:
		Australian University providing an undergraduate Bachelor of Nursing program
			n=1 consumer academician;
			n=2 nurse academicians;
			n=2 mental health researchers
				Thematic analysis	Key themes:
					• Seeking a united perspective – how different perspectives align in teaching programs;
					• How accurate is consumer perspective – doubting and contested knowledge;
					• One consumer, one opinion, one way and one delivery – limited experience, diagnosis –

					questioning limits of consumer led teaching, and positioning; and - Bias and poor portrayal of nurses in consumer led teaching.
Happell, B & Scholz, B 2018, 'Doing what we can, but knowing our place: Being an ally to promote consumer leadership in mental health', *International Journal of Mental Health Nursing,* vol. 27, no. 1, pp. 440-447. (LE)	Discursive paper	Australia: Discusses the role of ally	N/A Not a study	N/A	Non-consumers who support consumer partnerships and leadership (known as 'allies') have an important role to play in facilitating and supporting consumers in leadership roles. Role derived from work in LGBTIA communities in terms of support across distinct identity groups Allies do not identify as consumers, but advocate for greater consumer involvement. Allies often hold senior positions in organisations and have access to the resources required to both promote and directly establish the opportunities for consumers to gain and exercise power. The role allies can play in broader movements is described as essential in supporting 'those who have been denied equality and human rights'. Being an affective ally: nothing about us without us, let them tell it as it is, acknowledge and respect consumer knowledge, wear only one hat, oppose the one size fits all or a consumer is a consumer is a consumer. Rather than seeking 'consumer' expertise, it is important to consider more specifically what expertise is required. i.e. matching expertise.
Happell, B, Gordon, S, Bocking, J, Ellis, P, Roper, C, Liggins, J, Scholz, B & Platania-Phung, C 2018a, 'Turning the tables: Power relations	Qualitative paper	Australia: Explores views on power relationships between lived experience and non-	n=11 mental health researchers (social work, clinical psychology, psychiatry or	Semi-structured interviews and thematic analysis	Key themes from findings: The umbrella theme was prominence and presence (of consumers) at the table, followed by subthemes on barriers (tokenism, undermined potential) and surmounting them through reworking power (critical mass and openness to power dynamics).

between consumer researchers and other mental health researchers', *Issues in Mental Health Nursing*, vol. 39, no. 8, pp. 633-40. (LE)		designated researchers	mental health nursing).		• Unequal power seen as enduring and creates challenges for egalitarian relations central to collaborating with consumers in research. • Tokenism is seen as occurring because of the systemic power differences. • Critical mass: The presence at the table of a solitary or small number of mental health consumers is an issue of power and maintains situation of undermined potential. Research discussion need opening to discussion issues of power and presence.
Happell, B, Scholz, B, Gordon, S, Bocking, J, Ellis, P, Roper, C, Liggins, J & Platania-Phung, C 2018b, '"I don't think we've quite got there yet": The experience of allyship for mental health consumer researchers', *Journal of Psychiatric and Mental Health Nursing*, vol. 25, no. 8, pp. 453-62. (LE)	Qualitative study	Aust and New Zealand: Explores role of allies in research in in facilitating research-focused roles for men- tall health consumers	n=11 researchers. ranged from recently completing PhD student to department heads	Semi-structured interviews and framework for thematic analysis outlined by Braun and Clarke	Allyship was found to be a major support for the successful growth of consumer research in mental health. The activities and functions of allies in supporting mental health consumers in research and the significance of allyship were reflected in the identified subthemes: establishing and supporting roles, corralling resources, guiding navigation of university systems, advocacy at multiple levels, aspiring to co-production and consumer-led research, extending connections and partnerships, and desire to do better.
Horgan, A, Manning, F, Donovan, MO, Doody, R, Savage, E, Bradley, SK, Dorrity, C, O'Sullivan, H, Goodwin,	Qualitative	Iceland: Ireland (2 sites), Norway, Finland, the	Stage one: n=50 service users	Focus groups n=8 with interview guide	The first theme focused on the enablers and barriers regarding EBE involvement in nursing education: EBEs need to be respected and valued, use of knowledge is valued, EBEs need to have confidence and feel empowered to be involved in higher education. Confidence to negotiate

