McPin | Transforming
Foundation | mental health
research

Using lived experience in the workplace

How staff lived experiences are shaping work at McPin

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Foreword

Welcome to our resource, *Using lived experience in the workplace: How staff lived experiences are shaping work at McPin*. This is one of ten resources we've produced to celebrate ten years of the McPin Foundation.

For those new to us, we are a small mental health research charity that has been delivering on our mission to *transform mental health research* by placing lived experience at the center of research since April 2013. In this time, we have changed and grown from a six-person team to a network of staff, collaborators and partners covering the UK, with friends across the globe. To mark our anniversary we have produced a collection of ten resources that explain our approach to working in collaboration with lived experience expertise to lead and shape research, evaluations and public involvement work.

The '10 for 10' resources showcase our learning and reflections from working across a wide range of projects. They are not 'how to' guides but instead present our thinking and learning to date. Two years in the making, this collection has encouraged us to navigate differences of opinion, even amongst co-authors. We value the conversations this process sparked, and we believe the results are a collection of resources with more depth and nuance.

Now that we've published these resources, we'd like to continue that conversation. We don't have all the answers. At McPin, we are continuing to develop our expertise in coproduction, public involvement in research, peer research and supporting lived experience roles in the workplace. By sharing how we approach these issues and what we have learnt over the decade we hope the resources spark passionate conversations amongst the wider mental health research community, and beyond.

We do hope you find this resource on using lived experience in the workplace and others in the series useful, and we welcome feedback. Turning to this resource specifically, we define what lived experience means to McPin, dive into the complexities of disclosure and bring you tips on how to design a project to centre lived experience. We have found that our staff bring a huge diversity of strengths and skills into the workplace when they actively draw upon their lived experience. We hope that our learnings can help you to embrace the intrinsic value of lived experience in research.

Vanessa Pinfold

Vanessa Pinfold
Co-founder and research director

The resources in our 10 for 10 collection are:
1. Using lived experience in the workplace: How staff lived experiences are shaping work at McPin
2. Coproduction at McPin: Reflections and learning over 10 years
3. Peer Research at McPin: Our approach, reflections and learning over 10 years
4. Public Involvement in mental health research at McPin: Reflections and learning over 10 years
5. Research Involvement Groups: McPin's models and learning, and linked resource on 'recruiting for diversity'
6. Working as a co-researcher at McPin: Shaping young people's mental health research
7. Young People meeting guide
8. Wellbeing at work: What does it mean at McPin? and linked resources: Mentors and mentees (podcast); Neurodivergent meeting guide: A McPin lived experience perspective
9. McPin's journey towards antiracism
10. An Ode to Peer Research at McPin: You got the Power!: Dedicated to those who have crafted their pain into power (video)

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Introduction

In this resource we explore how people working at the McPin Foundation draw on their lived experiences in their job roles. Although this is something actively encouraged in our charity, we know that whether to use your lived experience or not is also a personal choice.

When you dive into the detail of what we mean by bringing lived experience to our work it gets complicated very quickly. This resource is about sharing some of our thinking and experiences. Our insights were gathered through workshops, online discussion spaces and one-to-one discussions across our team, alongside the knowledge gained through doing practical work in this area for ten years.

McPin is a mental health research charity. We believe that using lived experience in mental health research improves the quality of science and helps inform and deliver better systems, services and approaches to support mental wellbeing. It is also an effective way of dispelling some of the harmful myths that surround mental health issues and disability; myths that have generated stigma and discrimination.

For our team, using lived experience is about defining it in our own terms, embracing it as an asset and not viewing it as a deficit.

What do we mean by lived experience?

Lived experience at its broadest describes the knowledge and skills developed through everyday living. It covers lots of aspects of people's lives – for example: gender-based experiences; race-based experiences; parental or caring experiences; disability experiences; mental health experiences; place-based experiences from school or college; living in a particular neighbourhood; attending a faith or community centre; or contributing to a workplace.

At McPin we talk about mental health lived experiences a lot, however we are not only focused on mental health. We think it's important to recognise other life experiences that our staff bring to work; ones that intersect and connect with mental health experiences.

Lived experience yields distinct knowledge that is different to knowledge gained in professional or academic contexts. This can sit alongside and complement academic or occupational expertise generated through study or work.

Lived experience expertise is a term we use to describe the skill of using lived experiences in work. Having relevant lived experiences to draw upon is one thing, using them for work is quite another.

The skill of being able use lived experience in the workplace is sometimes inherent in people's ways of working, but it can also be developed over time with support and training.

We have seen first–hand the value of lived experience in the workplace. It shapes all our teams – Operations (HR, Finance), Communications, Research, and Patient and Public Involvement (PPI). What is clear is that people bring lots of knowledge and expertise to McPin based on mental health experiences. We have also found that, contrary to the stereotypes that exist about people who are labelled as having disabilities or mental health issues, people with lived experience bring their own networks with them and form valuable connections with other individuals. We believe this improves our work.

We hope this resource is useful to a wide range of people – to others working in mental health research but also other research fields and service provision. Many of the points may be useful to workplaces that want to focus on building opportunities for elevating lived experience knowledge. We share our learning about the skills and strengths that lived experience can bring to work, both within and outside of research. We also offer tips to help embed and encourage an inclusive workplace for using lived experience.

What does using lived experience in the workplace look like at McPin?

What using lived experience in the workplace looks like will be different for everyone. Sometimes how it looks will be dependent on the role and type of work undertaken. It also looks different depending on the context.

For example, at McPin if you are in an administrator role the way you interact with someone on the phone or in person might draw on your sense of how you would want to be treated when feeling distressed. That includes how a room is set up, how calls are answered, what questions are posed, or what tone is used. These factors can be influenced by the administrator's experiences and associated knowledge of managing mental health issues.

Using lived experience can be subtle. If you are a peer researcher interviewing someone for a research study, you might disclose your own lived experiences to help build rapport with the research participant. However, in a large external meeting you may not bring your lived experiences into the conversation.

There are many ways lived experience can be actively brought into the workplace as part of a job role, done through choice and with intentionality. We asked our team in a meeting to create a mind map of some examples (see Figure 1).

Challenging systems and calling people in to improve how they work with others with lived experience

Putting people at ease

Analysing data – reviewing transcripts

Setting up meetings and spaces to feel safe and welcoming – both online and in person

Translating jargon, communicating important information in accessible ways

Designing studies to reflect the priorities of communities with lived experience

Planning recruitment so people feel safe to participate and the study is appealing

Making paperwork understandable and not overwhelming

Interviews to build rapport and make people feel comfortable

Improving communication – using own experiences to make communication better for others

Supporting colleagues

Championing coproduction

Ways people use lived experience at work

Reflexivity

Planning agendas

Developing training

Empathy for others

Ensuring our work is culturally appropriate

Connecting people to issues they care about

Ensuring processes and policies are accessible and support people with different needs at work

Helping others share their stories

Validating other experiences

Debriefing

Facilitating meetings, using own experience to support others to contribute

Reviewing proposals, bids and funding applications

Identifying ways to bring other people with lived experience to the table

Ensuring the voice of lived experience is heard in research and impacts change for people

Ensuring management support recognises individual strengths and needs

When working in panels or groups to share thoughts from someone who has been impacted by the issues they are focused on

