

THE ALIVE NATIONAL **WRITER-IN-RESIDENCE** PROGRAM



About the writer



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Brett Scholz is a Senior Research Fellow / Senior Lecturer based in the School of Medicine and Psychology at The Australian National University. As a Critical Health Psychologist, Brett's research often focuses on ways in which health and health services can be more equitable, led by consumers, and challenging social norms and power structures. The majority of his 86 publications to date have been co-produced with and/or co-authored by consumer researchers, and his research program is concerned broadly with lived-experience leadership in health policy, health services, health research, and health education. According to SciVal, since 2017 he has been the leading scholar (in terms of number of research outputs) in consumer leadership.

Brett has served as a Board Member for the ACT Mental Health Consumer Network, and was co-founder and Chief Research Office for Spur Projects. He is an inaugural editorial board member for the International Mad Studies Journal, and serves on the editorial boards of the International Journal of Mental Health Nursing, Psychology of Men & Masculinities, and is an associate editor for BMC Health Services Research. He is current Secretary for the International Society of Critical Health Psychology. When he's not thinking about all things lived-experience leadership, he can be found on the hunt for the best bánh cuốn, sipping a matcha latte, or singing karaoke.



Issue 1

Trying to do co-design amidst a pandemic



In Mid-October 2022, the Australian National University (where I work as a researcher) announced that it was removing mask protections across campus. Up until the announcement, I was feeling confident that my team could still be running co-design sessions on campus, secure in the knowledge that mask protections sent a message that we were being inclusive of our wider community. I have spent the week since this announcement thinking about how we manage to progress collaborative work in the context of our institutions removing these protections, and who are thus enacting [“an ongoing commitment to purposeful exclusion”](#) of disabled staff, students, and visitors.

As many of us will know through experience (even if we have not consciously thought about it before), our universities and health institutions are already places which are rife with accessibility issues. This includes very basic or mundane considerations. For instance, every time I invite a guest to campus I need to have a parking permit made up for them, print it out, and perch by my window to see when they are arriving to bring the permit to the car. And all that is assuming they have their own car in the first place. It also includes issues about the practicalities of access e.g., if my guest is



unable to use the stairs, my own swipe card for the building will not let me take them in the lift so I need to go and ask someone else for access. This is not to mention the way our buildings and rooms are often illogically numbered or designed. For example, earlier this month I was giving a lecture in an unfamiliar building on campus, only to spend about 10 minutes completely circumnavigating the building *around* the one I finally identified as my target. So in many ways the odds of us doing *accessible* co-design are already stacked against us! Add to this the removal of simple mask protections in the middle of the pandemic, and we have become not only inaccessible, but also unsafe. There's no perfect answer to this conundrum, but here are some of my learnings from the past few years about how to create safe and accessible co-design spaces in our peri-pandemic context.

Digital Spaces for Co-Design

There are several challenges to translating co-design sessions to digital platforms, including:

- Differences in digital literacy and understandings of etiquette;
- Differences in internet bandwidth availability and other technological hurdles;
- *Zoom fatigue*; and
- Differences in facilitation skills and processes for co-design in digital spaces (Kennedy et al., 2021).

Further, when considering that accessibility is paramount to quality co-design, it seems clear to me that we need to give more thought to the ways using digital spaces actively excludes particular groups.

All that said, digital spaces can increase the accessibility of co-design for some. For instance, one of our current projects is concerned with co-designing a research project about suicide prevention services for young people. There are three different arms to the study: one specifically looking at the use of suicide prevention services for Aboriginal and Torres Strait Islander youth, another focusing specifically on young people living in regional, rural, or remote areas, and a final arm concerned specifically



with young people in metropolitan areas. We have used digital spaces for our co-design sessions so far partly because it has been difficult finding venues that will be COVID-safe for us all, and partly because of the relatively high levels of comfort young people have with digital spaces. I do note, however, that this option has likely excluded some people and their perspectives (which will of course have implications for the project if co-design outcomes rely on digital spaces).

Beyond Digital Spaces

When we think about using digital spaces, we are probably thinking about synchronous co-design. However, COVID-safe co-design could be done asynchronously too (in digital or non-digital spaces). This could involve iterative collaboration on co-design processes over time. Personally, as someone who doesn't mind that extra time to think, asynchronous co-design sounds quite appealing. I've often left synchronous co-design events and thought of a brilliant – or at least pertinent – contribution *after* the fact, but asynchronous co-design opens up opportunities for slower, more thoughtful processes. Langley et al. (2021) cover these alternatives to digital co-design in much more detail.

Although I've not done it myself (yet), I also think a COVID-safe, outdoor approach to co-design would be helpful for breaking down institutional barriers. Such an approach might even be considered an example of conducting co-design in a 'third sphere' that is neither inherently academic nor political (Dierckx et al., 2021). Planning would of course need to ensure that spaces were accessible (and that papers or tools don't go flying off in the wind). However, in the current context of universities and health institutions removing COVID protections, this may offer a more inclusive way to ensure co-designers feel safe and valued.