J, Greaney, S, Biering, P, Bjornsson, E, Bocking, J, Russell, S, MacGabhann, L, Griffin, M, van der Vaart, KJ, Allon, J, Granerud, A, Hals, E, Pulli, J, Vatula, A, Ellilä, H, Lahti, M & Happell, B 2020, 'Expert by experience involvement in mental health nursing education: The co-production of standards between Experts by Experience and academics in mental health nursing', *Journal of Psychiatric and Mental Health Nursing*, vol. 27, iss. 5, pp. 553-562. (LE)		Netherlands and Australia: Development and co-production of standards for experts by experience teaching into mental health nursing education	M: n=28; F: n=22 Stage two: n= 12 EBE[5] educators n=10 nursing academics	Thematic analysis using Braun and Clarks approach. Stage two involved consensus building approaches Co-production between experts by experience and nursing academics	university system, share stories and confidence in own education The second theme concerned the practical and informational support required. Participants highlighted the importance of receiving both informational and practical support when contributing to nursing education. In terms of information, EBEs identified that training on how to deliver a lecture and communicate their content in an accessible way for students was essential. Participants in all focus groups identified the importance of being paid for their time and expertise. The third theme focused on emotional and appraisal support. The need for emotional and appraisal support was identified as important for EBEs involved in mental health nursing education. Debriefing with peers was identified as essential, requiring universities to have more than one EBE educator involved in the education of nurses. Standards: • Induction and orientation; • External supervision; • Supportive teamwork; • Emotional and practical support; • Intervision and mutual support; • Mutual mentorship; • Pre and post sessional support;

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[5] EBE = evidence by experience

					- Role clarity); and - Equitable payment.
Hurley, J, Cashin, A, Mills, J, Hutchinson, M, Kozlowski, D & Graham, I 2018, 'Qualitative study of peer workers within the "Partners in Recovery' programme in regional Australia"', *International Journal of Mental Health Nursing*, vol. 27, no. 1, pp. 187-95.	Qualitative	Australia: Study into the experiences of peer workers The paper reports findings from qualitative interviews conducted in a Partners in Recovery programme in a rural setting	n=22 mixed sample n=4 peer workers, n=4 consumer, n=4 manager n= 10 support facilitators	Semi- structured interviews and thematic analysis within phenomen-ology paradigm	Themes: - role variance; - the challenges and opportunities for peer worker; (- the processes peer workers employed as they attempted to shape an identify and language; - the inconsistencies and challenges of employing lived experience as a defining feature of the peer worker role; and (v) the nature of trust arising from lived experience relationships. Seeking peer workers identity through 'systems change', recovery language and 'grassroots projects'. Lived experience is a variable construct and role needs additional capabilities. The role is powerful and highly regarded by consumers.
Janzen, R, Nelson, G, Trainor, J & Ochocka, J 2006, 'A longitudinal study of mental health consumer/survivor initiatives: Part 4--Benefits beyond the self? A quantitative and qualitative study of system-level activities	Mixed-methods	Explores impact of systems level activities of 4 CROs – public education, political advocacy, community planning and	4 focus groups and n=13 interviews CRO participants	Quantitative System-Level Tracking Tool - (track amount of activity of staff) Semi-structured interviews	Findings: descriptive actions: - Public Education and Relations. Activities in the public education and relations category were designed to increase awareness or change public opinions about mental health issues and the people who experience mental health issues. - Political Advocacy. Activities in the political advocacy category were

and impacts', *Journal of community psychology,* vol. 34, no. 3, pp. 285-303.		action research			designed to bring about changes in social policies and practices (e.g. mental health reform). Activities focused primarily on mental health reform but also included other areas of concern for consumer/survivors (e.g. housing, transportation). • Community Planning and Collaboration. Activities in the community planning and collaboration category were designed to effect changes in planning practices and existing services, as well as the creation of new supports and services. • Action Research. Activities in the action research category were designed to gather information to support the three system-level activities (public education, political advocacy, and community planning. Study defines a range of impacts from the above roles.
Juntanamalaga, P, Scholz, B, Roper, C & Happell, B 2019, '"They can't empower us": The role of allies in the consumer movement', *International Journal of Mental Health Nursing,* vol. 28, no. 4, pp. 857-866. (LE)	Qualitative	Australia: Mental health education or research organisations, private sector mental health services, government organisations, and state or territory peak bodies (NGOs)	n=15 (n=9 allies, (n=3 consumer/ ally, n=3 consumer)	Semi- structured interviews Thematic analysis	There were three overarching themes identified in relation to participants' discussion of allies and consumers' empowerment: • conceptualisation of consumer empowerment; facilitate the situation whereby [consumers] empower [themselves]. i.e. have choice and be decision makers. • understandings of allies; allies possess some degree of power within the mental health sector. Possible allies of consumer empowerment would involve professional roles including social workers, occupational therapists, nurses, doctors, policy

