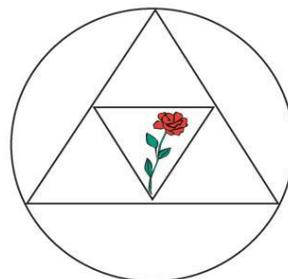# User/Survivor Leadership & Capacity Building in Research

White Paper on Promoting Engagement Practices in Peer Evaluation/Research (PEPPER)

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0. Introduction

What is a *user/survivor researcher*?

The term *user/survivor* refers to individuals who use mental health services and/or have experienced mistreatment or discrimination in response to emotional or psychological distress or disability.[1] One simple definition of a **user/survivor researcher** is an individual who not only has lived experience of distress or disability, *but explicitly uses that lived experience to inform research projects.*[2] In user/survivor research, participants are partners in determining the research questions and methods, even when the project *leaders* are themselves users/survivors. Transparency is valued in terms of control and claims grounded in researchers' lived experience, as are any researcher political goals or motivations.

> User/survivor research often works from a "democratic" model, where community members are empowered throughout the research process.[3]

In contrast, "conventional" research (i.e. non-user/survivor research) is more hierarchical.[3] For example, a primary investigator makes all the major decisions; often, the data analysis process is not shared with participants or stakeholders. "Conventional" research often claims political neutrality and objectivity; researchers are more disconnected from the community or population they study than in user/survivor research.

Types of user/survivor experiences in research

Due to the wide range of user/survivor experiences in the behavioral health and social service systems, not all such experiences may be equally relevant to a particular research project. For example, an evaluation of a housing first program for individuals who are currently homeless and have a psychiatric diagnosis as well as substance use challenges would ideally involve individuals in key roles who share these experiences (or experiences that are as close to these as possible). Similarly, a project focusing on the experience of psychosis would ideally involve individuals with direct experience of psychosis, as opposed to any type of mental or psychological distress. Examples of other dimensions for consideration include form, duration and severity of distress; type of service and level of coercion experienced (e.g. private vs. public clinic or hospital; voluntary vs. involuntary); and other factors that could substantially

influence the experience (e.g. race, gender, socioeconomic status, religious or political affiliation).

The value of a researcher's lived experience is not in generalizing one's experience to others. Rather, lived experience can bring other benefits to the research process, including sensitizing a researcher to lines of inquiry, improving rapport with research participants, and enhancing credibility of the findings. Even while drawing from owns own experience, individual differences must be considered and acknowledged throughout the research process.

Involvement, collaboration and leadership in research

Broadly defined, **user/survivor research** is research in which users/survivors are leaders or equal partners in all phases of the research process.[2] Service-user involvement in research is not, in itself, user/survivor research.[3] Leadership or genuine partnership is key. Leadership in research is achieved when users/survivors are the project leads, or when users/survivors hold *genuine* control of the project through collaboration. In projects that are led by users/survivors, collaboration involving user/survivor participants is still of value. Indeed, that collaboration is the most fully democratic approach and maximizes the benefits of user/survivor research.

One collaborative research approach is *community based participatory research* (CBPR)[4], in which skilled researchers engage in equal partnerships with collaborators (in this case users/survivors) that may not have experience conducting research. The goal of CBPR is for all members of the research team to equally share in decision-making and expertise. Skilled researchers contribute expertise in research methods and academic disciplines; users/survivors contribute expertise based on lived experience and deep familiarity with the context of the research question or *specific* site. This is particularly important on evaluation

> **Research vs. Program Evaluation**
> Research and program evaluation share many common features. Both activities require many of the same skills, and involve collecting and analyzing data (e.g. surveys, observation, interviews). In general, the difference between research and evaluation is their purpose: researchers develop knowledge that is generalizable or transferable beyond the site of a study; evaluators explore a specific program or site, for the purpose of improving or describing processes in that particular context. Though there is often overlap, the distinction is sometimes very important. For instance, some government agencies may provide grants for evaluation, but not for research. In these cases, the purpose of the grant proposal should be on specific program improvement, not on gathering data from one program to be generalized to other programs.

Box 1 – Comparing Research to Program Evaluation

projects (Box 1). A drawback of CBPR is that individual differences in research experience or skills can limit equity in decision-making and control of the project. Indeed, the history of users/survivors being "involved" in research has often amounted to *tokenism*.

Tokenism is the act of inviting users/survivors to "collaborate" in minimal ways so the project leaders can claim the project included "community involvement."[3]

Whereas CBPR is a collaborative approach, user/survivor-led research involves users/survivors carrying out research projects as leaders or principal investigators. In user/survivor-led research, the user/survivor researchers have sufficient skills in research methods to carry out the project without non user/survivor experts. Therefore, the power imbalance resulting from differences in knowledge of methods are reduced. The same individuals have both expert knowledge of research methods and lived experience. Still, user/survivor led research can also involve power imbalances between researchers and participants. For this reason, user/survivor led research is often *also* collaborative and uses CBPR methods. Thus, user/survivor research can be placed on a continuum based on degree of collaboration and extent of user/survivor leadership (Figure 1).