Figure 1: How people who work at McPin have chosen to use lived experience

Illustration credit: Kremena Dimitrova. Bridge Between Worlds
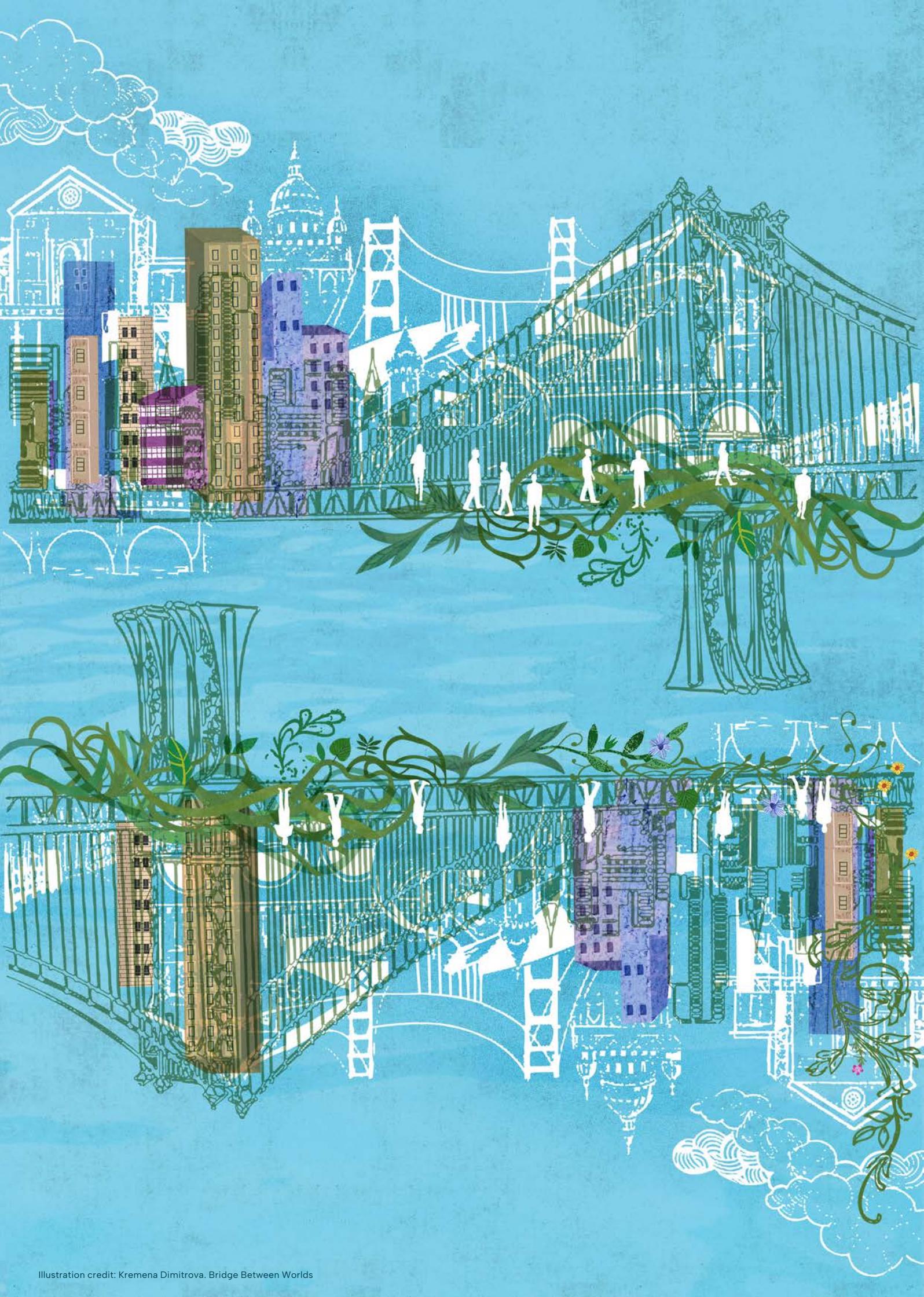
Disclosure

An important aspect of using lived experience in the workplace is **disclosure** and decisions around disclosure. Disclosure is a term used to describe the process of sharing lived experience. McPin believes what, when and how someone discloses should be up to the individual. In our work at McPin disclosure can be explicit or implied.

Disclosure is explicit when someone chooses to disclose. The staff member is in control of what, when and how much is shared. In our work this might be in conversations with Human Resources and line managers, as well as with colleagues, lived experience advisors in groups or research participants in projects.

For example, people in peer research roles may openly share that they have lived experience with an interviewee or discuss how their lived experience has impacted their analysis when working reflexively. Comparatively, someone working in our Operations team may draw on their lived experience more subtly by thinking about what adjustments might be made for other team members based on their own lived experience as well as their professional knowledge. Another aspect of disclosure in the workplace is routine day to day practices. This starts on applying for a job. At McPin we encourage open conversation to ensure everyone can be best supported to thrive at work. This includes conversations about wellbeing, and reasonable adjustments.

Disclosure is implied through association. Working for McPin links all staff to the ethos of involving people with lived experience in research. Members of a lived experience advisory group are recruited because they have a specific lived experience. A researcher actively using a peer research methodology on a mental health study will be using their lived experiences to shape the research. Their role title as a peer researcher means a lived experience of mental health issues is also implied. Even in these roles the details of what and how much is disclosed is ultimately a personal choice.

Disclosure is often context dependent. People may feel comfortable sharing in one place and not another. It is important when embedding lived experience into your workplace to respect people's decisions around disclosure; to not assume what is shared in one interaction or meeting is okay to be shared elsewhere. We also believe we shouldn't assume someone doesn't have any lived experience just because they don't disclose. We encourage team members to check in with, or give a 'heads up' to, colleagues before disclosing. This is to ensure sharing is not distressing for other people.

We believe disclosure can be very helpful when exploring adjustments and support in the workplace. It can be hard for managers or human resource teams to know how to best support people if they do not know someone is impacted at work by their mental health. It is important for managers to create spaces for these conversations. Disclosing in these contexts might be in a one-to-one conversation, through an occupational assessment, or as a discussion around Access to Work. What is shared in such conversations shouldn't be discussed more widely without consent.

Learn more

**To learn more about the various roles that use lived experience at McPin check out our patient and public involvement resource and peer research resource.
Find them on our website.**

Tips for Disclosure

Disclosure is a big topic and we cannot do justice to it in full here, but we have collated a few tips. Sometimes disclosure can be tricky; people often worry about what others will think of them and whether it will impact their career and progression. What and how you disclose is always up to you.

Before deciding to share take time to think and talk it through with someone you trust, and consider which places and settings you feel okay sharing in.

Think about:

- What's good for you?
- Do you want, or feel ready, to share?
- What's good for other people?
- What's helpful to get the support you need to do your work?

If you decide to disclose…

- **Do you feel you have support if needed?**
  Via your own personal network or at work.

- **How is your wellbeing?**
  Note comfort with sharing can change when wellbeing changes.

- **Use content warnings.**
  People who have experienced difficult or traumatic events should be able to make an informed decision about whether to view/hear sensitive content, such as discussions of abuse, suicide, rape, substance misuse, eating disorders, or death.

- **Respect the privacy of others.**
  Avoid naming others who have lived experiences unless you have their consent to do so.

- **If someone tells you they aren't ready to hear your lived experience, that's okay.**
  This might mean they have their own experiences that might be triggered or are not feeling mentally up to it.

- **Think about your environment.**
  Who can hear this conversation?