					makers, politicians, and lawyers as being possible allies of consumer empowerment. - attitudes towards ally involvement as supporters of consumers' empowerment. Participants discussed perceptions of allies in relation to their role. There were three particular subthemes related to these perceptions: a lack of understanding of consumer perspectives, hidden agendas, and the domination of ally perspectives – taking over interpretation.
McDaid, S 2009, 'An equality of condition framework for user involvement in mental health policy and planning: Evidence from participatory action research', *Disability and Society,* vol. 24, no. 4, pp. 461-474.	Participatory Action Research	Ireland: Explores engagement in policy and planning involving service users and activists	n=15 service users; n=5 service user activists	Semi-structured interviews. Use of grounded theory techniques for analysis and aligned with Equality of Condition Framework	Identifies context of user involvement in the mental health, and four major concerns: the capacity of service users to participate; their lack of participation skills; the need for a positive organisational culture; and the need for arenas of participation. Barriers: unequal cultural, physical, mental and economic resources, time, power, 'stigma'(prejudice) and lack of respect for their experiential knowledge and emotional expression.
Middleton, P, Stanton, P & Renouf, N 2004, 'Consumer consultants in mental health services: Addressing the challenges', *Journal of Mental Health,* vol. 13, no. 5, pp. 507-518.	Qualitative	Victoria, Australia: Public mental health program	n=10 consumer consultants Purposive sample	Semi-structured interviews	Results presented in narrative form. No data from the interviews to back up statements. Roles include community education activities, networking with community-based agencies, Identifies a range of positive and negative experiences of consumer consultants which relates to recognition of roles of promoting engagement, connected to management and decision making, having control of own budgets, supports

					and constraints, relationships with other staff, acceptance. In teams and dominance of medical model.
Moran, GS, Russinova, Z, Gidugu, V & Gagne, C 2013, 'Challenges experienced by paid peer providers in mental health recovery: a qualitative study', *Community Mental Health Journal*, vol. 49, no. 3, pp. 281-91.	Qualitative study as secondary analysis of larger mixed-methods study	USA: Explores challenges among variety of peer worker in diverse positions and roles	n=31 peer workers	Two semi-structured interviews for each participant via questionnaire Content analysis	Challenges in the work environment differed between conventional mental health settings and consumer-run agencies. Barriers and issues: Work environment: lack of infrastructure/accommodations, low payment, direct and indirect expressions of prejudice, lack of recovery orientation, problems in relationships with supervisors, being the only peer provider in the agency, unstable relationships, loose work structure and roles. Organisational occupational pathways: insufficient knowledge, skills, competencies, lack of congruence between training and job requirement, uneven training/qualification, assigned tasks unrelated to peer work (administer medication), lived experience not valued by supervisors or staff, difficulties in establishing a peer-relationship (disclosing/sharing, setting boundaries), difficulties in establishing a helping relationship (keeping a helping approach, dealing with consumers stuck or in crises), peer label experienced as confining, peer label limits other opportunities. Personal mental health: taking worries home, hearing about extreme negative experiences, triggers, depression, recurrence of symptoms.
Mowbray, CT, Robinson, EA & Holter, MC 2002, 'Consumer drop-in centers: Operations, services,	Quantitative	Michigan, USA: Explores numerous variables between drop-	n=32 majority drop-in centre directors	Descriptive survey Descriptive statistics and ANOVA	Funding levels, salaries, and services showed great heterogeneity among the centres and in comparison, with reports in the literature. Centres autonomously run by consumers and centres with consumer involvement (operated by a non-consumer agency) were found to differ