Community Advisory Board
•No access to raw data

User/survivor interviewer
•Uninvolved in analysis or writing

One or two user/survivors
•Involved in multiple stages

Project leader(s) or co-leader(s)
•Lived experience
•Additional community involvement

User/ survivor leader/ co-leader
•Full community involvement in all stages of the research process

Less Intensive   *More Intensive*
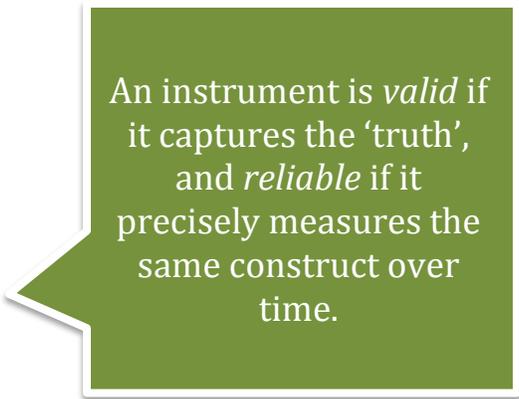
Figure 1 – Aspects of various participatory inclusion strategies in the United States by level of intensity

Consultation and Capacity Building

Any given user/survivor research project might proceed in terms of a consultation or capacity building model, though the overlap of these is project-specific. Ideally, no individual's perspective is more valued than another simply because of formal training; lived experience is at least as vital as expertise in research methods or academic disciplines. Both consultation and capacity building should be maximized in working towards the goal of transforming systems to be more responsive to users/survivors and creating user/survivor-led alternative programs.

Consultation involves active collaboration between users/survivors with expertise in research and those with lived experience relevant to the particular research question or site. The goal of consultation is to develop relationships and build trust, such that all parties can contribute equally to the research process based on their own knowledge and expertise (be it grounded in lived experience, research methods, or both). For instance, users/survivors with lived experience of a particular program might provide crucial insight into appropriate questions for a survey, while methods experts may construct the survey instrument to maximize accuracy (also known as *validity* and *reliability*). The expertise of both parties is vital to good research and evaluation. Consultation allows for involvement of users/survivors who have a stake in a particular research question or evaluation, without being required to develop more formal research skills.

> An instrument is *valid* if it captures the 'truth', and *reliable* if it precisely measures the same construct over time.

Capacity building refers to the enhancement of community members' skills in ways that empower them to independently achieve community goals and effect change. Capacity building can range from a variety of activities, such as providing opportunities for user/survivor collaborators and developing skills in specific research tasks (e.g. conducting interviews, assisting with data entry or analysis). Another example of capacity building is supporting users/survivors interested in obtaining advanced formal training in research methods, to enable them to carry out complex research projects independently. See Table 1 for a summary of the expertise brought to the research process by various individuals.

Table 1 – Expertise and credentials of users/survivors (u/s) and non-u/s in research

Individuals	U/S Identified	Experiential expertise	Context-specific expertise	Methods expertise	Professional credentials
User/Survivor Stakeholder Collaborator	YES	✓	✓		
User/Survivor with Research Training	YES	✓	?*	✓	✓
Stakeholder Collaborator	NO		✓		
Professional with Research Training	NO			✓	✓
* A user/survior has context-specific expertise when they have experience of the *particular* research question or evaluation site.					

1. User/survivor history & context in the United States

User/survivor–led research projects have been funded in the United States since at least the early 1980s, some of which were led by the early user/survivor research pioneer Jean Campbell.[5,6,7,8] The California-based "Well-Being Project," conducted between 1986 and 1989, is an early landmark in United States user/survivor research.[6] The project was entirely user/survivor-led, involved community-based advocates in all stages of research design and analysis, and sought to better understand what promoted or deterred the well-being of adults with significant psychiatric disabilities.[6]

Other milestones in the development of user/survivor research in the United States include the creation of the Consumer/Survivor Mental Health Research and Policy Work Group in 1992,[9] under the National Association of Mental Health Program Directors; and the incorporation of the Massachusetts-based user-led evaluation and consultation non-profit Consumer Quality Initiatives in 2000.[10] Pat Deegan, Priscilla Ridgway and others did important early user/survivor-led or co-led studies on recovery.[11,12,13,14] A number of researchers with full-time, tenured appointments at large universities, including Pat Corrigan at the Illinois Institute of Technology and Larry Davidson at Yale University, have publicly disclosed their lived experience of psychiatric diagnoses, mental health services and hospitalization.[15] More recently, a number of junior researchers and scholars have explicitly linked their research to lived

experience, including faculty working in the humanities rather than the social or health sciences.[16,17]

In addition to leadership, a growing number of researchers in the United States (some of which identify as users/survivors) use participatory methods to more fully include non-academic users/survivors in research and program evaluation.[15] Common aspects of different participatory inclusion strategies used in the United States typically range from less to more intensive inclusion of users/survivors (Figure 1).

United States-Specific Barriers and Challenges

User/survivor research in the United States remains under-funded and under-developed compared to that of the United Kingdom and to a lesser degree Canada, Australia and New Zealand. For example, not one edited volume on United States user/survivor research, methods or theory has been published in the United States.

Though no published studies address this gap, some contributing factors might be:

1. A lack of dedicated federal or state funding or mandates for user/survivor research involvement and academic training;
2. Discrimination against students with lived experience in university & research settings;
3. Difficulties locating "user/survivor friendly" mentors and advisors in higher education settings; and
4. Doubts about researchers' motives due to experiences of disempowerment in professionally led "community-based" participatory projects.

Stigma in Action

How to Avoid the Kisses of Death in the Graduate School Application Process:
"Avoid references to your mental health. Such statements could create the impression you may be unable to function as a successful graduate student."
-from Appleby & Appleby (2006)

Box 2 – Stigma in Graduate School Applications

Students with significant psychiatric system involvement and/or major mental health challenges face many barriers. Among these, are getting through college, gaining acceptance to a graduate program (Box 2), finishing a research degree, and securing funding for progressive or non-biomedical user/survivor-led research. Only very limited federal or public funding is available to support true grassroots research or activist capacity building.