The diagram below (Figure 2) provides an example of one research activity and the many different ways people may choose to use their lived experience, including decisions around disclosure.
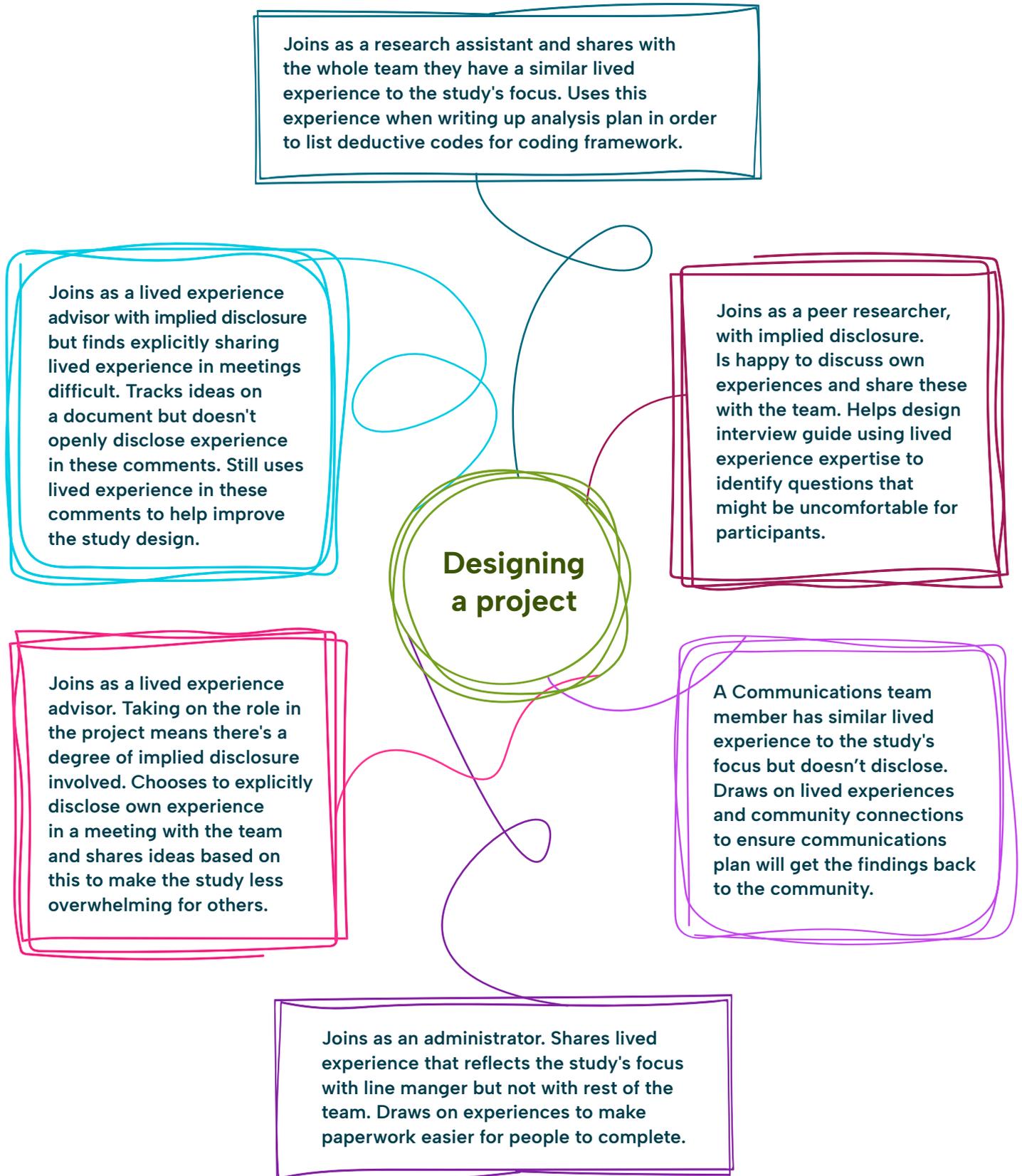

Joins as a research assistant and shares with the whole team they have a similar lived experience to the study's focus. Uses this experience when writing up analysis plan in order to list deductive codes for coding framework.

Joins as a lived experience advisor with implied disclosure but finds explicitly sharing lived experience in meetings difficult. Tracks ideas on a document but doesn't openly disclose experience in these comments. Still uses lived experience in these comments to help improve the study design.

Joins as a peer researcher, with implied disclosure. Is happy to discuss own experiences and share these with the team. Helps design interview guide using lived experience expertise to identify questions that might be uncomfortable for participants.

Designing a project

Joins as a lived experience advisor. Taking on the role in the project means there's a degree of implied disclosure involved. Chooses to explicitly disclose own experience in a meeting with the team and shares ideas based on this to make the study less overwhelming for others.

A Communications team member has similar lived experience to the study's focus but doesn't disclose. Draws on lived experiences and community connections to ensure communications plan will get the findings back to the community.

Joins as an administrator. Shares lived experience that reflects the study's focus with line manger but not with rest of the team. Draws on experiences to make paperwork easier for people to complete.

Figure 2: Different ways of sharing lived experience while designing a project

When our team choose not to disclose lived experience

Our team have shared that there are occasions when they choose not to disclose lived experiences. This often relates to how safe people feel in an environment. Where staff have chosen not to disclose, they have still been able to draw on their lived experience to inform their work.

It is important to recognise that using lived experience is not dependent on disclosure, and people can draw on their knowledge and skills in many ways. There are several situations in which staff have told us that they have not felt safe to disclose.

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The choice is always there whether or not to share your lived experience. Feeling safe to do so is crucial and if you feel yourself withholding your lived experience, remind yourself that there are reasons for this, to do with the environment you are in, and that this is worth exploring."

Large group meetings

Large meetings, particularly those in which a proportion of the group might be academics or clinicians, or where others are not open with their lived experience. In these spaces it may not always feel safe to disclose due to power imbalances or concerns about stigma. At McPin we have staff who prefer to introduce themselves as a researcher, not a peer researcher, in such meetings.

In our experience the way these meetings are run is crucial. If seeking to work with open disclosure, investment in relationship–building – such as through personal introductions and sharing by all attendees – can level existing or perceived power imbalances.

On public–facing materials

We have worked with people who choose to 'wear different hats' in different professional situations. This may be in 'live' environments, but also relates to how people identify themselves in written documents. In our work, for example, a lived experience researcher might not want to be identified by name in a peer review publication or on a blog. This is often because of the very real impact that mental health stigma could have on a person's career.

In our experience staff are concerned they will be labelled or stereotyped due to association with mental health issues. They may also be concerned they will be viewed as unable to take on other types of roles irrespective of their skills, other experiences, or qualifications. Staff with lived experience may choose to not disclose for a range of other reasons, and these should all be respected as a personal choice – for example:

- **Concern for those listening:** People may choose not to disclose specific details or entire stories if they are concerned that there are people listening who may be distressed or triggered by those accounts.

- **Feeling their lived experience isn't relevant to the situation:** Part of the skill of using lived experience is understanding how your own experiences may be relevant in different situations. Some people will make the judgement that their experiences are not relevant on that occasion.

- **Choosing not to overshadow someone else's story**: On some occasions people with lived experience may choose not to share part, or all, of their story where they know someone else is sharing for the first time or in difficult circumstances. They may choose to do this to give the other person the time and space they need to express themselves.

- **Not feeling well enough to share:** Sometimes individuals may not feel well enough in a particular moment to share difficult experiences, irrespective of the environment they are in. Staff should be supported to make this decision for themselves, rather than feeling that they are obliged to do the emotional work because their job title implies lived experience.

- **Preserving emotional energy:** Sometimes staff need to conserve emotional energy for other things. Not disclosing is an active self–management strategy. Sharing can involve emotional work and at times people may not feel they have the emotional energy to manage this.