Concluding Thoughts

With mask protections being removed across our institutions, the spaces in which we practice co-design are at risk of becoming actively exclusionary and unsafe (Wallace & Moss, 2022). Given universities and health institutions are already often difficult to



navigate, it is becoming difficult to plan for co-design sessions in the coming months. While there are many digital tools that could be used to facilitate co-design, we need to think critically about whether these options are accessible and whose perspectives we might be excluding by relying on them. Asynchronous or outdoor approaches to co-design offer some potential solutions. As with most inclusion initiatives, these creative approaches to co-design are likely to help everyone (not *only* those with disabilities or vulnerabilities to COVID) feel more included and safe.

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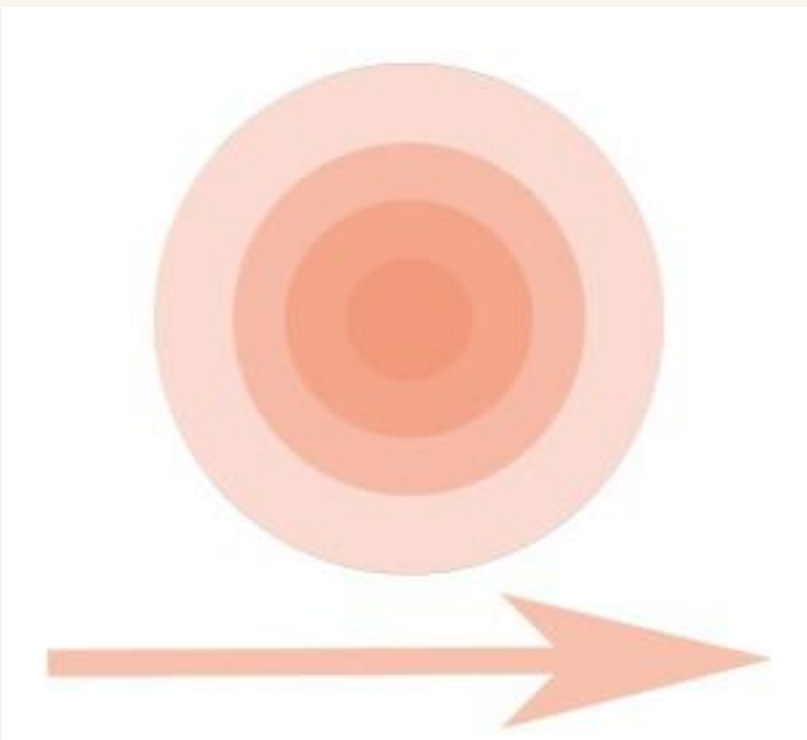
Issue 2

Open Access: Supporting consumer leadership and co-production across the ecosystem



International Open Access Week has *just* come to an end (October 24-30, 2022). Founded in 2008, #OAWeek aims to increase awareness of [open access initiatives](#). Reading about the [first years of Open Access Week](#), I felt frustrated that many of the same barriers to open access (including prohibitive costs and imbalances in which researchers and organisations have access to resources to publish open access) persist despite decades of advocacy for change in dominant publishing models. There are people far more qualified than I to discuss the [background, philosophy, importance, processes, and implications of open access](#). The majority of published research remains locked behind paywalls, and expensive to access without an existing academic affiliation. However, in this piece I wanted to outline why open access is important to those of us who seek to co-produce policy, services, research, and education with people with lived-experience.

Academic structures often exclude people with lived-experience, and [this exclusion occurs across multiple layers of the academic system](#)¹ (including institutions, research funding, and publishing and dissemination practices). It can be helpful to view these challenges using the figure below (inspired by the use of ecological systems theory in relation to consumer-led research; Scholz et al., 2019) shows a series of concentric circles with the innermost circle representing the ‘microsystem’ or a specific partnership between consumers and non-consumers in an academic setting. The increasingly broader circles (the mesosystem, exosystem, and macrosystem) represent increasingly distal but powerful organisations and structures shaping and constraining the partnership. For instance, specific schools within a university may constitute the mesosystem, and research funding bodies may be part of the macrosystem surrounding the partnership. The arrow at the bottom of the figure represents the chronosystem, representing the relationship between time and the structures constituting the ecosystem.



¹ I appreciate and apologise for the irony in linking to publications that are not open access!

In the context of this ecosystemic view of partnerships between consumers and non-consumers, publishing practices (including open access publishing) may be considered part of the broader, or macrosystemic layers of the academic system. Open access publishing is growing, but freely available online publications remain in the minority (Piwowar et al., 2018). There are some standard practices for challenging these barriers at the microsystemic level, such as authors happily providing consumers (or anyone without institutional access) with copies of publications, or through sites that illegally host content (Piwowar et al., 2018). Microsystemic solutions may be helpful to support individual partnerships with consumers (Scholz et al., 2019), but our research also calls for greater support (including employing, funding, and co-producing) for consumer leadership at broader systemic levels too.

What kinds of peer-reviewed literature is accessible?

One argument I often see is that funding bodies are moving towards models that support greater open access publishing (although there are several funding bodies that exclude these direct costs from their schemes). While this is a step in the right direction it does give me pause. [A significant proportion of research is unfunded or cross-subsidised](#) and many open access options are prohibitively expensive for researchers. [Funding for science is also politicised](#). If there are more open access publications emerging from research that has been publicly funded, could this constitute a form of censorship of research that goes against the popular or mainstream grain? When we consider that consumer-led or co-produced research is still inherently political and often silenced (Scholz et al., 2018), it seems particularly important to think more deeply about open access publishing and what kinds of knowledge we value.