Finally, many users/survivors who have participated in research—especially those in subordinate roles—have had negative experiences. Though no published literature in the United States has explicitly documented these user/survivor experiences, the issue emerged throughout the interviews and focus groups for our case studies, and in on-going interactions with community-based peer organizations. We heard many heartbreaking stories from community members who initially entered research or evaluation projects with considerable enthusiasm, only to realize that they were merely tokens, that their perspectives were not in fact valued, or that they had little or no "real" decision-making power."[7]

2. User/survivor history & context in the United Kingdom

In an important early paper, Beresford and Turner describe efforts by British members of the user/survivor community to develop and undertake independent research projects. These were sometimes funded, yet sometimes carried out with only volunteer and few or no institutional supports and resources.[17] Since the 1990s, multiple larger projects have been developed within the auspices of both user/survivor-controlled organizations (e.g. community-based non-profits) and non-user/survivor controlled organizations, such as national mental health charities and university departments. Three examples of these larger projects are the Mental Health Foundation's (MHF) Strategies for Living initiative, the Sainsbury Centre's User-Focused Monitoring (UFM) project and the Service User Research Enterprise (SURE) within the Institute of Psychiatry at King's College London.

> For more information on SURE, read our case study

The MHF's Strategies for Living initiative was carried out in two phases from 1997-2000 and 2000-2003 .[19,20] Strategies for Living involved a core user/survivor-led research team who investigated community-based user/survivor strategies for dealing with mental health-related difficulties. They also supported smaller research projects carried out semi-autonomously by other users and survivors with varying degrees of formal research training and institutional involvement. In the core project, 71 members of the user/survivor community were interviewed in-depth concerning the supports and alternatives they found most helpful and empowering. The MHF has since supported dozens of significant user/survivor-led research and evaluation projects, including investigations and action research involving young adults, issues related to mental health and aging, and British ethnic and racial minority populations.[21] The MHF promotes both user/survivor leadership and involvement in non-user-

led projects, acknowledging that exclusively user/survivor-led projects are often significantly harder to pursue, given unequal supports and access to institutional resources.

The Sainsbury Centre's User-Focused Monitoring (UFM) project was initiated in 1996 under the leadership of Diana Rose (a prominent British user researcher who now co-directs SURE).[22] UFM has subsequently been adopted across the United Kingdom by a variety of mental health service and community outreach organizations. Departing from traditional professional service evaluation models, UFM utilizes qualitative methods to capture the perspectives and experiences of service users currently involved in a particular mental health program or service initiative. All interviewers are current service users who receive training and supports in interviewing; users/survivors lead both data analysis and dissemination efforts. UFM emphasizes stakeholder buy-in (to ensure that any barriers or problems identified will actually be addressed—and could be used to make complaint/grievance processes more robust) and careful dissemination strategies to ensure that affected programs and individuals are aware of the evaluation team's findings.[22,23]

In addition to these examples of early and influential national initiatives, governmental support for user/survivor involvement in the United Kingdom contributes to the ongoing development of participatory projects. The British National Health Service provides virtually all physical and mental health care in the United Kingdom, and serves as a major funder of research and evaluation projects. Currently, the British National Health Service mandates user involvement in all service delivery and some NHS regions explicitly extend such involvement to research.[24,25] In addition, many British universities support the involvement of users/survivors in educating future clinicians and researchers.[26] Collaborations between university-based researchers and user/survivor activists, jointly organized conferences and trainings, and honorary university research fellow positions allotted to user/survivor activists, are also far more common in the United Kingdom than the United States. Finally, although the United Kingdom is a fraction of the size of the United States, there are now multiple active independent user/survivor researcher consulting groups, including *Making Waves*, *Survivor Research* (which focuses on critical ethnic and racial minority perspectives), and *Recovery in Sight*.

3. Value of research to the community

Community-based activists and advocates are often wary of research. The value of research projects is often unclear; activists may feel that their constituents derive no direct benefit from participating in or supporting

research initiatives. Historically, psychiatric research has supported sometimes brutal "treatments" such as frontal lobe lobotomies. Pharmaceutical industry corruption and researcher-industry conflicts of interest are also frequently cited as problematic. While these problems are certainly real, user/survivor researchers have argued that the exclusion of individuals with lived experience from academics and evaluation allows non-peer professionals to dominate the "evidence base", perpetuating damaging stereotypes about users/survivors' mental "dysfunction" and supposed inability to carry out more difficult intellectual work.[27]