and consumer involvement', *Health & Social Work,* vol. 27, no. 4, pp. 248-261.		in centres that are CROs and those of non-consumer run centres that have consumer involvement			significantly on several variables, including consumer control, funding and service levels, and challenges. One finding indicated that consumer run centres had more active participation of consumers and their boards in governance, planning and budgeting, decision-making, personnel decisions, and other operational issues, than consumer involved services. Furthermore, the designation of CR[6] versus CI[7] had a significant effect on the consumer control scale score above and beyond the contribution of control variables and operational variables (urban/rural location, longevity of the centre, and level of services).
Mulvale, G, Wilson, F, Jones, S, Green, J, Johansen, K-J, Arnold, I & Kates, N 2019, 'Integrating mental health peer support in clinical settings: Lessons from Canada and Norway', *Healthcare Management Forum*, vol. 32, no. 2, pp. 68-72. (LE)	Case study	Norway and Canada: Peer support roles in diverse clinical settings including hospitals, assertive Community Treatment teams, early intervention programs and	n=68 participants n=9 consumers n=33 peer support workers n=20 managers/ health team members n=6 policy makers	Individual interviews and focus groups with peer workers N= N/A	Value of peer support – 3 areas Perceived positive impact on peers across all settings: PSPs[8] can link peers to broader community supports and programs, PSPs may be influential in creating a circle of support around peers who can assist with problem-solving , overwhelming day-to-day challenges. PSPs work to foster peer independence in decision-making Some PSPs find their work beneficial, to their own recovery and personal growth Quality: PSPs can reach out to hard-to-reach peers and link them with the rest of the team, PSPs help create a relaxed relationship that can encourage less inhibited discussion, PSPs provide a living example of recovery and hope, PSPs

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[6] CR = consumer run

[7] CI = consumer involved

[8] PSP = Peer support providers

		consumer run initiatives			may assist by conducting debriefings from all perspectives, PSPs help to fosters peer- centredness in the team. A range of organisational change strategies are summarised: Systems level: train all staff, PSP certification, increase funding, support evaluation and knowledge exchange. Organisational leadership: culture change, build champions, evaluation, focus on resistant groups, continue improvement, organisational priority, link to person-centred care.
Nelson, G, Janzen, R, Trainor, J & Ochocka, J 2008, 'Putting values into practice: public policy and the future of mental health consumer-run organisations', *American Journal of Community Psychology,* vol. 42, no. 1-2, pp. 192-201.	Reflective paper reporting on PAR study	Ontario, Canada: Explores the values and functions of CROs – identifying four value dilemmas that organisations need to manage	Reports on earlier studies with four CROs	N/A	Identifies key value dilemmas: • Dilemma is how to reconcile personal values (self-determination and personal empowerment) with relational values (peer support and consumer solidarity) towards the goal of recovery; • Self-help vs. peer support by paid staff or volunteers; • The third value dilemma concerns the tension between relational values and collective values; • value dilemma pertains to organisational autonomy vs. organisational support.
O'Hagan, M 2009, 'Leadership for empowerment and equality: A proposed model for mental health user/survivor leadership ', *Journal of Leadership in Public*	Reflective paper	New Zealand: Mental health sector services and leadership	N/A	N/A	Movement needs explicit, unique model of LE leadership based on values of empowerment and equality. Needs philosophical, psychological and political shifts in service systems. A framework is offered for leadership at different levels: Services/Consumer run organisation level: Articulating and promoting an explicit values base. • Governance by the members or other users/survivors.

Services vol. 5, no. 4, pp. 1-13. (LE)					• Management decisions by consensus with staff and members. • Active promotion of different types of leadership within initiatives e.g. leading one's own recovery, leadership in particular activities, informal leadership among close peers. In Mainstream services – operative via values of power and equity in distribution of power in governance, management, delivery, training and evaluation. Systems level: systemic leadership roles such as politicians, senior public servants, planners and funders, researchers and systemic advocators. Article lists competences related to roles
Ochocka, J, Nelson, G, Janzen, R & Trainor, J 2006, 'A longitudinal study of mental health consumer/survivor initiatives: Part 3—A qualitative study of impacts of participation on new members', *Journal of Community Psychology*,	Qualitative study, no equivalent control group design – longitudinal	Ontario, Canada Explores impact of participation of consumers in Consumer survivor initiatives - CROs	n=15 active participants and n=12 non active participants. Active 4 hours or more	3 x qualitative interviews over time with each participant. Ground theory – thematic analysis	Compared with non-CSI[9] participants, CSI participants reported more stable mental health, enhanced social support, sustained work, stable income, and participation in education and training at 9 and 18-month interviews. The helpful qualities of CSIs that participants reported were: • safe environments that provide a positive, welcoming place to go; • social arenas that provide opportunities to meet and talk with peers;