Without more widespread open access, what does that mean for consumer leadership or co-production?

Access to peer-reviewed literature may be an intangible power imbalance between consumers not employed within academic institutions, and people who are. It may be something that many university employees do not even consider because



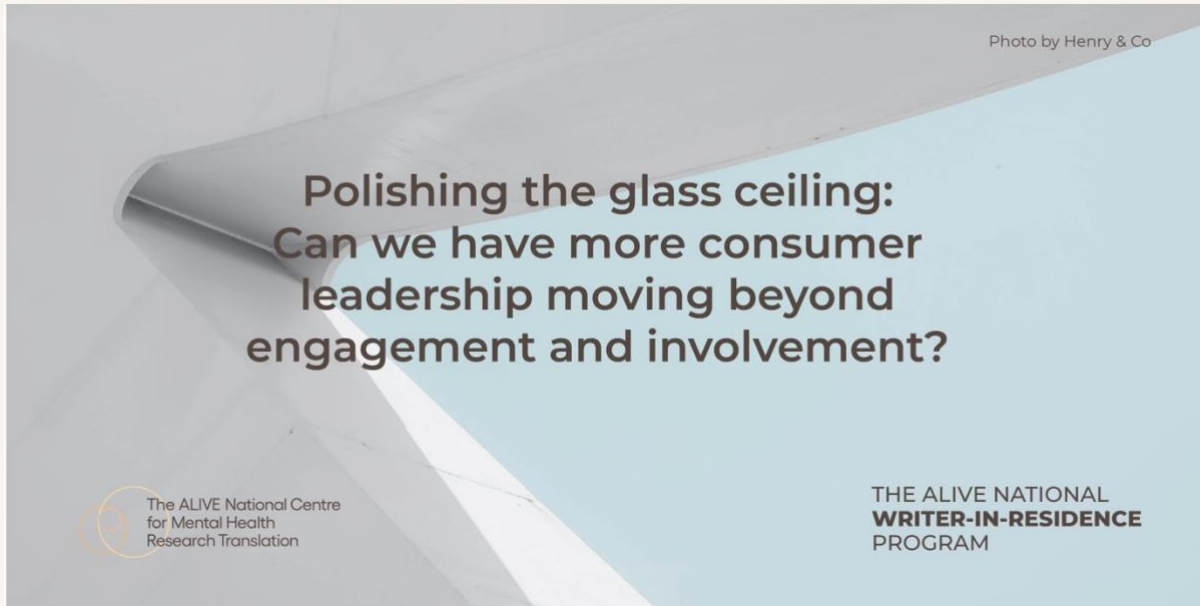
mainstream publishing practices are an entrenched part of academia. This access then becomes taken-for-granted. However, failure to redress power imbalances may be another way in which the people with lived-experience are marginalised. In turn, partnerships with consumers fail to achieve a meaningful exchange of expertise (Scholz et al., 2018). Providing consumer partners with institutional access to peer-reviewed literature would be a step towards redressing power imbalances – leading to better collaboration and outcomes. Ideally this would include consumers on academic staff, but could also involve honorary or adjunct appointments for consumers, or agreements between libraries and consumer organisations.

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Issue 3

Polishing the glass ceiling: Can we have more consumer leadership moving beyond engagement and involvement?



Trying to demonstrate collaboration with consumers has become something of the flavour-of-the-2020s. Whenever I see a new initiative about consumer engagement (such as [this recent framework from Cochrane](#), or like the current review of the [NHMRC Statement on Consumer and Community Involvement](#)) I really want to get excited and believe that *this time* there really will be a difference (and that this initiative or that will *really* redress power imbalances between consumers and the health system). On the other hand, I find myself increasingly disappointed that as soon as you scratch the surface a little, initiatives for engagement and involvement reveal that they're just new tools to exclude consumers from decision-making and agenda-setting roles. These engagement or involvement initiatives are becoming less like a hammer designed to [break the glass ceiling](#) for consumers, and more like Windex designed to polish it (i.e., making it look superficially like consumers are part of the health system hierarchy while not challenging structures keeping consumers out of leadership).

Readers are probably already familiar with Arnstein's ladder (personally I really like the version appearing in [this great resource by Indigo Daya](#)). It helps to categorise initiatives based on the extent to which 'citizens' have power over decisions. There has been a push to move up the ladder and in doing so, we appear to have forgotten that "It's good to move up the ladder—but it's even more important to be honest" (Daya, 2021). In other words, we should not get so caught up in the importance of moving up the ladder that we claim to be higher up than we really are. For example, if an initiative is at a more tokenistic or consultative stage, it should be stated upfront and honestly instead of trying to claim that a higher level (such as co-production) has been achieved.