Conversely, user/survivor control over research and evaluation projects returns critical decisions to members of the community, and empowers activists to (1) design or help design projects that support progressive alternatives to mainstream practices; (2) document the potential risks or harms of conventional or mainstream treatments; and (3) acquire, understand and utilize research findings in order to influence policy (Figure 2).User/survivor involvement need not consist only of collaborations with or involvement in university-based research centers. For instance, peer run organizations often carry out internal program evaluations (or hire consultants to conduct them); national networks often survey members in order to better understand their needs (also a form of research). Similarly, participatory action research (PAR) is typically based in the community and is primarily geared toward accomplishing particular concrete goals, such as opening a peer crisis respite or reversing a local policy decision.
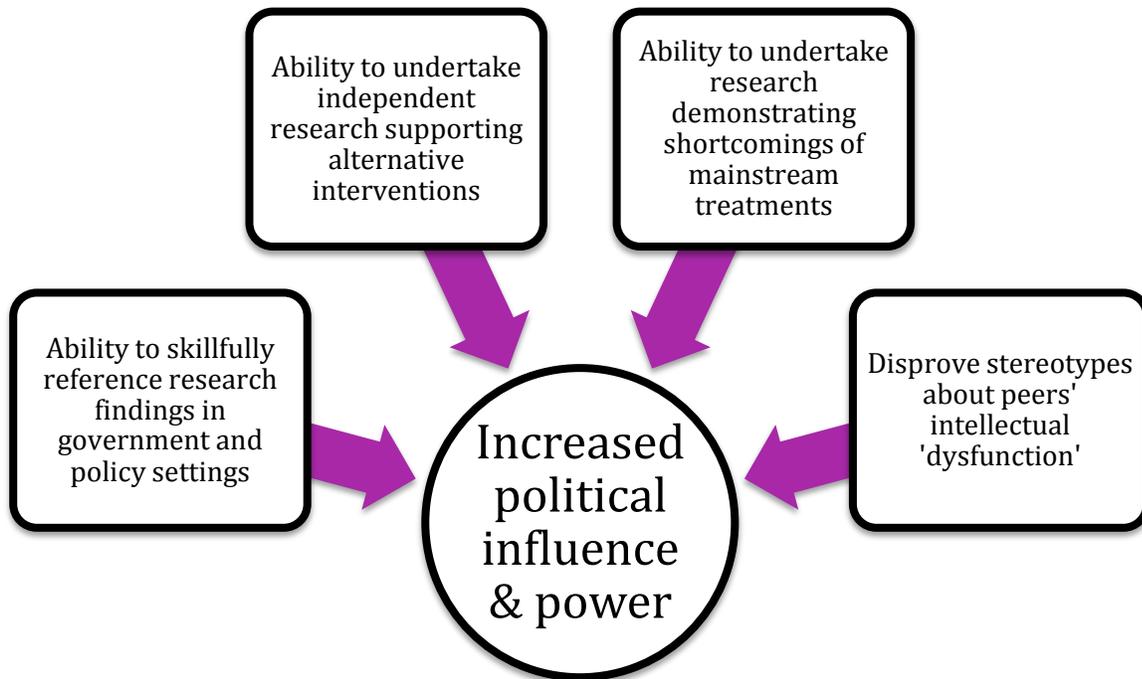
Figure 2 – Advantages of including users/survivors in research

4. The realities of academia & CBPR

Unfortunately, university departments and research centers are typically extremely hierarchical and non-egalitarian—even when no users/survivors or community members are in the picture. These structures, unsurprisingly, often spill over into conventional research "collaborations" with community members.[3]

Many universities have rigidly hierarchical cultures; this can limit real power sharing, both within academic departments and in "university-community partnerships." Universities have different policies, but these often involve real limitations on who can have leadership or carry out independent projects. For example, policies can determine or limit who is permitted to apply for or manage grants. Project staff without doctorate-level degrees may be treated poorly, and given few or no opportunities for meaningful involvement or professional advancement. Shared, collaborative, or democratic decision making processes, often common in progressive NGOs and community-based organizations, are extremely rare in academia. Thus, the often devalued or minimal role of community co-researchers in mainstream CBPR or "university-community partnerships" often simply reflects the everyday subordination of students and staff working under a senior researcher.

Perhaps the biggest danger of such practices is that community members and activists conclude that research is "intrinsically" hierarchical and dysfunctional based on what they have seen in mainstream university projects or settings. Research, however, is what a particular team makes of it and, as some of the user/survivor-led projects described in the United States and United Kingdom sections above attests, can be liberating, genuinely social justice-oriented, and truly collaborative.

5. Research methods & implications of their use

There are various key methods in research and evaluation, each with its own advantages and disadvantages (Table 2).[28,29] **Qualitative research** refers to interviews, focus groups or "free report" surveys in which participants are asked open-ended questions. Participants are encouraged to describe their experiences and perspectives in their own words. Qualitative research can then be "coded" in order to systematically identify themes across individual interviews. **Quantitative research** generally involves the use of close-ended scales, measures or questions with numerical or yes/no response. An example of this includes questions that ask a participant to rate various aspects of their quality of life on a 7-point scale. Quantitative data is typically analyzed using statistical software and can yield both descriptive information (such as how many individuals reported a high level of satisfaction with a particular program) or test hypotheses (such as whether a particular program helped Black/African American participants statistically more than Latino/a participants).

Table 2 – Advantages and Disadvantages of Key Research Methods

Method	Advantages	Disadvantages
Qualitative interviews or focus groups	• Content co-directed by participant(s) • Can better capture what participants think is important • Allows important nuances and contextual factors to emerge	• Difficult to use with large groups • Small samples do not allow for generalization to larger groups • Small or selective samples can lead to biased results • Coding data often very time consuming
Quantitative surveys or measures	• Community members can contribute to measurement development and selection • Can be used with large samples • Faster to analyze • May better reflect differences	• Measures used may not capture important information or context • Statistical significance may have little real-world meaning (sometimes called "clinical

	and heterogeneities of experience • Maybe be perceived as more compelling evidence by policy makers	significance") • Numbers can be manipulated through statistical methods; statistical significance may come from sample sizes more than other factors
Ethnographic or auto-ethnographic observation	• Can capture interpersonal, social and cultural dynamics in a very nuanced way • Accounts for observation (how people actually act) as well as self-report (what people say they do or feel)	• Number of people observed is often small • More subject to subjective biases in interpretation of behavior • Extremely time-consuming • May make informants feel constantly watched or monitored in an unpleasant way
Pre-Post and Longitudinal Research	• Objectively documents change over time • Often more persuasive than other forms of research to policy makers • Can be qualitative, quantitative or both	• Time intensive and often expensive to collect • Attrition (loss of participants at follow up) can be large • Participants might feel "stalked" • If no control group, usually documents correlations only, not causation

Ethnographic and autoethnographic approaches typically involve both interviews and observation of what participants or informants are actually doing. Sometimes, ethnographic work explicitly examines the ethnographer him or herself and/or analyzes his or her experiences. An example of ethnography is when a researcher spends hours every week at a drop-in center watching what people do and how they interact, sometimes talking to them, sometimes just observing. Finally, **pre-post and longitudinal research** describes projects in which data is collected at multiple time points: often immediately before (pre) and following (post) a specific intervention, or simply as a way of better understanding change over time. For instance, the Chicago Follow-Up Study has documented the long-term outcomes of a group of individuals, starting with their initial hospitalization and tracking outcomes over the course of over 20 years.