- **When people may not be ready to hear:** It may be that the audience is not sympathetic, leaving the person who shares feeling isolated or vulnerable. It may also be that someone listening has their own unprocessed lived experience or trauma and listening to someone else's similar experiences may re–surface difficult memories or feelings that are hard to cope with. There are also some details that may only be safe to share within specific circumstances. For example, sharing the specific details of self–harm or suicide attempts (as opposed to sharing more general feelings of pain or suicidality) is not advisable in most contexts.

In the workplace, sharing lived experience should be done after careful consideration of why it is appropriate to do so, and what the impact might be on other people.

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As a manager I have found when people choose not to share their lived experiences it can be helpful to have a conversation about why this was. It's not useful to pressure individuals to share their lived experiences. This can be undermining of an individual's autonomy and can cause people to feel a loss of control over their own story to which may cause emotional harm."
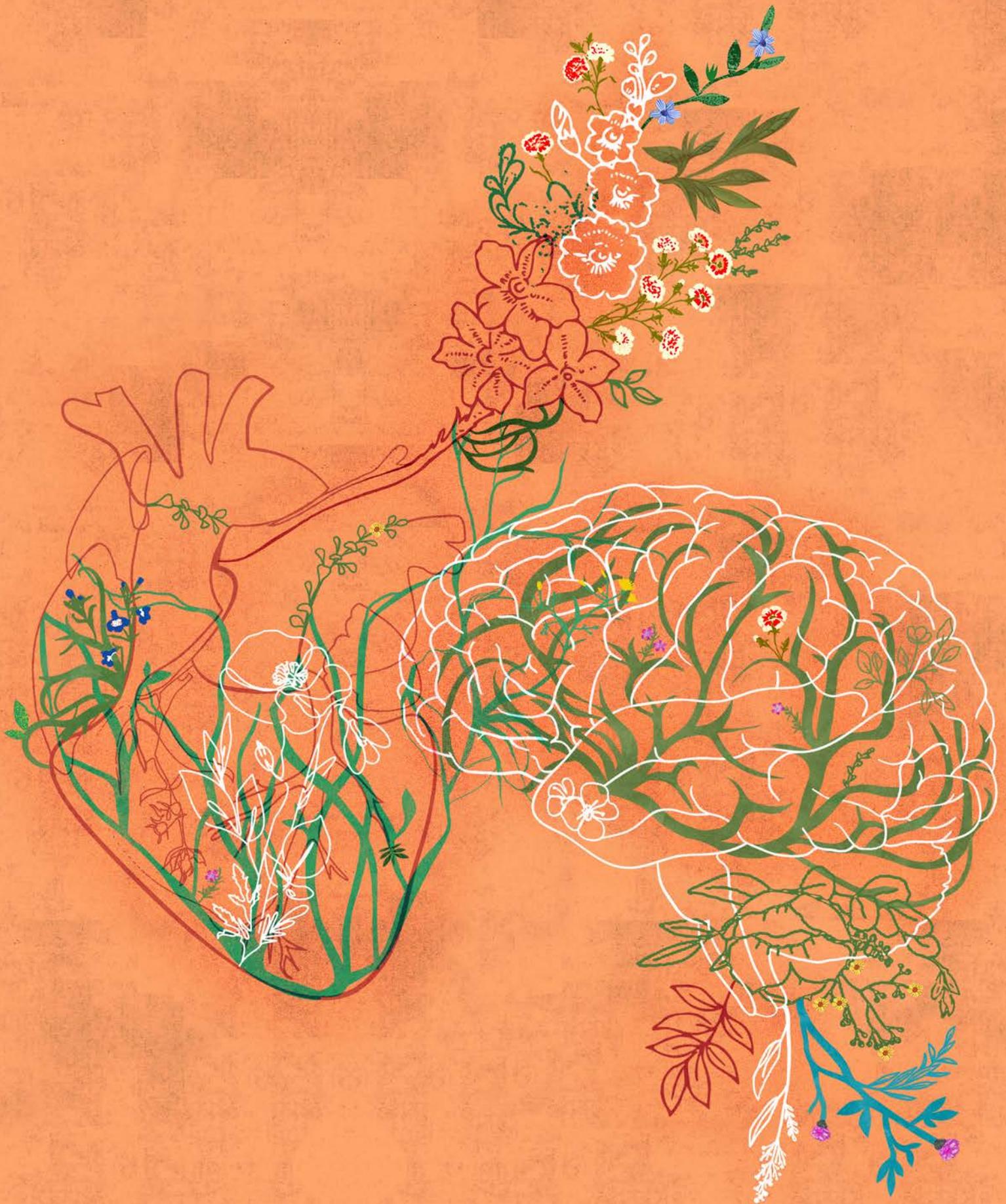
What can lived experience bring to the workplace?

We have found that our staff bring a huge diversity of strengths and skills into the workplace when they actively draw upon their lived experience. Recognising these strengths and giving people the space to reflect on their skills has improved our work both internally and externally. We have collated the skills and strengths shared with us by staff:

Empathy

Our team has told us that being able to draw on their lived experiences helps them better use empathy. This was described as helpful with external partners, other lived experience experts in groups or projects, and with each other as a team.

Empathy was seen as a useful tool in conflict resolution, in building strong, reciprocal working relationships and in helping team members to hear other people's stories.

> **You're more empathic, you know how it feels to feel a certain way, so you use that lived experience in how you approach and support other people."**
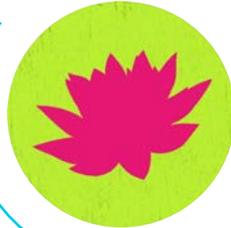
Connection

People who use their lived experience have talked to us about disclosing small parts of their lives in ways that help them connect to others. This may include participants in research studies but may also include other staff working on a project, or members of the public who are interested in hearing about our work. They feel sharing in appropriate circumstances can normalise and destigmatise difficult mental health experiences and help form a more genuine connection based on authentic knowledge of each other.

> **It does change the way we do things; it makes people feel more comfortable to share things."**

Curiosity

We have found that staff using lived experience tend to be especially curious, and more open to hearing about the experiences of other people, particularly where they are similar in nature to those of the staff involved. Moreover, this curiosity is rarely accompanied by judgement, meaning that those talking about their experiences are more likely to feel heard. In our work this can be of great benefit within many stages of the research process and is also an asset to people managing staff or working within a HR team. Curiosity at work is always applied with boundaries; this is an important skill.

> **I'm interested, it makes me ask questions, prompt and really listen."**

Inclusivity

Our teams have described using lived experience to help them draw on language that is more inclusive and less stigmatising, and to have an appreciation that people have a wide range of experiences that impact them differently. People who can share lived experience in appropriate circumstances can be less intimidating and make workplaces more accessible. Our team felt their lived experience helped them in actively building more inclusive spaces across our work and organisation.

Motivation

People we work with who use their lived experience talk about how they are motivated to change things for the better for people who experience mental health issues. Having that lived experience keeps them grounded, genuinely engaged with a project, and focused on the people they are trying to change things for.

Communication

We have found being conscious of lived experience – both our own and that of other people – has improved communication with each other, the people we engage with and our wider audiences. Lived experience was felt by our team to help them speak authentically to others with lived experience and to be sensitive to language and ideas that, although commonly used, might upset people.

Being a critical friend

Using lived experience has allowed our team to act as a critical friend, especially with external partners.

This role allows us to provide feedback and suggest changes based on our experiential expertise, which strengthens our work in research and PPI. Using lived experience was described as empowering to challenge the status quo.
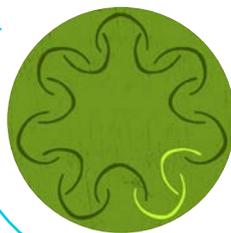
Learn more

If you are interested in learning more about the skill and strengths of using lived experience in different areas of McPin's work take a look at our Peer Research Resource, Advisory Groups Resource and PPI resource.