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[9] CSI = Consumer survivor initiatives

vol. 34, no. 3, pp. 273-83.					- an alternative worldview that provides opportunities for members to participate and contribute; and - effective facilitators of community integration that provide opportunities to connect members to community. CSIs not only offered people an alternative worldview, but equipped members to provide support to others. This important shift in providing support, from passive receiving to active contributing, was crucial for people's sense of empowerment, self-confidence, and self-worth.
Ostrow, L & Hayes, SL 2015, 'Leadership and characteristics of nonprofit mental health peer-run organisations nationwide', *Psychiatric Services,* vol. 66, no. 4, pp. 421-425.	Quantitative – survey research	USA: This study reported organisational characteristics of peer-run organisations nationwide and how these organisations differ by degree of consumer control.	n=380 peer run organisations	The survey contained 83 questions concerning governance, staffing, activities, and perspectives	A pattern of consistently involving members in decision making was more apparent in peer-controlled organisations, suggesting that this organisational form conforms to evidence that less hierarchical, more lateral peer support programs decrease stigma and increase empowerment and inclusion compared with programs with more hierarchical structures. The data also suggest that peer-controlled organisations viewed themselves as alternatives to the traditional mental health system and provided more choices for community members in accessing supports independently. However, peer-directed organisations were more connected to other peer supports and offered more activities and supports.
Patterson, S, Trite, J & Weaver, T 2014, 'Activity and views of service users involved in mental health	Cross section survey	UK: Aiming to represent the involvement and	n=166 service users	National cross-sectional online questionnaire survey, using snowball sampling.	The survey revealed a previously undescribed, highly qualified service user research workforce. Topics: - Self-defined roles included researcher, non-designated, user researchers;

research: UK survey', *The British Journal of Psychiatry*, vol. 205, no. 1, pp. 68-75.		experiences of service users in mental health research in the UK		Descriptive statistics and framework analysis undertaken collaboratively with a service user reference group.	• Employment status included, self-employed, research consultant, paid employment as university post or in NHS post grad students, voluntary roles, voluntary peripatetic mental health researchers. Types of mental health research activity reported; research governance, project advisory group, project leadership roles, support project team, support intervention delivery, project administration/general support activities, data collection and related activities, data analysis, peer-reviewed publication, other publication/dissemination. What supports involvement? Support, both emotional and practical, the sponsorship of a senior researcher or mentor, membership (formal or informal) of a service user/survivor researcher network, peer networks functioned as critical friends providing moral support, practical advice and peer review, being able to select projects and roles that matched capacity and flexibility to manage workload were described as enabling participation.
Piat, M, Sabetti, J & Padgett, D 2018, 'Emergent leadership among tenants with psychiatric disabilities living in supported housing', *International Journal of Mental Health Nursing,* vol. 27, no. 3, pp. 1127-1136.	Qualitative study	Canada: With residents in independent support housing. Explores resident perceptions on housing, relationships,	n=24 service user/residents	Semi-structured interviews and thematic analysis	Consumer leadership emerged informally. Consumers recognise leadership via three identifying traits or qualities, and three behaviours of leaders. The three identifying qualities are as follows: (1) people who are knowledgeable and articulate, (2) people who are fearless, and (3) people who are less mentally ill. The three behaviours of leaders are as follows: (1) people who represent or speak for the group, (2) people who are active and mobilise others, and (3) people who give good example.

		participation and experience of leadership			Leadership cannot be appropriated to oneself – needs to be recognised and legitimised by others. Other themes were: Debating who is in charge: service users or staff Becoming a leader for others: pathway and processes to leadership as follows: displaying natural leadership qualities; enjoying a good reputation; projecting experience and wisdom; getting involved in house politics; voicing complaints; and taking responsibility for others.
Rose, D, MacDonald, D, Wilson, A, Crawford, M, Barnes, M & Omeni, E 2016, 'Service user led organisations in mental health today', *Journal of Mental Health,* vol. 25, no. 3, pp. 254-259. (LE)	Ethnography	UK: To explore mental health service ULOs[10] in England, in terms of relationships with funders and use of institutional norms behaviour and specialised knowledge	n=5 ULOs; n=10 participants writing journals	Participant observation and qualitative interviews with group informants and analysis of reflective journal entries. Interpretive analysis	Findings and themes: Autonomy, knowledge and institutional norms: The theme of autonomy was identified for all the groups. All the ULOs wished to retain some degree of autonomy and uniformly based this on their specialised, experiential knowledge of mental health conditions and services. Leadership: three leaders of ULOs in our ethnography were long-standing user movement activists. Leaders faced questions about their ’representativeness’ which term is often used as critique. Complexity and change: The different places where service users might intervene, and influence are now immense and diverse (of policy context).