Debates over the relative advantages and disadvantages of different research methods are often intense and emotionally charged, even within academia. These debates have also spilled over into user/survivor research, with some

> All research methods have advantages and disadvantages. Research methods are tools that one can combine to address specific questions as needed.

activists contending that qualitative research is more egalitarian. As Table 2 indicates, each approach has its own strengths and weaknesses; each tool can be combined with other tools to provide the most benefits when the method matches the research question. For example, a program director who wants to know whether one particular trauma-based intervention is, on average, more helpful than another, may be best served with a quantitative pre-post study; a program director who wants to know how members or clients feel about racial dynamics within a small organization might be best served asking an external researcher to conduct in-depth individual interviews and/or focus groups.

6. Mirroring of political problems or dynamics within the movement

When we consider user/survivor research or research involvement, not all tensions are "academic." Some of the political problems and dynamics within the United States user/survivor movement may also play out when it comes to research or evaluation. For instance, just as activists are often concerned with the legitimacy and authenticity of other activists (e.g. whether or not they have sufficient lived experience to claim a peer identity), community members may wonder what qualifies a given researcher as a "peer." To this end, it is important for user/survivor researchers to acknowledge differences in experience, even while using their lived experience to inform research. As within the user/survivor movement, some peer researchers may prefer a more aggressively activist approach to research (e.g. the development of "radical" alternatives) while others may focus more on reform or incremental change. User/survivor research is grounded in the idea that when users/survivors have power to decide which research questions are explored and have leadership in the conduct of research, this research will better serve the community. A research project can be an opportunity for users/survivors with different perspectives to work on a shared goal, emphasizing areas of agreement while learning from points of difference. Whatever the goal of any particular user/survivor group, user/survivor research is a means to improve that work.

7. Building research capacity

As previously described, *capacity building* refers to the enhancement of community members' skills in ways that empower them to independently achieve community goals and effect change. In the context of research, community capacity building might involve increasing community members' understanding of research methods and analysis (including basic statistics), the development of skills needed to conduct program evaluations without

"professional" help or assistance, and increased research literacy with respect to using evidence to change or support new policies and substantiate proposed projects for the purposes of obtaining grants.

Building research capacity can seem daunting, but users/survivors can "up-skill" using various strategies. Formal education—community college courses and free online seminars, webinars or MOOCs ("massive online open courses")—is one option. Users/survivors working in community-based organizations that collaborate with or hire external evaluators might also request that they conduct the evaluation in a participatory way, with opportunities for hands-on learning and observation. User/survivor-run organizations might also see if researchers from local colleges or universities would be willing to teach research methods "intro classes" *pro bono* or mentor interested individual staff.

At the level of policy activism, peer-run organizations and national advocacy coalitions might also demand increased support for both formal and informal research training/education, as well as dedicated federal funding for user/survivor-led research projects.

8. Individual perspectives

Nev Jones

"*Much of my research focuses on voices, psychosis and early intervention. I tend to use mixed methods—a combination of qualitative and quantitative approaches—in order to synthesize the important nuances and complexities revealed in in-depth interviews with more generalizable quantitative data.*

"*Regardless of the method I'm using, I try to experiment with project designs that maximize participant involvement. For example, in one of my qualitative projects all the individuals involved in coding and analyzing the data have themselves also been interviewed for the project (myself included). I also try to figure out ways that once data is de-identified it can be made freely available to all participants involved for their own projects or use.*"

Laysha Ostrow

"*In my research, I use primarily quantitative and survey methods approaches to look at issues in policy and practice for recovery-oriented community-based supports—in particular peer support modalities and the organization and financing of behavioral health systems.*

"*While ultimately my research focuses on quantitative methods, I always involve multiple stakeholder perspectives in the development of research questions, study design, interpretation, and dissemination. Just because people do not have formal research training does not mean that they cannot significantly contribute to research projects. I feel I am a part of a larger voice and community that wants and needs research evidence, and that my particular role in that is to produce a high quality quantitative evidence-base, as that is where the field needs to go next to support substantive social change.*"

Lauren Tenney

"*I am a survivor of psychiatry and that informs my research agenda, which looks mostly at institutional and structural classism and racism in state sponsored organized psychiatric industries, including human rights violations such as murder, torture, and slavery committed therein. I use environmental community based participatory action research as a framework and makes emancipatory claims. I believe just because one has formal research training, does not mean one knows what questions to ask--or knows how to ask them, for that matter. Often qualitative, I use video as a research tool, go on archival digs, search out population data, and incorporate mapping techniques in interview processes to develop an understanding of what I, and those whom I am working with, make inquiries of through the research process. I believe what we add to the academic research base is a rich understanding of why and how things happen, with guidance on how to resolve the institutional and structural oppression people involved with psychiatry experience.*"

9. Case studies

Case Study #1:

Case Study #1:
Service User Research Enterprise (SURE)
Institute of Psychiatry, King's College London (United Kingdom)

What: SURE is the only research center in the English speaking world that exclusively coordinates user/survivor-led research, and provides dedicated master's and doctoral level training to students with lived experience. SURE has pioneered the development of user/survivor research methods and published multiple influential studies and reviews.