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Part of using lived experience is being able to ask difficult questions, but to do that in a sensitive and compassionate way. It's about gently challenging others' mindset and building bridges."

In addition to the strengths that lived experience brings across all our teams, we have also identified some that are more apparent depending on role. However, there was also a lot of overlap.

We would encourage people to explore how those in different roles can use their lived experience at work.

In our Operations team

Training

Our Operations team has shared that, when exploring training options for the organisation, using lived experience helps with finding opportunities that are welcoming and accessible. When running internal training, drawing on lived experience has helped to create sessions that are engaging and focused on developing people in a constructive and positive way, tailored to their goals. It has also helped when considering activities that are inclusive and don't feel overwhelming or uncomfortable for other people.

Support

Drawing on lived experience has helped the Operations team develop support systems that recognise wellbeing as a critical aspect of work, and that people have different needs. It has also helped this team build supportive relationships with staff rather than creating a fear of HR and asking for help. This support has helped people to stay in work, even when wellbeing fluctuates. In recruitment, our Operations team has drawn on lived experience to develop processes that help people feel more comfortable to share their own lived experience and ask for adjustments.

Day to day, drawing on lived experience in administration has helped communication, and ensures we interact with people in a non–judgmental way. Although McPin doesn't provide support services, sometimes people contact us in distress. Our administrative staff have said they have drawn on their own lived experience to be empathetic and help direct people to appropriate supports. Lived experience also allows staff to consider any adjustments needed to ensure processes, such as invoicing, are suitable for external partners.

Designing policies, procedures, and job descriptions

Using lived experience has helped our Operations team develop policies that are clear and supportive, and considerate of the impact of lived experience. It has also allowed them to develop job descriptions that are accessible, avoid jargon, and clearly detail what people will be doing at work. This has improved McPin's recruitment of a diverse workforce with a wide range of lived experience.

Learn more

To find out what wellbeing means to McPin employees take a look at our infographic on wellbeing in the workplace on our website.

In our Communications team

Translation

In our Communications team, drawing on lived experience has helped translate complex information into engaging and accessible content for a wider range of audiences. Lived experience also helps us to avoid jargon and explain things clearly. It has helped ensure the language we use is not stigmatising, and is acceptable to the people we work with. The team has found this particularly useful in making study and project findings accessible to broader audiences, allowing more people to continue to learn from research.

Connecting people to the issues they care about

Lived experience in communications gives insight into what issues might be important to a community at any given time, and how the team can support people to share their views and experience in outputs such as blogs or reports. It also has allowed our Communications team to understand where we can amplify our organisational voice on issues important to our work, in support of wider societal changes.

Working with people's stories

Our Communications team has found that using their lived experience helps them to work with people to share stories in ways that feel authentic to the contributors and gain good audience reach and engagement. By drawing on their lived experience they can give feedback on content, especially stories, with sensitivity. They are also able to ensure people can make informed decisions about publishing their work in public spaces.

You're working with people's very emotive stories; you work to help them share in a way that has impact but doesn't cause them to feel any distress or like you are overly editing their voice."
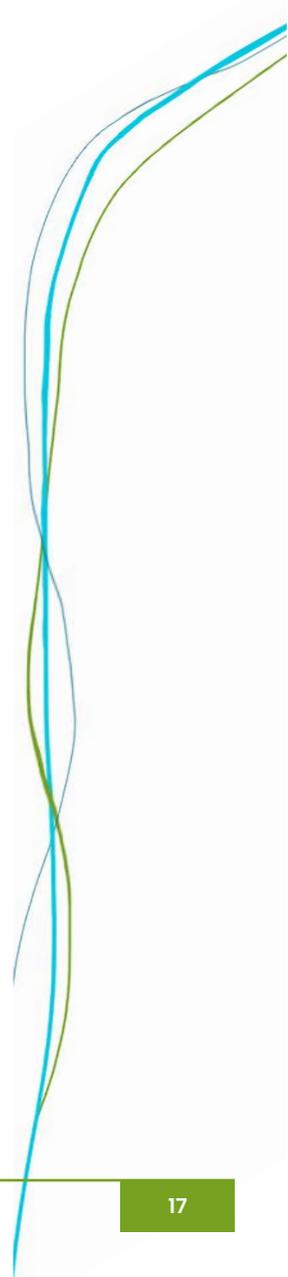
In our Patient and Public Involvement (PPI) team

Recruitment

Our PPI–focused staff can use lived experience to recruit widely for advisory groups, whilst ensuring accessible recruitment processes. They consider an individual's needs in applying for advisory groups, and what might need to be put in place to connect with specific experiences. For example, a staff member who is neurodivergent might use their own experience to help them set clear agendas and ensure time for reading preparation materials.

Learn more

If you would like to read more about the recruitment process for groups at McPin take a look at our infographic.

Meeting facilitation

Our PPI team actively use their lived experience in facilitating meetings, especially those that are attended by other people with lived experience. The team use their experiential knowledge to develop spaces that feel welcoming and safe, and considerate of different access needs and preferences in communication. They are able to translate meeting information to be more accessible for people who don't have academic experience and set up groups to make people feel welcome and safe no matter their level of experience in PPI. They are aware of issues such as nervousness in group scenarios and deploy different types of introduction activities.

They also use disclosure to connect with people to make them feel more comfortable in sharing their views and can manage differing opinions compassionately. Although much of the work our PPI team does is facilitating lived experience advisory groups, these skills are highly transferable, allowing them to run effective and engaging meetings with a wide range of people.

Drawing on lived experience both openly and in third person, for example, is a good way to prompt discussion or open conversation in involvement groups and meetings."

Engagement/support for other people with lived experience

Using lived experience in PPI has helped our team provide good support for other people with lived experience. This ranges from being able to understand and make accommodations for contributing, through to content warnings and provision of space to debrief after meetings when needed. Our PPI team has described their lived experience as helping them intuitively know when to reach out to someone during or after a meeting.

It's so wonderful to be able to support others to grow as well and to facilitate conversations where people can feel empowered."

Learn more

Take a look at our Patient and Public Involvement resource that covers our learnings over the last ten years. You might also be interested in our experience setting up and running advisory groups for mental health projects (Research Involvement Groups: McPin's models and learning).
We do a lot of work with young people and have creating a guide for running meetings: Involving young people in research work.
10 for 10 resources will be available on our website: mcpin.org

In our Research team

Project planning

We have found that where our Research team uses their lived experience in project planning, the robustness of patient and public involvement and/or the peer research methods used are improved.

Embedding lived experience at this stage of the project allows people to draw on their experiential expertise to inform design, resulting in projects that are well received by others with lived experience, and are more reflective of communities' priorities and needs.

"

I've used lived experience to inform academics that not all participants are able to contribute via interview and suggested creative ways of helping people have their voice heard."

Recruitment

Using lived experience in recruitment can help engage a wider range of voices, especially those that are less often heard. Our Research team has drawn on lived experience to adjust recruitment processes to be less stigmatising and more accessible. They have also been able to undertake recruitment in creative ways and in communities or spaces that they have access to through their lived experience.

Data collection

Members of our peer research team have felt that using their lived experience in data collection settings has allowed them to gather richer data from participants. However, there are important skills that can be learned and developed when working in these settings. Researchers who are skilled in using their own lived experience can disclose details about it sparingly, enabling them to build rapport with the participants without allowing their stories to overshadow those of the people they may be interviewing. They can also pick up and prompt on issues participants may be sharing that other researchers might miss.