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[10] ULO = User-led organisation

Russo, J 2012, 'Survivor-controlled research: A new foundation for thinking about psychiatry and mental health', *Sozialforschung/Forum: Qualitative Social Research*, vol. 13, no. 1, pp. 1-29. LE)	Reflective paper	UK and Germany: Discussed roles and barriers of survivor-controlled research in the field of mental health	N/A	N/A	Principles of user led research: Shared identity and closeness to the research topic and joint analysis and interpretation. Includes section on barriers and challenges. Barriers: dilution of Consumer controlled research their rapid co-optation of perspectives, the pharmaceutical industry has a powerful and determining influence over the research agenda, consumer researchers are often faced with a stigmatizing attitude when applying for funding. Other barriers include the lack of accessible specialist training and the diversity of viewpoints and lack of clear philosophies in the movement.
Scholz, B, Bocking, J & Happell, B 2017, 'Breaking through the glass ceiling: Consumers in mental health organisations' hierarchies', *Issues in Mental Health Nursing,* vol. 38, no. 5, pp. 374-380. (LE)	Qualitative study	Australian Capital Territory: engages mental health organisations and explores perceptions of how consumer leadership strategies shape relationships and hierarchies within mental health services.	n=14 mix or leaders, consumer leaders and allies (not detailed)	Semi-structured interviews. Analysis via principles of discourse analysis	Explored observations on consumer leadership and hierarchies. 4 key themes: Benefits of consumer within hierarchies: bringing, embedding consumers' perspectives into decision-making that span 'silos'; improving the reputation and legitimacy of offerings (gives agency to mental health work) and draw on consumers' networks. Enabling consumer leadership within existing hierarchies: being supported by other leaders – pivotal impact; ally leaders set tone and agenda for consumer leadership - creates recognition and attitude change across organisations. Issues with existing organisational hierarchies: 3 key issues: Organisational structures with a lack of clarity around structure and roles within hierarchies, that lack authentic support of consumer engagement, and a lack of acceptance of consumers within these structures. Organisations need clear principles and values about consumer leadership;

					alternative models of hierarchical structures: Financial model- consumer leaders approving financial decisions – will shape organisational planning and outcomes; electoral model – mental health boards elected by consumer members. The board then drives organisation to community outcomes.
Scholz, B, Bocking, J & Happell, B 2017a, 'How do consumer leaders co-create value in mental health organisations?', *Australian Health Review,* vol. 41, no. 5, pp. 505-510. (LE)	Survey of organisations.	Australian Capital Territory: Focus on organisational responses about consumer leadership	n=13 organisational representatives	Descriptive survey and descriptive statistics on responses	Ways in which organisations may create opportunities for consumer leadership include soliciting feedback, involving consumer leaders in service design, having consumer leaders involved in hiring decisions and employing consumer leaders as staff or on boards. Training programs for consumers focus on governance, meeting facilitation, advocacy, representation, peer education, mentoring and co-facilitating training programs. Barriers and challenges noted in study: recruitment of leaders with appropriate skills, competencies and understandings a challenge leadership requires time and commitment. At the organisational level, requires cultural adjustment. Organisational priorities may conflict with consumer interests and that ill-defined roles and expectations would present problems.
Scholz, B, Bocking, J & Happell, B 2018, 'Improving exchange with consumers within mental health organisations: Recognizing mental ill health experience as a 'sneaky, special	Qualitative study	Australian Capital Territory : engages mental health organisations and explores perceptions of how consumer	n=14 (n=5 in consumer designated roles; n=9 not in lived experience roles).	Semi-structured interviews and thematic analysis	Key themes in analysis on perceptions within organisations regarding consumer leadership, which organisations should work to overcoming stigma and promoting value: Deficit view of consumers: experience of stigma in terms of behaviours, perceptions of others of reduced capacity. Inherent value of mental ill health: source of value – helps for knowledge and skills gained. Sharing can have positive value for/influence on mental health organisations,

degree'', *International Journal of Mental Health Nursing,* vol. 27, no. 1, pp. 227-235. (LE)		leadership strategies shape relationships and hierarchies within mental health services.			particularly on mental health system experience, and shaping how services are planned: brings credibility to services. Value of consumers to other consumers: (Peer roles) sharing knowledge and using knowledge to benefit others, power relations can be collapsed; service users can feel safe and be supportive when mostly peer operated. Role of offering hope, getting beyond negative stereotypes of stigma.
Scholz, B, Stewart, SJ, Bocking, J & Happell, B 2019, 'Rhetoric of representation: the disempowerment and empowerment of consumer leaders', *Health Promotion International,* vol. 34, no. 1, pp. 166-174. (LE)	Qualitative	Australia: Health services	n=34 (n=21 consumers, n=8 health professionals and n=5 people identifying both as consumer and health professional	Story completion Comparative method	Three overarching themes were developed: how consumer representative roles remain unvalued, how such lack of value translates to not achieving co-production, and how consumer representative roles can be better supported through allyship or subversion against organisational cultural norms. An empowering role is holding the organisation accountable for representation. Defining representation: for individuals working in 'representative' roles, it is not always made clear to them what it meant to be representative, and how representation should be used to influence their work. Training for representation: could be used to reproduce disempowerment through the requirement of being representative. The rhetoric of 'representation' might empower consumers as it is being used to hold the organisation to account to seek out diverse representation rather than being used to