Original funding source: SURE is housed within a large research university; the co-directors are salaried faculty at the Institute of Psychiatry. Most funding for graduate students and staff comes from large research grants based at SURE, grants involving senior SURE researchers, or from national training fellowships.

Organizational structure: SURE is co-directed by a non-peer clinical psychology researcher (Til Wykes) and a survivor researcher and activist (Diana Rose). A combination of Master's level research associates, graduate students and post-doctoral fellows work under the co-directors' supervision. SURE also collaborates with external user/survivor researchers, community-based mental health organizations, and charities.

Types of projects: SURE researchers have developed focused approaches to creating and validating user-valued outcome measures and patient-centered systematic reviews. Through their research efforts, they have successfully challenged national guidelines concerning the safety of ECT.

Contribution to user/survivor capacity building: SURE has helped train and jumpstart the careers of numerous user/survivor researchers in the United Kingdom and Europe, many of whom have subsequently secured important posts in academia and community-based settings. The program serves as a stable home base for aspiring researchers with lived experience. SURE has contributed to the training and involvement of community-based service users through projects incorporating non-academic user/survivor interviewers and focus group facilitators.

Challenges: While funding for user/survivor involvement in the United Kingdom easily outpaces that in the United States, securing grants remains a significant challenge. In many cases, SURE researchers are asked to serve as co-investigators on larger (non-user/survivor-led) projects, with control over only particular project components. In addition, United Kingdom funding agencies have placed increasing emphasis on proof of the added value of user/survivor inclusion, which poses a significant challenge.

While supports and accommodations for SURE students exceeds those available in other settings, the full inclusion of individuals with more chronic or challenging mental health problems, or who experience more significant relapses while in the program, remains problematic. Other tensions include potential negative implications of a "user/survivor-only" research and training program; and struggles to negotiate the tradeoffs between less conventional vs. more mainstream research methods, particularly when located within a very mainstream, research-intensive university setting.

What We Learned: A project like SURE might not be possible in the United States for various reasons. For a similar project to be implemented in the United States, we would likely need to see a much stronger commitment to user/survivor research leadership on the part of senior researchers, university administrators and research funding agencies, as well as support from community-based activists. Minimally, this would include graduate fellowship opportunities for users/survivors, and dedicated sustainable funding for user/survivor-led projects or project components. SURE nevertheless continues to demonstrate not only the impact of institutional investments in the training of user/survivor researchers, but also the value of strong user/survivor leadership and top-down administrative support.

Case Study #2:
Field School (FS), Center to Study Recovery in Social Contexts (Center), Nathan Kline Institute & Columbia University

What: The FS was developed to build research capacity among users/survivors living the great New York City region. The project was funded from 2009 to 2011 by the National Institute of Mental Health (NIMH) and sought to provide both intensive research training and practice for community based peers with lived experience.

Original Funding Source: NIMH. Some former FS students now work directly with or for the Center or the Nathan Kline Institute.

Organizational structure: The FS project was headed by senior (non-user/survivor) researchers Mary Jane Alexander, Director of the Nathan Kline Institute, and Kim Hopper, a faculty member at Columbia University. Other non-user/survivor Center research staff, including doctoral students, helped administer FS programs, develop curriculum and teach or lecture the formal FS courses.

Types of Projects: The FS was designed as a single continuous research training and capacity building project. Participating users/survivors—most of whom had experienced significant disruptions in their education and career trajectories following a psychiatric diagnosis—were recruited as FS students. The FS training curriculum involved:
- In-depth training in both qualitative and quantitative research design, methods and data analysis;
- Formal classroom-based courses, including training in research-related technology; and
- Community-based research practice and mentored apprenticeships working on particular Center-funded projects.

Contribution to user/survivor capacity building: A stated goal of the FS was to increase the diversity of the United States mental health research workforce through training otherwise under-represented individuals with lived experience, and with significant extra barriers to full inclusion and integration in academia. The FS aimed to move beyond the tokenistic inclusion of users/survivors as project "advisors", and instead aimed to empower community members to assume more significant leadership roles in research and evaluation.

Challenges: An ambitious project, the FS faced multiple implementation challenges. These included tensions over definitions of "rigor" in research, conflicting student and professional researcher goals or values, students' discomfort with an institutionalized academic environment, and challenges finding or obtaining research-related work (or additional professional development) after the end of the projects' formal funding period.

What We Learned: Fully funded training programs for non-academically-based users/survivors, who have experienced significant barriers to higher education due to their diagnoses and associated discrimination, are an extremely appealing option for egalitarian capacity building in the United States. At the same time, significant challenges persist, including the need to address common power hierarchies in academia, to address potential conflicts proactively between disability-based benefits and training activities or financial compensation, and to ensure that there are actually paying opportunities for research-related work and/or continued formal educational advancement following the completion of a training program.

<div align="center">

Case Study #3:
Peer Qualitative Research Group (PQRG)
Canada

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What: PQRG emerged as a user/survivor-only research group within a larger research project. Participants in the PQRG were involved in the At Home/Chez Soi project - a national randomized controlled clinical trial, with the effort to include people with lived experiences on the research teams. The goals of the PQRG included "to bring forth substantial experiential knowledge," and to "develop richer information." Another goal was to develop a group for power, and to eliminate the tokenization which some experienced as single members on large traditional research teams.