"

I think you need skills in using your experiences in a way that doesn't overshadow the stories of the people we work with in a research context. Self–reflection and compassion for others."

Analysis and write up

Drawing actively on lived experience and being open and reflexive about this in analysis can deepen understanding of the data and highlight themes and findings that may have been missed by researchers without lived experience. Further, using lived experience in write–up can help ensure findings are accessible and useful, and that dissemination occurs in ways that are meaningful to those most impacted by an issue.

Learn more

Our resource Peer Research at McPin: Our Approach, Reflections and Learning over 10 years explores the rich and nuanced ways lived experience is used in the research process. We have also coproduced an animated poem exploring the role of peer research from a lived experience perspective. It is dedicated to all those that have crafted their pain into power.

In our Management team

Disclosure

Several of the line managers at McPin have their own lived experiences that relate to mental health and may use these when supporting colleagues through challenges, where appropriate. For example, one of our managers has experience of workplace anxiety and may share examples of past challenges and how they resolved them. This includes sharing practical strategies that they have found helpful, though it does not usually involve sharing extensive personal details.

Sharing relatable experiences can help the development of rapport and foster supportive and open relationships with teams. Staff can feel safe to raise issues that trouble them or disclose their experiences and how these intersect with their work. However, care has to be taken by line managers in this situation. It is important not to share details of distressing or traumatic events, or expect people who are being line managed to be in an equal position to provide emotional support to you.

Solution/strengths–based approaches to working with people

Through line management and project management we work with people to help them identify what they are good at, what they enjoy, and how they may be able to develop themselves in other areas. Using lived experience was felt by managers to make them focus more on the strengths of staff, as they understand the feeling of being judged for your lived experience in a negative way.

We try to encourage staff to take positive risks and view feedback on their work as part of the skills development process, rather than a process that is critical of them personally.

We have managers with lived experience that have experienced feedback processes which have harmed their own mental health, or not felt supportive. Examples of this may involve encouraging staff to step out of their comfort zone in relation to something like speaking in public, sharing early drafts of documents that do not 'feel perfect', or taking on a leadership role such as learning how to chair meetings.

> **As a manager, it's thinking about people who don't work the same as you, and you think more about what will help them be successful and what supports you can provide, rather than assuming they should just be able to do something."**

Flexibility

The management approach at McPin is based on working flexibly with staff and having frequent and regular conversations about what may and may not be working for them. Using lived experience has helped managers understand that different people may need different adjustments. This encourages line managers to have conversations with people to collaboratively identify what can help manage mental health, or other health or disability related situations. For example, we have found that some people who are taking medication need to start later in the day, while others find an early start suits them best.

Some individuals thrive when working to structured plans and mutually agreed interim deadlines, while others find such tools restrictive and difficult to navigate.

"

You're more aware that people need different things, that you need to think about how you can accommodate that so everyone can have success at work."

Consistency

While we try to work with each staff member as an individual, discovering together what kind of working practices are best for them, we need to balance this with the needs of all staff members to be treated equally and fairly. Drawing on lived experience, line managers try to avoid unexpected changes, which can be distressing.

All staff are expected to have regular meetings with their line managers to help them track their own progress and ensure they are working to the same policies and procedures. Adjustments need to be worked out jointly between the staff member and line manager so that they work within this framework.

Project planning

Our Management team actively draws on their lived experience when considering how best to set up projects. This includes methods, staff support and balancing workloads. Lived experience helps them view these through a different lens, considering what is best, both for the organisation and the staff involved, especially in relation to wellbeing.

Our Management team approaches planning decisions in an inclusive way, seeking shared decision–making and co–design wherever possible, recognising that many people with lived experience may have had their autonomy limited in previous decision–making, or had difficult experiences in healthcare or previous education and workplaces.

What skills can help people use their lived experience in the workplace?

Our team has shared the skills they found useful when drawing on lived experience in their work. Some of these skills are also useful when not using lived experience. Our team felt it important to recognise that these skills might be innate for some people, but that they are also skills that can be developed with support and training. Based on our learning we would recommend that employers wanting to build their lived experience workforce embed regular training opportunities about lived experience into their support structures.

"

Some of these skills take a lot of practice. If you haven't used lived experience in the workplace before it can take time to know how to do this."

Self–awareness

Our team said being self–aware was an important skill in actively using lived experience. This included being aware of topics that might be distressing, where one might hold strong feelings about an issue, knowing when to reach out for support and what one's boundaries were. Some of our team shared that this can be a difficult skill for some people with lived experience to learn, and that it needs time and good supervision to develop.

"

You need to be pretty self–aware to do this work. You need to be aware of your biases and blind spots and know they exist."

Boundary setting

Boundary setting was a crucial skill most of our team identified in relation to using lived experience. Understanding how boundaries can be helpful in providing a level of emotional safety, both to staff using lived experience and to participants in our studies, is a skill that can be developed over time and with experience.

Staff spoke to us of the importance of knowing their own boundaries on a number of issues, including what they were and were not happy to disclose, and what kind of subject areas they may avoid to protect their own emotional safety.

Many people were also sensitive to setting boundaries around the depth or level of detail they may include in disclosures in different settings to ensure their own stories do not overshadow the stories of others we may be working with.

"

Make sure you debrief and have coping strategies. Set boundaries and be aware of yourself and how you are feeling."

Managing disclosure

Knowing what and when to disclose is a skill, both to ensure one's own safety/sense of comfort and that of those you are working with. Many team members have shared it can be helpful to 'test out' disclosure before you know what feels best for you and your work colleagues. Training can help people feel more confident in how to address disclosure, what to do when it doesn't go well and how to decline sharing details.

"

Establish your boundaries around disclosure – what you are and aren't comfortable with and in what contexts. Training around this is helpful too."

Reflection

Where people draw on their lived experience, it is important that they are able to think about how their own experiences may affect how they interpret or deliver their work. We have found that it enables staff using their lived experience to identify areas they may be troubled by or struggle with, including around the emotional labour involved in their work.

Reflection work can help staff understand why that may be and to think about, sometimes with the help of other people, how they may overcome or work around those difficulties. More details of our reflective work at McPin can be found on page 28 under "What kind of supports".

"

This work requires you to think deeply, it requires introspection. It takes people being courageous to look at themselves and how we do things or how we think."

Respecting different views and experience

This may also involve embracing the diversity of thinking and experiences we often find amongst people who have been through similar events or share similar characteristics. It is an important aspect of lived experience work to understand the differences and nuances that may be present. This skill can often be developed through team building and training.

"

Working this way gives me openness to other people's perspectives. You're aware even if you have a similar experience, it might be vastly different to someone else's and you're more aware of that and make space for that."

Resilience

In the context of our work, when our team speak of resilience it is described as a skill that allows them to manage stress or emotional difficulties in their roles. For some people resilience is developed through difficult life experiences, for others it is a skill they learn which allows them to draw on their lived experience knowledge. People can feel they are more able to be resilient in some contexts than others.

Connected to resilience is adaptability, planning and problem-solving skills. These can all help our team mange stress in their work, and are all skills that organisations can develop through training. In our work resilience is often needed when meeting people with different and opposing views of lived experience expertise, and it can be helpful to know how to de-personalise the things one reads or hears in a meeting.

"

There is something important about compartmentalising, even when you feel close to a topic or hear something upsetting, bringing stuff out to process it, but ensuring it doesn't impact your entire life."