					hold individual consumers to account for being representative.
Segal, SP, Silverman, CJ & Temkin, TL 2013, 'Self-stigma and empowerment in combined-CMHA and consumer-run services: Two controlled trials', *Psychiatric Services,* vol. 64, no. 10, pp. 990-996.	Quantitative – cross sectional	California, USA: Study looks at leadership types of Consumer operated service programs (CROs) – self-help and board-staff run Looks at consumer ratings of leadership style	n=250 consumers attending services n=5 CROs	5 different empowerment scales used To identify changes in personal, social and organisational settings of empowerment ANOVA and MANCOVA used for analysis	Findings: SHA[11] participant democracy members scored significantly better than board/staff-run program members on three of the four empowerment measures. SHA participant democracies, with a lower focus on system maintenance, and an emphasis on power sharing between staff and non-staff members, appeared to more effectively use organisational decision-making processes to empower their members.
Shepardson, RL, Johnson, EM, Possemato, K, Arigo, D & Funderburk, JS 2019, 'Perceived barriers and facilitators to implementation of	Qualitative	Study within Veterans Health Administration peer worker services in primary	n=25 participants n=7 peer support specialists n=6 supervisors	Qualitative interviews Content analysis within 4 categories of barriers, initial facilitators, long-term facilitators, and leadership support	Findings: Perceived barriers included poor program functioning, inadequate administrative support, role confusion, and negative stakeholder attitudes. Key perceived facilitators of initializing and maintaining peer support were similar; administrative support was emphasised followed by

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[11] SHA = Self-help agencies

peer support in Veterans Health Administration Primary Care-Mental Health Integration settings', *Psychological Services*, vol. 16, no. 3, pp. 433-44.		mental health care settings	n=6 primary mental health providers n=6 primary care providers		program functioning and team cohesion. Stakeholder buy-in and access/visibility were perceived to facilitate initial implementation, and evidence of success was believed to facilitate maintenance. Stakeholder buy-in and administrative support were considered key elements of leadership support. Results were consistent with prior research from specialty mental health settings, but identified unique considerations for settings, particularly clarifying the peer support role based on local needs, obtaining buy-in, and facilitating integration of PSSs into the primary care team.
Stewart, S, Scholz, B, Gordon, S & Happell, B 2019, '"It depends what you mean by leadership": An analysis of stakeholder perspectives on consumer leadership', *International Journal of Mental Health Nursing,* vol. 28, no. 1, pp. 339-350. (LE)	Qualitative study	Australian Capital Territory Mental health sector	n=14 mix of sector leaders, consumer leaders and allies (not detailed)	Semi-structured interviews and thematic analysis	Findings indicate constructions of consumer leadership within mental health organisations can be understood in relation to four themes: consumer leadership roles, requirements, purpose, and process. Inconsistencies across participants' perceptions of consumer leadership were identified as constituting barriers to its development, highlighting the need to better clarify the nature of consumer leadership. Roles associated with consumer leadership fell into 5 categories including advocacy, service design (representation), service delivery (peer support work), education and training and funding, management and governance. Requirements of consumer leadership: lived experience, service use and leadership capacity. The purpose of consumer leadership – enacted to achieve change, increase influence and availability of lived experience perspectives.