Even though Arnstein's ladder was published 53 years ago, and even though consumer movements have called for greater control in the health sector for decades, so-called "new" initiatives based on consumer engagement and involvement rarely push beyond the tokenistic 5th rung of the ladder of 'placation'. This rung [has been described](#) as "co-option of hand-picked 'worthies' onto committees" and as allowing consumers "to advise or plan infinitum but retains for power holders the right to judge the legitimacy or feasibility of the advice" (Wilcox, 1998). The next rung up – *Partnership* – is rarely met because it requires the redistribution of power through negotiation between consumers and those in power.

When new 'consumer engagement and involvement frameworks' are developed and published, I am extra-troubled to see them accompanied by fanfare and claims that they are ["bold" and "new"](#). They often seem to contain more structures that reinforce Rung 5 (*Placation*) on the Ladder of Participation as the highest rung we need to reach. For instance, I rarely see frameworks for bold, new initiatives to ensure there are consumer executives in every health organisation, or that divisions of health services include an Executive Director (Lived-experience). (Noting of course some pockets of great developments such as the [development of a role](#) in the Mental Health and Wellbeing Division in the Victorian State Government last year of an Executive Director Lived-experience – but we need so much more!).

My worry is that there is a lack of understanding and appreciation of lived-experience leadership across the health sector. I want to be clear that I'm not saying consumer engagement or involvement is worthless. It's important and I want more of that too.

But the proliferation of consumer engagement and involvement only demonstrates how poorly we are doing by reinforcing the glass ceiling with placations to consumers, and limiting lived-experience leadership across the health sector. [We need to set the bar so much higher](#) – and call for consumer leadership.

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Issue 4

Rehashing Representation (And three things you can do right now to help!)



Working in consumer leadership, there are a lot of related concepts or words that I notice are used inappropriately or problematically (if you missed [my previous piece explaining why if I never see 'involvement' or 'engagement' again it will be too soon](#), then have a read). In this piece, I wanted to take the opportunity to explore the word 'representation' (as in consumer representation) and the ways that it enables and limits the kinds of roles possible or imagined for consumers.

Although I've written a lot about consumer representation in academic publications, there are two particular conversations about representativeness that I've never had the space to write about that still make me sad when I think about them.

The first is the idea that "consumer representatives" should stay in their lane. This was illustrated when I was reaching out to relevant organisations across Australia to collect data for a project about how consumer representatives are excluded in health organisations (that led to [this very-fun-to-write paper](#)). One response in particular stood out as worrying. This was from a then-staff member at a mental health



consumer peak, who said they wouldn't support recruitment for the study because consumer representatives should 'stick to' consumer representation roles, implying that we shouldn't strive for more.

The second was in relation to gate-keeping lived-experience representation by people who do not share that lived-experience. Specifically, in 2020 I was involved in facilitating the development of a [collaboratively-produced triage process for COVID-19](#) in the Australian Capital Territory. It was critical that relevant lived-experience was included in the development of triage – and in the context of COVID-19 that included older adults, people with disabilities, and Aboriginal and Torres Strait Islander people. I was seeking more opportunities for Aboriginal and Torres Strait Islander people to shape COVID-19 policy. A (non-Indigenous) stakeholder from an Aboriginal and Torres Strait Islander organisation implied that representation was not a concern, because there are common experiences of marginalised groups “regardless of who is representing them”. Thus even now, it seems there is still reluctance to include people with relevant lived-experience in projects.

If you've been working in the health system for long, you've probably heard people use an appeal to representation (or lack of representation) as a way to justify their exclusion of consumers. These appeals function in several ways. The views of a consumer representative could be downplayed or dismissed by referring to them as being a loud consumer with an axe to grind (with the implication being that they therefore have a very specific experience that is not representative of the majority), or you might have heard the disparaging term 'career consumer' (with the implication being that they're often too high-functioning to really represent the general service user). You may even have heard a doctor or a nurse say “it's ok, I've been a service user, so I can represent that perspective on this committee” which ignores that they of course have not experienced the same power imbalances as people without their medical background.

[This paper](#) from 2006 is sadly all too relevant still today. It articulately explains how appeals to representation can silence activism, question the legitimacy of consumer



roles, and hold consumers to standards other health professionals are not held to. To illustrate, I'm a psychologist, but I've never had my views ignored because someone said they weren't 'representative' of most psychologists.

Drawing on this seminal work, a few years ago my team and I wrote [a paper discursively analysing this appeal to representation](#). Some of our key findings were that:

- Consumer representation seems to be often poorly defined, with organisations and representatives unclear about *what* is being represented
- Consumers' expertise is still ignored, with claims that their views are not representative being used to legitimise their exclusion
- Consumers are still held to standards not required of other health professionals to ensure their individual experience does not dominate their representative roles. However, people who criticise consumers for only being able to 'represent' limited views or experience never seem to offer resources for these consumers to go and canvas broader views.

There are 3 things I want YOU to do right now to improve these issues:

- 1) **Put the onus for broader representation on organisations** rather than individual consumers. If a health service is running an initiative requiring broad consumer representation, then they should take responsibility for working with a wide range of people. I really don't want to see more people being silenced because they weren't 'representative enough'.
- 2) **Think about whose views need to be represented and keep making space for them.** It's easy to be confused about seeking representation from marginalised groups and people who need to be included or part of collaborative processes because they are **centrally impacted** by a particular project. As an example, in a project that has direct implications for, say, asylum seekers, their experiences are centrally impacted and their representation is required. Other marginalised groups (such as, e.g., non-binary people or older adults) may not have experience crucial to the project or outcome. I want us to continue to think

about whose perspective needs to be central and ensure people with those experiences are central.