Illustration credit: Kremena Dimitrova. Bridge Between Worlds
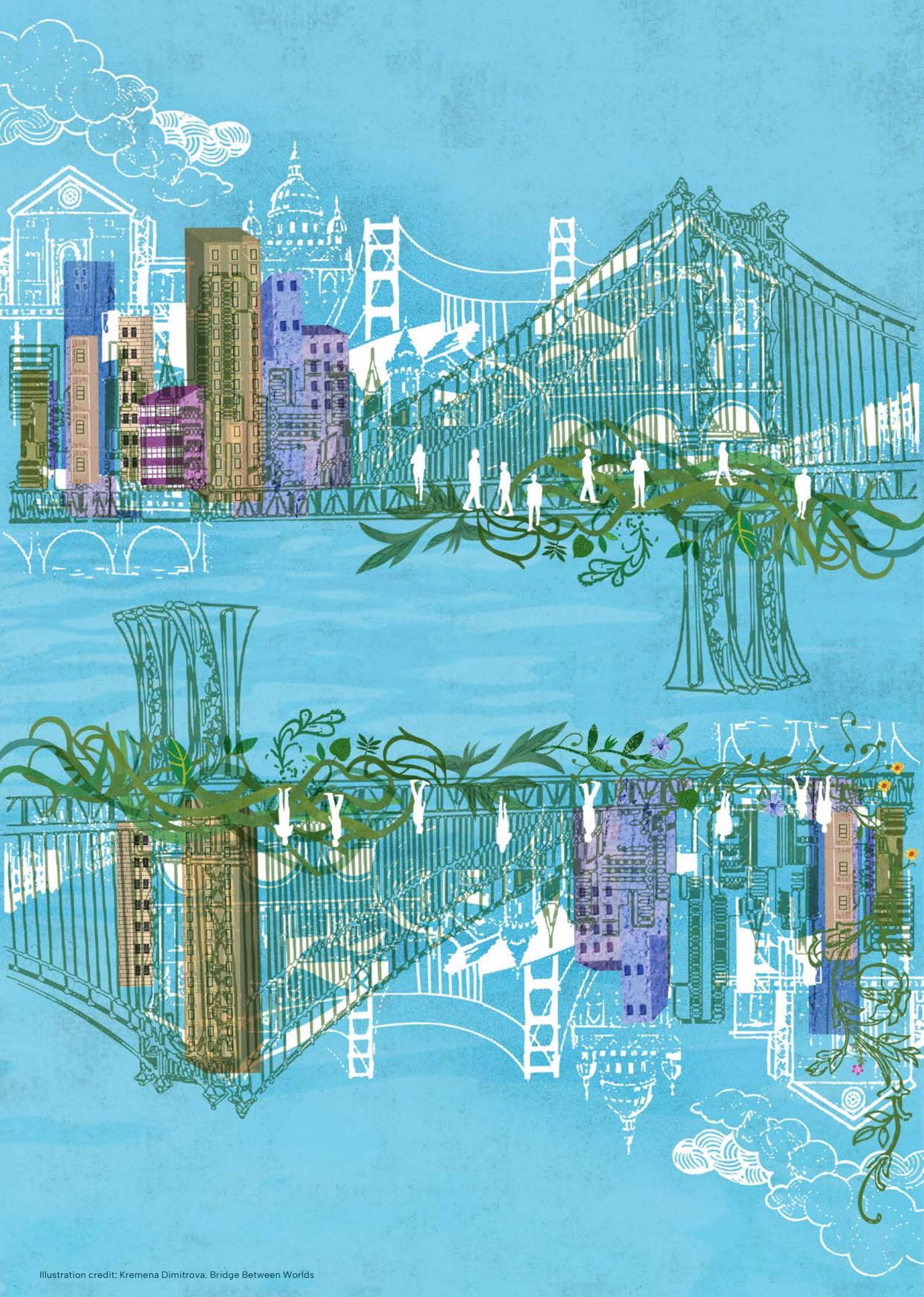
What challenges might people face when using lived experience in the workplace?

It is important to emphasise that when we refer to sharing lived experience in the points below, we are not talking about in–depth detailed sharing. Workplace disclosure of lived experience tends to be subtle and limited. In our research work, our role is to centre and hear others' stories, and we must consider when and how sharing lived experience is most useful in that work.

Stigma/discrimination

We know stigma is something that people with mental health issues face. There are awareness campaigns to end stigma and discrimination in mental health, such as the problems faced by people with mental health issues arising from negative attitudes, poor knowledge and discriminatory behaviour. The experience of stigma can make people feel uncomfortable about drawing on their own lived experiences in certain work situations. The risk of further discrimination can invoke feelings of fear and shame.

Our team have struggled most to use their lived experience in spaces where they are tokenised, not listened to, compartmentalised as only bringing lived experience to a role, or when disclosures are made about their lived experience by others without their consent. It is important when embedding lived experience in the workplace to consider processes for managing discrimination, including safe spaces to report problems and training on issues such as microaggressions.

> **I've had jobs where I thought if I share my lived experience, I'll lose my job."**

Imposterism

This can arise when people feel they are not 'good enough' or, in the case of lived experience, do not have enough – or the right type of – experience and expertise in comparison to others. Our team have shared that these feelings can cause people to feel less confident, or anxious, about work and this can impact work output and/or quality. In our work we have also found that it can be difficult to actively use lived experience when a job role does not specifically call for it.

We have found there can be pressure to speak for all those belonging to a particular group when recruited for some specifically lived experience–labelled roles. We have discovered that it is important that good supervision, training, and opportunities for progression, as well as timely, strengths–based feedback, are implemented to address this challenge.

> **Feeling like you have to share, and that if you don't, you are judged for not being 'lived experience' enough. It takes commitment to choose to look beyond the 'seen' or 'heard'."**

Inclusive and supportive workplaces can help people feel more confident. We have also found that open discussions about the importance of diversity in lived experience are useful; not everyone will have the same experiences of a diagnosis or mental health supports, or gender, sexuality, race and ethnicity. We also have found that recognising there are 'seen and unseen' things in people's lives is an important tool in reducing comparison between lived experiences, as is respecting choices around disclosure.

In our experience as an organisation, it's useful to work carefully with our partners to ensure everyone is aware of the risks of imposterism, as well as their role in acknowledging these feelings of not being good enough.

Emotional cost

There can be emotional consequences to both sharing and listening to lived experience, and at times there is potential for people to be harmed by it. Some people regret sharing too many details or incidents that cause them to become emotional in the workplace. Once shared, experiences can't be unshared. For others, hearing details of another person's experience may hit 'close to home' and bring up difficult feelings that relate to their own previous experiences.

Some of the people we have worked with also felt that, even though their lived experiences are a strength and an important aspect of their work, the emotional labour in using them is not always recognised by people without lived experience. We have been doing more work on this recently, including writing about emotional labour.

"

It can be really hard, being your whole self at work, but good support and safe spaces help."

Re-living trauma

Working on a project that has a close match to your lived experience, especially trauma, can result in the resurfacing of memories and feelings that are difficult to manage. There are many ways that memories might resurface, including someone touching your arm, or a phrase a person uses in an unexpected place. This may happen more so if the trauma is relatively recent or unprocessed but can still affect people with traumas in their more distant past.

Our team has at times felt actively using their lived experience would not be helpful to a project where it still feels upsetting for them, or where they might not be able to untangle their own experiences from the experiences of others. In these cases, open communication with managers is important, as is respecting decisions around disclosure, support needs and content warning requests.

"

I was at a very large group meeting with academics from across England. I felt intimidated and triggered, as it reminded me of treatment reviews where I sat alone amongst many academics who had asked me many questions. I withdrew and felt very uncomfortable so could not contribute to the meeting in any way."