					The process of consumer leadership, through application of lived experience, through exercise of influence, through relationships with others (conformity or disruptive) and through culture development.
Stewart, S, Watson, S, Montague, R & Stevenson, C 2008, 'Set up to fail? Consumer participation in the mental health service system', *Australasian Psychiatry: Bulletin of Royal Australian and New Zealand College of Psychiatrists,* vol. 16, no. 5, pp. 348-353.	Descriptive survey: role and training needs analysis- industry level research	Australia: Survey exploring roles of consumer participation Administered through NSW Consumer Advisory Group Membership	n=35 consumer respondents who were active as user providers	Descriptive analysis	Many mental health consumers have been placed in the untenable position of being engaged in representation and/or advocacy roles with unclear job descriptions and no training. The majority of consumers want a code of ethics and performance standards for consumer workers. Common roles include consumer advocate and consumer consultant/ advisor. Main tasks undertaken included representative on committees and boards, individual advocacy, policy development, events, service management, social support, administration, education and counselling. Respondents indicated that 30% consumers had received no training for their positions. Training needs identified included advocacy skills, communication skills, administration, policy and legislation, meeting skills, conflict resolution, confidence building, assertiveness, understanding health system jargon. Code of ethics and performance standards received support as means to guide consumer workforce. Conclusion: clear job descriptions, common understandings of their roles, adequate preparation, ongoing support and access to supervision required.
Stratford, AC, Halpin, M, Phillips, K, Skerritt, F, Beales, A, Cheng, V, Hammond, M,	Discursive paper	International; Outlines principles,	N/A	N/A	Achieves a definition of peer support for the purposes of the charter: Based on using lived experience of recovery, training and support to facilitate and guide recovery for

O'Hagan, M, Loreto, C, Tiengtom, K, Kobe, B, Harrington, S, Fisher, D & Davidson, L 2019, 'The growth of peer support: An international charter', *Journal of Mental Health*, vol. 28, no. 6, pp. 627-32 . (LE)		values and practices essential to peer support as developed by international consortium			others, through instilling hope, modelling recovery and supporting autonomy. List key principles of human/civil rights perspective and empowerments, avoiding use of social control function, and enhancing autonomy, the role of using lived experience and reciprocity, mutual, non-hierarchical relationships.
Stringfellow, JW & Muscari, KD 2003, 'A program of support for consumer participation in systems change: The West Virginia Leadership Academy', *Journal of Disability Policy Studies*, vol. 14, no. 3, pp. 142-47.	Descriptive paper	USA: Describes processes and content of West Virginia Leadership Academy and resulting national CONTAC leadership program	N/A	N/A	Leadership program description: Advocacy framework informs training content. Training based on adult education principles. Sessions run from 2 to 3 hours, combined into approximately 7-hour workshop days. Content: • knowledge of problems: Participants receive instruction in monitoring organisational and community environments for important events; • Skill in presenting issues: Concise and comprehensive reporting of events is taught; • Skill in forming and leading groups: Instruction in organisational structure and meeting process is provided. Rules of order and organisational officer roles are outlined and practiced; • Strategic planning: Participants learn how to choose projects and generate alternative solutions to community problems using cost– benefit analyses of resources and outcomes;

					- Controlling consequences for critical actors in the system: Emphasis is placed on techniques for controlling consequences experienced by decision makers, both positive and negative; and - Structural variables: Participants learn how to access the power inherent in critical information sources such as minutes for boards of directors' meetings or meeting agendas of elected officials. National program has scholarships.
Tanenbaum, SJ 2011, 'Mental health consumer-operated services organizations in the US: citizenship as a core function and strategy for growth', *Health Care Analysis*, vol. 19, no. 2, pp. 192-205. (LE)	Descriptive study	USA: Study of leadership characteristics and roles COSOs	n=23 Directors of consumer operated service organisations n=17 via survey n=5 via telephone interview	Descriptive analysis	COSOs[12] are have roles and relationship in linking consumers with a range of community services and organisations apart from mental health services. Consumers also provide peer supports services and make up at least a majority of the organisation's leadership. The dominant conception of the COSO as an adjunct service to clinical mental health services and can be reframed that COSOs are a civic organisation. COSOs are membership organisations with democratic norms and strong ties to local communities. This perspective opens opportunities for advancing citizenship and recovery.
Wituk, S, Vu, CC, Brown, LD & Meissen, G 2008, 'Organisational capacity needs of consumer-run organisations',	Descriptive study	Kansas, USA: Identifies organisational development needs of CROs including	n=27 CROs	Uses framework for organisational capacities to measure requests of CROs to assistance/development agencies	Findings indicate a range of requests for assistance. Listed in order of most common requests for assistance: grant writing, quarterly reporting, board development, business management, staffing, conflict resolution, policy development, activity planning, partnership relations, non-profit status, transportations, computer issues, increasing

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[12] COSO = Consumer-operated services organisations

Administration and Policy in Mental Health and Mental Health Services Research, vol. 35, no. 3, pp. 212-219.		leadership needs			membership, volunteer development, financial mismanagement, strategic planning, public awareness. Requests increased two-fold over two years, as the organisations have grown in service numbers.