Original funding source: PQRG received funds through a larger national project At Home/Chez Soi, which studied a Housing First intervention with homeless participants, and was funded by Health Canada through the Mental Health Commission of Canada. The national and local research teams contributed to PQRG funding, including in-kind resources. 'Peers', working on the larger national project and on the PQRG, were compensated for their time.

Organizational structure: There was a great effort to ensure diversity amongst people who participated in the PQRG, including experiences of homelessness and psychiatric experiences, as well as race, gender, sexuality, and class. The sentiment, "You have to work hard to be sensitive to intersectional oppressions that people experience," was a motivating goal. PQRG held one face-to-face meeting, which brought members of the group from across the country together. The PQRG accomplished most of its work via the internet, through e-mail, and telephone, with bi-monthly conference calls. All of the members of the PQRG had outlined expectations; it was important to the group that each person was held accountable for the work they were to accomplish.

Types of projects: A main project of the members of the PQRG was learning how to conduct research, including different methodologies and approaches to analysis, in a non-threatening, equitable manner, "with a level of comfort that allowed for the freedom to share whatever we wanted and that we allowed for a lot of discussion." A main project of the PQRG was to develop an article based on the qualitative analysis of data from the national research project.

Contribution to user/survivor capacity building: The PQRG aided in enhancing the understanding group members had concerning research methodologies, implementation, and analysis, and furthered their development as user/survivor researchers. The PQRG also enhanced the members' understandings about academic work and publishing processes and practices. Of vital importance, the PQRG aided in developing sense of solidarity amongst users/survivors who were working on the national project, and aided as a support for creating sense out of being a person with lived experience working with traditional researchers.

> *"If they know that you are a troublemaker they aren't going to hire you if they know that you are a dissident. You cannot display any kind of emotion, if you show any anger – oh, this person is not talking like a robot, palatable, functional way that doesn't offend anyone, that's how you have to speak. You can't make anyone look bad."*

Challenges: The barriers that members of the PQRG faced were far greater when they were working as members of the research sites than any challenges the group faced itself. The main challenge to the group was adequate and continued funding. There was also a desire expressed that the PQRG should have existed at the inception of the project, as opposed to when it was established— which was in the midst of the research project. Another pressing issue was what it is like for someone with a psychiatric history to work as a 'peer' researcher on

a non-peer team. The comfort of learning amongst peers and being accountable for their work were among the greatest benefits of the PQRG. As a result, the greatest barriers remained that the need to "bridge the gap" when associated with non-peers was great. Challenges included the high level of controls put on 'peer' researchers by non-peer researchers concerning how, what, and with whom to communicate; receiving inadequate levels of guidance on how to do research; and being remanded to 'solo' projects with no actual function in the overall group work. These barriers motivated the establishment of a 'peer-only' workgroup.

What We Learned: PQRG demonstrates the value of research coordinated and conducted by users/survivors. When individuals on large research teams struggled to be more than tokens, they banded together instead of giving up, and created academic work that satisfied the inherent substantial knowledge they possessed. When a traditional environment working toward an established research agenda included user/survivor researchers, they faced a variety of frustrations. These included feeling marginalized and tokenized, as well as not being authentically informed or included in their participation. However, when these same users/survivors had the opportunity to work amongst themselves, were able to hold each other accountable, produced academic work later accepted for publication, and built a base for power and solidarity amongst researchers who publicly disclose their own psychiatric histories. In the United States, it would be advisable to include a funded mechanism on every research project for people who are researchers with psychiatric histories to have their own funded group inside of the project.

10. Recommendations

The background on user/survivor research, as well as the case studies described above, underscores challenges that need to be addressed.

1) Power imbalances are typical in research. The mental health system has often taken from users/survivors the power to determine the meaning of our own experiences, or to determine what services are helpful or harmful to us. For this reason, it is especially important to make real efforts to disrupt power imbalances in user/survivor research. Differences in knowledge of research methods, control over funding, professional credentials, and perceptions about who has the "ability" to take on positions of leadership and responsibility are all factors that contribute to power imbalance. We should always avoid tokenism, or the "involvement" of users/survivors in research without meaningful power or influence on the project. Power dynamics should be honestly acknowledged and addressed.

2) Diversity *within* the user/survivor community needs to be substantially considered. User/survivor research is grounded in the idea that lived experience is crucially important in developing more effective and ethical services. Race, ethnicity and socioeconomic status, for instance, are aspects of lived experience that need to be much more seriously considered in the context of user/survivor research, as are degree of disability or extent of service experience. Exclusion and lack of representation in research extends beyond just user/survivor status, and must be acknowledged. Every effort should be made to accommodate users/survivors who experience ongoing distress and disability. Otherwise, only more "able" or "fully recovered" users/survivors will be contributing to research. Leadership development and genuine collaboration with users/survivors from diverse backgrounds should be a top priority in user/survivor research.

3) Different approaches to research vary in terms of values and what kind of information is considered valid or important. The values, interests and goals of the *specific* project team and site need to be considered when selecting methods.

4) Many of the barriers to user/survivor research that need to be addressed are structural. Discrimination and stigma against users/survivors in higher education is a significant challenge. Legal advocacy and the development and funding of supports for students with psychiatric disabilities are among the ways to address these issues. Nonetheless, the presence of stigma and discrimination and stigma *within* user/survivor "academic-community" partnerships needs to also be considered.