- 3) **Be clear about what roles and responsibilities representatives and their collaborators have within a specific initiative.** When collecting data for [our study on consumer representation](#), several people spoke of interactions they had (either as consumer representatives or people working with consumer representatives) in which they realised stakeholders were unclear about the role of representation.

By including these additional steps, we can continue to ensure more space is made for consumer representation to influence our health systems.

Issue 5

All I Want for 2023...



Recently, I [tweeted](#) that all I wanted for Christmas is a [National Statement on Consumer and Community Involvement in Health and Medical Research](#) that goes beyond engagement or involvement of consumers. It made me think about other things I'd add to my wishlist that I hope 2023 might have in store for us.

As I have just returned to the office after returning from celebrating Tết with family, I thought it was timely to indulge my hopes for lived-experience leadership for the Year of the Cat ahead!

- I saw a lot more references to consumer engagement and involvement in 2022 than I had seen in previous years. While this could be a good thing, I worry there is also a lot more tokenism than we have had before. I hope in 2023 health policy, services, research and education are done with a view to [moving beyond engagement or involvement towards lived-experience leadership](#).
- We entered [2022 with the new appointment of an Executive Director Lived-experience](#) in Victoria which is a great step. In 2023 I want to see more lived-experience roles at these top levels – and indeed at all levels – across the health sector.



- I want to see more health professionals educated *by* people with lived-experience. Some mental health professions seem more reluctant than others to take this up. For instance, when I discuss the issue with my own psychology colleagues, I am often told they already have a session in which a consumer comes to tell their story. While story-telling is important, it is not [consumer-led curricula development](#) providing opportunities for students to better understand consumers' lived-experience or value the expertise this experience brings. I hope 2023 brings more identified positions for consumers to teach the next generation of health professionals.

I also have to point out that one of my wishes for 2023 has already come true – with the publication of the [first volume of the International Mad Studies Journal](#). You can read more about the journey leading to the publication of the Volume [here](#). All the articles are available open access – so add them to your 2023 reading list! Having read all of them now at least once, I'm reassured that the journal is making great progress on its goal to create space for scholarly work that may be excluded from conventional mental health journals for various reasons. I can't wait to see what 2023 has for the journal.



Issue 6

New Frontiers in Lived-Experience Leadership Part 1: Current developments



In my previous piece, I presented [my wishlist for lived-experience leadership in 2023](#). This week, I want to focus on some key lived-experience developments that have been happening in recent months.

As I'm based in Australia, a lot of the lived-experience leadership I am exposed to is within an Australian context. However, a very high-profile example of lived-experience leadership in 2022 came from the UK, where we saw an increase in senior lived-experience roles across the National Health Service. In December, one such role for a "Director of Lived-experience" in the Midlands Partnership NHS Foundation trust was advertised. On social media, the responses to the creation of the position were polarised. Posts about the position that were negative seemed to suggest that the public still do not understand the importance of lived-experience in shaping, planning, delivering, and evaluating health services (e.g., "[Can anyone explain what exactly the job is as well?](#)"). There were health professionals who critiqued the position on financial grounds, arguing that supporting lived-experience leadership was at the expense of other health professionals (e.g., [The NHS has a never ending pot](#)



[of money for jobs like this](#)). Nonetheless, the creation of such positions suggest that these health organisations are at least starting to understand they [cannot benefit from lived-experience leadership without demonstrating they value experiential expertise](#).

A more recent platform for lived-experience leadership here in Australia [was announced at the end of January](#) this year? in the form of over \$7m in investments into establishing separate national consumer and carer peak bodies, and into mechanisms to enable dialogues between peaks and the government -an exciting ([and very overdue](#)) development. The establishment of these peaks may be another means to ensure that lived-experience leadership becomes an embedded [part of the hierarchy of the mental health system](#).

While I often complain that an increase in awareness about lived-experience leadership also leads to an increase in the co-option or tokenistic application of related practices ([such as co-design](#)), I also saw signs in 2022 of systems genuinely challenging power imbalances against consumers:

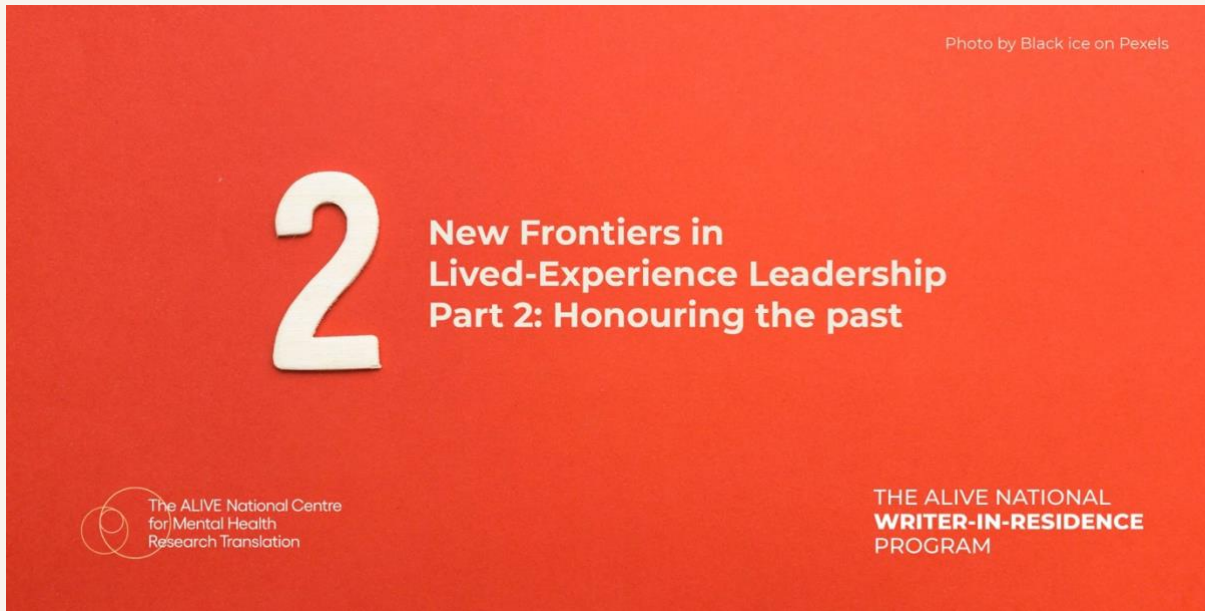
- One close-to-home (for me here in Ngunnawal Country) example was the development of a working group at Canberra Health Services to develop a plan for the implementation of the [organisations' research strategy's](#) commitment to “create impactful research *partnerships* with consumers and communities”. While a lot of other plans I see relegate consumers to engagement or involvement roles, this approach to partner with consumers (including half of the members of the working group coming from a lived-experience perspective) feels promising and exciting.
- Other key examples comes from the Victorian Collaborative Centre for Mental Health and Wellbeing who developed their [Lived-experiences Advisory Panel](#), and the ALIVE National Centre for Mental Health Research [embedding lived-experience expertise in its co-directorship model](#). These are reflective of a general trend I see in organisations working to embed lived-experience leadership across all stages of initiatives.

There is clearly still a long way to go until lived-experience leadership is widely understood and embraced, but these developments have given me some hope and inspiration this past year. In the next part of this series, I'll talk about the importance of recognising the foundations of lived-experience leadership in “New Frontiers in Lived-experience Leadership Part 2: Honouring the past”



Issue 7

New Frontiers in Lived-experience Leadership Part 2: Honouring the past



Amongst the fanfare of [the recent announcement from the Health minister recently of the establishment of national consumer and carer peak bodies](#), I was struck by the sheer volume of calls to remember the incredible previous achievements of the consumer movement that has led us to this point. Supporting and doing lived-experience leadership has been and continues to be a lot of labour, and it is warming to see [reminders](#) that each advancement made by the consumer movement is because of a lot of work by those who have come before.

The origins of lived-experience leadership are founded by a strong mental health consumer movement. I often find myself returning to [Merinda Epstein's memoir](#) of the earlier days of the consumer movement and reflecting on the ways in which it grew together with other social justice movements.

The [first publication in the academic literature about lived-experience leadership](#) was by Sarah Gordon who now leads the [World of Difference](#) service user research group at the University of Otago. I've drawn significantly on Sarah's seminal paper in my



own research about lived-experience leadership, and sometimes I find it frustrating that her words from 2005 still feel just as relevant almost 20 years later:

“the actual realization of consumer involvement within the mental health sector is extremely variable and the extent of ‘real’ participation highly questionable.... It is contended that the paradigm shift from consumer ‘participation’ to consumer ‘leadership’ may be more fruitful in realizing the considerable benefits that result from effective consumer involvement in mental health services.” (Gordon, 2005; p365)

It wasn't all that much earlier than that, in 2000, when the [world's first identified lived-experience academic position](#) was established at the University of Melbourne. More than two decades later, I don't see as much lived-experience leadership in the academy as I would have liked. Although there are some more dedicated positions for lived-experience academics, they are few and far between. Agenda setting within the sector remains in the hands of those who have traditionally held the reigns, with people working from lived-experience perspectives remaining trapped [outside the hierarchy by a glass ceiling](#). The university ecosystem (including funding bodies, internal university structures, and research production and dissemination) [continues to put up barriers at all levels](#) to lived-experience leadership.

I think this history is why I often feel ambivalent about developments in the sector. I genuinely do want to celebrate the huge strides the consumer movement has made ([and I truly am excited by all the developments in 2022 I outlined earlier](#)) but it can also be difficult to see how consumer leadership is still far away in many ways. However, I am buoyed by seeing similar movements globally striving for similar goals and calling for lived-experience leadership (such as can be seen in initiatives in the [Caribbean](#), the [UK](#), and [Ethiopia](#)) and this includes lived-experience leadership within the health system but in disciplines beyond mental health. Together, I think we can stand on the shoulders of the giants of consumer movements and continue to build momentum for lived-experience leadership.