Lack of space to use lived experience

Our team shared that in the work we do, the biggest challenges to using lived experience are limited funding, short-term projects and fewer resources available for reflection practices.

There was also a sense that sometimes lived experience work isn't valued as highly as other forms of work, and that this can be harmful to people, especially where they have been recruited to a lived experience role. This challenge is not specific to research, and it's important for all workplaces to consider how their organisational and project structures, wellbeing supports and workloads support lived experience expertise.

What kind of supports do organisations need to have in place to facilitate using lived experience expertise in the workplace?

Line management

We take a supportive approach to line management at McPin. The priorities of line managers are to support the professional development and wellbeing of our staff; the majority of whom have lived experience related to mental health. It is a line manager's role to regularly talk to staff about their wellbeing and the impact that projects may have on them, particularly where they relate closely to their lived experience.

Some staff may have specific disability or mental health–related needs in the workplace. It is also the line manager's role, sometimes in collaboration with relevant project managers and members of the Operations team, to develop work plans that include reasonable adjustments, Occupational Health Assessments or Access to Work and other elements to provide tailored appropriate support in partnership with staff.

The line manager is responsible for recognising, reporting, and attempting to mitigate circumstances where there may be a risk that we, as an organisation, may put a member of staff in a situation that may be traumatising or re-traumatising for them. This responsibility needs to be balanced against the temptation to take a paternalistic approach where we make decisions on behalf of staff members to protect them from risk, instead of making decisions with them following fully informed discussions of potential risks. This is also balanced with team members taking a proactive approach to their wellbeing, reaching out for support when needed, advising of issues and implementing available support mechanisms.

Mentorships with external mentors

Staff at McPin can access a mentor through our mentoring programme. This is designed to allow them to have confidential conversations with someone who is not directly involved in their work about things they may be struggling with, and to think about strategies that may help them address those struggles or explore development and goals.

Learn more

Check out our 10 for 10 podcast on workplace mentoring. Check out our podcast on mentoring on workplace mentoring on **McPin's Soundcloud.**

Reflective practice

We hold regular reflective practice sessions with a trained reflective practice facilitator. These sessions allow staff a confidential space to reflect upon things that impact on, or are connected to, their work, and to think about why they may feel a specific way about it or what actions they could take.

This is also a space for the group to think collectively about solutions to difficulties that may be common experiences for staff. We train all our staff in reflective practice but allow people to choose if this is the right space for them to be actively involved in.

Flexibility for self–care

Through our experience of working with many people who have lived experience of mental health issues we know that there is great diversity in the way people approach self–care. For some, relatively simple things can be included in their work plan, such as ensuring they can have time to go for a walk after an interview. For others it may involve making modifications to their working day, for example starting an hour early so they can leave work early enough to attend an exercise or art class. For this reason, we encourage all staff to prioritise their wellbeing in the workplace and discuss modifications to the way they work that will allow them to fit in self–care activities. This is distinct from making reasonable adjustments for disability–related reasons or a formal flexible working adjustment.

Training

We have an ongoing commitment to all our staff to support their development through training. At times this may include training specifically around using lived experience, particularly on issues such as thinking through when to disclose or not to disclose, or what kind of details an individual may or may not be comfortable with other people knowing. We also help people develop responses they can use when they are feeling uncomfortable about being pushed to disclose, and how to identify when they are beginning to feel distress and when and where they can seek support.

> **Training is really an important tool to help leverage lived experience and bring it forward."**

Valuing people holistically

One of the challenges we have faced at McPin is where people (often external partners) view staff using lived experience as only having value to a project where they are sharing that experience. Most of the people we employ have a much broader range of skills and talents, and to reduce their contributions to the single dimension of lived experience can be demoralising.

However, this is a complex issue. For some staff their identity is strongly intertwined with their lived experience of mental health issues. For others, it as a small part of a complex set of life experiences and skills. For this reason, we work with people to understand how they define and use lived experience, and actively seek to support people to develop their own personal understanding of how their identity relates to their experience.

We work both with our own team and external partners to ensure lived experience does not become a reductive label imposed on our staff, and to recognise the intersection of different forms of lived experience. When we are developing new project teams, we take time to allow everyone to get to know each other. This can help break down the 'othering' of lived experience.

Making time for people

Whatever role you may hold within an organisation, it is important to understand that supporting people to use their lived experience in the workplace involves an investment of time. For many people, their understanding of how and when to use lived experience evolves with time and experience of different types of work. This will often involve many conversations with many different people – from a line manager to a member of the Operations team to a fellow peer on a project – about how a person's lived experience is emerging in relation to some work, and how they are feeling and dealing with that.

The task of making space for these conversations is often invisible and may be difficult to account for in work and project plans. However, it is highly valuable, both to the people who voice their experiences and to those who listen to them: frequently both parties learn from these experiences.

> **It's about not putting yourself in someone else's shoes, you need to ask them...what are your shoes?"**

Top ten learnings about lived experience at work
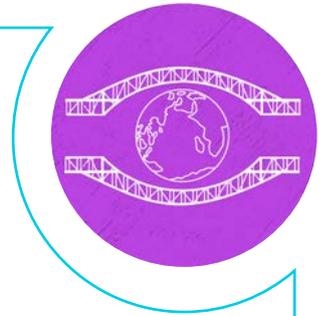
1 People bring a range of knowledge to their workplace, both lived experience and learned. Both add value in any job. Organisations need to be open to people drawing on different forms of expertise to innovate and create environments that people feel are inclusive and meaningful.

2 Expertise developed from lived experience adds another dimension to many types of work. This is frequently valuable to the project and can be motivating for the staff involved.

3 Avoid generalising lived experience; even when people have similar lived experiences, they will still be unique. Work with the person, not the label. Work from non–judgemental standpoints and embrace the intersectional nature of lived experience.

4 Doing work involving people who are actively using their lived experience requires an investment of time and resources.

5 Build inclusive workplaces, focused on making work accessible for people with multiple and different types of lived experience. People feel more confident in drawing on lived experience knowledge in spaces where they feel safe and respected, and where other people are explicitly using their lived experience.

6 If you are supervising staff with lived experience, you need to invest in your skills around doing so. Use a different approach to traditional management practices.

7 Establishing boundaries around disclosure is important for staff using their lived experience. It can help to make a list of what you are and aren't comfortable with talking (or writing) about, and in what contexts. Training around this is helpful. It can be useful to acknowledge that your comfort may change over time.

8 Using lived experience can be emotionally challenging. It is important that staff doing this as part of their roles have support in place at work.

9 It can be helpful for people who work from a lived experience perspective to develop a list of responses for when they feel pressure to share in environments where they do not feel safe or comfortable.

10 Be open to learning and hearing other perspectives; drawing on our own lived experience doesn't always mean we have the right answer or view.

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Final thoughts

Over the last ten years we have learned a lot about the value of lived experience in our work, and how to support the people who use it. We want to expand the range of opportunities available to people working from a lived experience perspective and ensure that people thrive in their roles. We have learnt this requires effective support that needs to happen within the boundaries of employment processes and legal structures.

There is value and strength in lived experience. However, we learned there is no right or wrong way for people to use their lived experience; there are many ways. We hope this will encourage people and other organisations to consider embracing the expertise that can be brought to projects and workplaces by people working from a lived experience perspective.

There is still much to learn about this area of work, and we want to continue developing alongside other people and organisations. Do get in touch – we would love to hear about your experiences.

McPin Foundation | Transforming mental health research

We want mental health to be better understood. Our mission is to improve everyone's mental health through research informed and directed by lived experience expertise. We want the value of lived experience of mental health issues to be upheld and embraced, which is why we put it at the heart of all our work.

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