Table 3 – General Recommendations

Challenge	Recommendation
"Everyday" academic power & status hierarchies	Proactively discuss and address power imbalances and decision hierarchies; ensure that all stakeholders feel empowered to honestly speak their minds
Diversity, inclusion & representation	Critically investigate and acknowledge the exclusion of users/survivors with more serious disabilities or challenges, intersecting stigmas, and histories that have prevented past formal educational attainment
Socioeconomics	Consider the impact of work and/or training on community members receiving income- or disability-based entitlements
Keeping it real	Tokenism or the inclusion of users/survivors in strictly subordinate roles (with no actual power/authority) should be avoided at all costs
Methods & values	Project teams or initiatives should proactively address the different implications of research methods, and their connections to researcher and community-member-driven values (which may significantly diverge)
Structural & institutional stigma & discrimination	In addition to immediate project work, all stakeholders (researchers, administrators, students, community members, activists) need to identify and challenge broader barriers to the full participation of users/survivors in research and higher education

11. Conclusion and summary

Substantial involvement and leadership of users/survivors in research and evaluation is a crucial goal for transforming behavioral health systems. Equally, it can be used to improve and demonstrate the effectiveness of user/survivor created alternatives. Users/survivors can contribute to the "evidence base," and influence funding of programs and services through involvement in research and evaluation. Peer run and delivered services, as well as user/survivor created alternatives, are promising examples of services that have been implemented on the basis, in part, of user/survivor research. User/survivor activists can also challenge harmful and ineffective practices by developing skills to effectively critique the methods and conclusions of published research. This can support more effective influence of both programs and policy.

Still, user/survivor research has been met with a number of challenges.

- Many users/survivors are rightfully skeptical of research, due to a history of exploitation and support for harmful and disempowering practices by researchers.
- Traditional academic hierarchies contribute, at times, to involvement of users/survivors that is tokenistic or exploitative, even when well intentioned.
- Discrimination and stigma in higher education settings, as well as a lack of support (e.g. dedicated funding and mentorship) have hindered the development of users/survivors as independent scholars and researchers.

In this White Paper, we provided an overview of user/survivor research in the United States and United Kingdom, and highlighted three case studies of user/survivor research initiatives. Our findings point to challenges and support specific recommendations. A variety of strategies can address these challenges, and support the advancement of user/survivor research.

1) The broader research community should acknowledge that past and present research has contributed to both harmful practices and user/survivor skepticism of research.
2) Researchers and evaluators, including user/survivor researchers, who seek to involve users/survivors in collaborative or "participatory" projects, should acknowledge power hierarchies. They should consider the findings and recommendations of this report in actively working to avoid tokenistic or exploitative involvement of users/survivors. Researchers and program administrators need be mindful of the ever present risk of co-

optation of user/survivor perspectives, even when the intent is collaboration.

3) Users/survivors with an interest in research should be supported in developing skills and knowledge to lead their own projects. They can learn research and evaluation skills through informal self-study and apprenticeship on formal projects. Formal academic training is often helpful, but not necessary in developing these skills. Community-based users/survivors without formal research credentials should be supported in collaborating or carrying out independent projects; targeted support for users/survivors who wish to pursue more formal academic training should also be developed. This should include efforts to address discrimination and stigma faced by users/survivors in higher education.

The information provided in this white paper is intended for anyone interested in advancing user/survivor research. Positive transformation of the behavioral health system, development of user/survivor-led alternatives, and the empowerment of research participants are all goals that can be supported through such efforts. We hope for the continued advancement of meaningful collaboration and, more importantly, leadership of users/survivors in evaluation and research.

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13. Resource list

Books on User/Survivor Research

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Freely Accessible User/Survivor-led Research Methods and Evaluation Reports

A Guide to User-Focused Monitoring: Setting Up and Running a Project
> *Sainsbury Centre for Mental Health (United Kingdom)*
> *Authors: Nutan Kotecha, Chandra Fowler, Anne-Laure Donskoy, Peter Johnson, Torsten Shaw, Karen Doherty*
> *Other contributors: Julia von Hausenchild, Krys Farrell, Graham Saxton, Shelley Welton, Derek Williams*

Mental Health Service User Leadership in Research
> *Service User Research Enterprise*
> *Institute of Psychiatry, King's College London*
> *Authors: Felicity Callard and Diana Rose*

Transforming Services: Changing Lives (Working for User Involvement in Mental Health Services)
> *The Centre of Excellence in Interdisciplinary Mental Health*
> *The University of Birmingham and Suresearch*
> *Authors: Marion Clark , Ann Davis, Adrian Fisher, Tony Glynn, Jean Jefferies*

Review of Consumer's Perspectives on Electro Convulsive Therapy
> *Service User Research Enterprise*
> *Institute of Psychiatry, King's College London*
> *Authors: Diana Rose, Pete Fleischmann, Til Wykes, Jonathan Bindman*

User Controlled Research: Its Meanings and Potential. Report Summary.
> *Shaping our Lives & the Centre for Citizen Participation*
> *Brunel University*
> *Authors: Michael Turner, Peter Beresford*

Active University and Community-Based Projects and Centers that Promote User/Survivor Research Leadership by Country

Australia and New Zealand:

- Australian National University, Depression & Anxiety Consumer Research Unit
- International Association of Service User Academia

United Kingdom:

- Brunel University, Centre for Citizen Participation
- Durham University, Service User Led Research in Mental Health
- INVOLVE User-Controlled Research
- King's College London, Service User Research Enterprise
- Making Waves
- McPin Foundation
- Recovery in Sight
- RETHINK Research Program
- Survivor Research
- Suresearch
- National Service User Network, Survivor Researcher Network

United States:

- Consumer Quality Initiatives
- Lived Experience Research Network
- The Opal Project

Canada:

- Ryerson University, School of Disability Studies