Seeing how lived-experience leadership has spread further and faster in recent years does make me hopeful. Join me next time (for my final piece during my tenure as Writer-in-Residence!) when I explore what recent research would suggest is coming up on the horizon for consumer leadership in the final part of this three-part-series: “New Frontiers in Lived-experience Leadership Part 3: Where to next”

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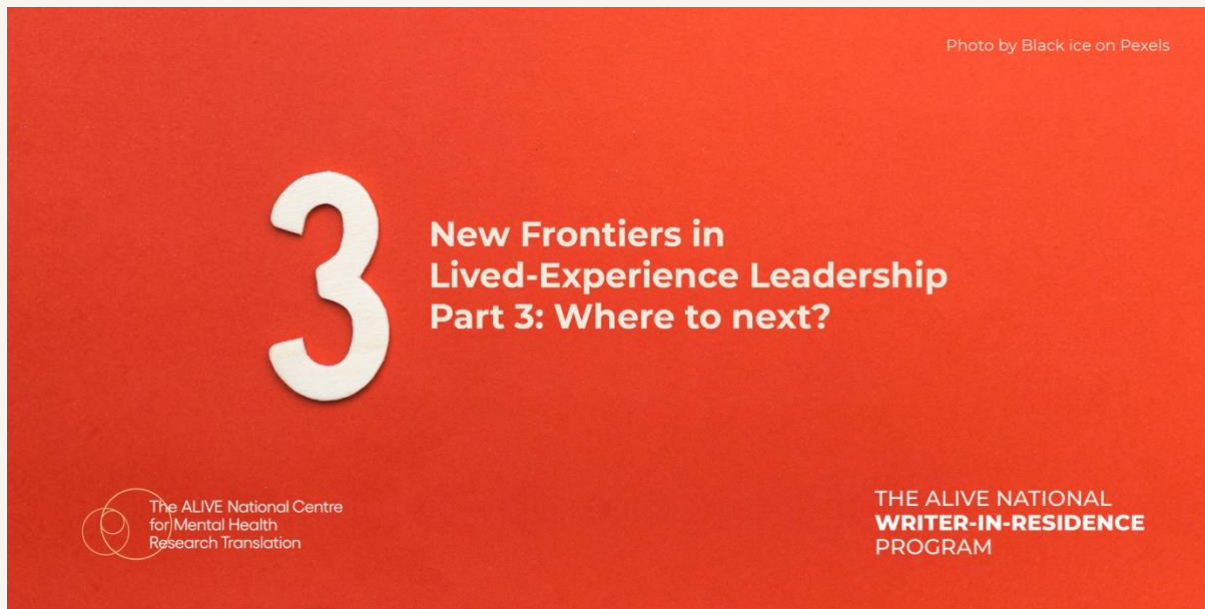
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Issue 8

New Frontiers in Lived-experience Leadership Part 3: Where to next?



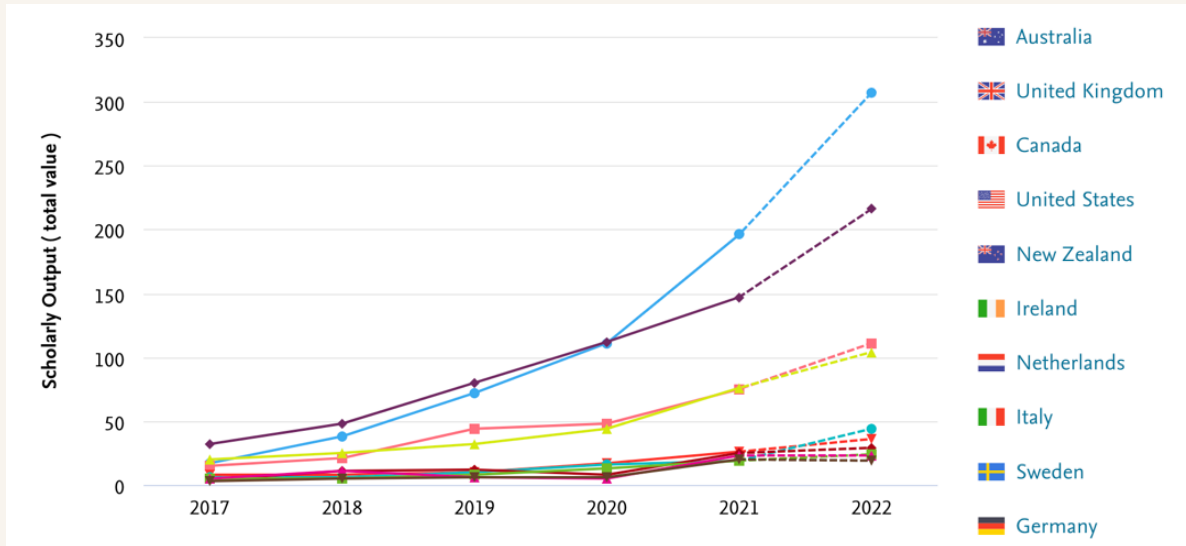
Reading back through my posts during my tenure as Writer-in-Residence, I can see my ambivalence about where lived-experience leadership is headed. On the one hand, I'm optimistic. We have seen great developments in the space, and the sector is well positioned to continue to develop lived-experience leadership. On the other hand, it seems to be a real struggle for people to envision policy, services, education and research moving beyond consumer engagement and involvement and into a consumer-led paradigm. There is a strong evidence base for lived-experience leadership, and in this final piece in the 'New Frontiers in Lived-experience Leadership' series, I draw on this research to suggest a way forward (and highlight some potential pitfalls to remain wary of!)

What is holding us back from achieving lived-experience leadership?

- 1) *The rhetoric of a 'participatory turn' without the action.* Scholars across health disciplines have argued that we amidst a participatory turn in health and medicine, whereby consumers are "reconfigured as co-equal participants and



collaborators in research and care” (Siffels et al., 2021). We see a lot of talk of this, but I worry that there is less action backing it up.



For instance, this graph maps scholarly publications about ‘co-design’ in the health disciplines since 2017 across the 10 most prolific countries in the field (SciVal, 2023). The upwards trend may not be surprising, but the extent to which truly collaborative approaches have been practiced is less clear.

It is exciting that co-design has received so much attention. At the same time, it is worrying to see co-design and other participatory terms used inappropriately. For instance, in the last few years I’ve reviewed dozens of NHMRC grant applications that have used such terms in the title or summary. However, [there has been only one](#) that I can remember that demonstrated genuine co-design by having consumers in the chief investigator team, a conceptual or theoretical framework underpinning the use of co-design, or capacity for co-design demonstrated by a track record in such practices. It worries me, then, that this ‘participatory turn’ may be more performative, lacking structural changes in systems for participation to occur.

Indeed, there is a growing body of literature about lived-experience leadership that critiques rhetoric rather than action. [Research by my team has found](#) that ambiguous terminology (such as ‘consumer representatives’) for a range of participatory roles

may contribute to disempowerment of consumers in the sector (Scholz et al., 2019a). This has served to silence consumers' views: I've often heard people decide a given consumer representative is not actually 'representative enough' as grounds to dismiss their input on a project. This is another example of other health professionals gatekeeping and holding consumers to their sometimes impossible standards. I worry that the 'participatory turn' is a lot more rhetoric and a lot less action – with power imbalances against consumers still rife.

For the participatory turn to become participatory in action, consumer leadership needs to [not be an afterthought](#), but a part of how we do everything in health policy, services, research and education (Scholz et al., 2018a)

- 2) *The glass ceiling keeping consumers in their place.* [Research by my team explored the impact of hierarchies](#) in the health system and found that consumers are excluded from decisions in the senior levels of organisations (Scholz et al., 2017). Those on the 'lower' rungs of the hierarchy (or even *outside* the hierarchy altogether as is often the case with consumers in the health sector) are treated unfairly or as though they are incompetent (ibid).

- 3) *The low bar of consumer engagement and involvement.* I've written about this before during my residency, but I think the point bears repeating: [we are stuck at the level of lived-experience engagement or involvement](#) (nebulous umbrella terms which may refer to actions with power-sharing but may also ignore power altogether). This is the case despite a long history of advocacy for and research about lived-experience leadership (Scholz, 2022). It seems that the proliferation of participatory approaches has ironically led to more projects and initiatives that 'involve' consumers in trivial or low-level decisions, leaving the agenda to be set by mainstream health professionals (ibid).

What will help us achieve lived-experience leadership?



- 1) *Valuing lived-experience.* Not just *say* we value lived-experience – rather, we need to truly value lived-experience [as if it were a sneaky, special qualification](#) just like, for instance, a psychology degree or medical training (Scholz et al., 2018b). As discussed above, however, people working from a lived-experience perspective are often still outside the health system hierarchies (Scholz et al., 2017), disempowered because they are assumed to lack capacity for decision-making and agenda-setting roles (Scholz et al., 2019a), or are relegated to specific or low-level decision-making processes (Scholz et al., 2018a).

- 2) *Ensuring our ecosystems are flexible enough for people with lived-experience to be engaged at every level.* [A lack of flexibility in terms of deadlines, employment pathways, HR processes, and project management](#) means that consumers experience ecosystemic barriers to their career progression (Scholz et al., 2019b). While individual colleagues can (and should – see #3 below) engage in advocacy at the microsystemic level (i.e., within individual projects or teams), the macrosystemic barriers (including organisational- and systems-level context) are harder to challenge (ibid).

- 3) *Actively engaging in allyship.* Allyship with the consumer movement can be conceptualised as other health professionals [using their power or privilege to make space or create opportunities for consumers](#) to be part of decision-making and agenda-setting in health policy, services, education or research (Happell & Scholz, 2018). Allyship requires action and avoids paternalism. For instance, it is important that allies do not try to ‘empower’ consumers in a performative way, but rather engage in political processes that [challenge power imbalances against consumers](#), creating opportunities for consumers to empower consumers (Juntanamalaga et al., 2019)

I'd like to leave you with a question (and please feel free to get in touch to let me know your answer: what are you going to do in your team/organisation/system to go beyond engagement or involvement and to help bring about lived-experience leadership?



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