Making activism a participatory, inclusive and developmental process: a research programme involving mental health service users

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Abstract:	Understanding real world experiences and issues is a priority for research funders, yet there are challenges in directly engaging with people for evaluation and investigation of the professional services they receive. Much professional work takes place within institutional restrictions, arising from legislation, policy and local practices. Collaborative research is therefore complex but relevant for improving services. This research programme started in 2002 with focus group research, led by occupational therapists based in a local NHS trust and a university, followed by 8 further projects including a Photovoice project. This programme and our perspectives from reflections suggest we do not always know who we are, what we want or who cares about research outcomes, but it is important to embrace the potential of activism, to energise and focus people for positive action, wherever they are based.

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Introduction

This research programme involved mental health service users and occupational therapists from local NHS and non-statutory mental health services, and the local university in London, UK. To set the scene for the research programme, understandings of activism have been explored, starting with the importance of activism as a driver for improving mental healthcare. Occupational therapy, as a core profession in mental healthcare, has had an unclear relationship with activism, although its roots and development were dependent on social activists. This unclear relationship has characterised the research programme, as activism was part of the research process rather than a central driving force. This was because projects within the programme gave voice to direct experiences of mental health services, without campaigning for specific changes. Yet the products of the research projects were used to support service transformation. Reflections on being involved suggested that identifying as an activist was a personal decision, as the benefits of collaboration and action became more apparent. Therefore, it is suggested that collaborative research can foster activism in the context of mental health service use and provision, but those involved might not self-identify as activists. In this research programme, focusing on collaboration, inclusion and occupation in its widest sense was important for sharing strengths and resources.

Understandings of activism

Activism happens when people take actions for social change (Laverack 2012). People who lead and get involved in activism often draw on their direct experience of the issue(s). Activism can be individually pursued (such as Brian Haw https://en.wikipedia.org/wiki/Brian_Haw) but usually involves groups of people. Often these groups are described as social movements, reflecting how the membership, actions and focus evolve over time (Beresford 2016). This means that activism is political, because of the processes required to negotiate what actions are taken and who leads them. To come together and act, people have to have a sense of their own power, which may vary over time. People who are activists may not be marginalised, but protecting powerful positions, sustaining inequality. Increasing hardship has been observed in the UK by Alston (2018), the United Nations Special Rapporteur, who reported that "poverty is political", emphasising how powerful messages had forced the major impact of austerity on those who could least cope with it. For disabled people, including mental health service users, this has been evident in cuts to services, withdrawal of benefits and funding crises for user-led organisations (Beresford 2019). Protests about long term services being cut have been overshadowed, by powerful messages about promoting individual mental health and wellbeing, reducing reliance on services

(http://cambskonp.org/lifeworks/). Faulkner (2017) suggests this is an unwelcome threat to opportunities for people to meet and support each other.

For this research programme, the work of radical educators Freire (1996) and Brookfield (1987) was influential, because most people had not been involved in activism or research before. Freire offered a structural understanding of power in collaborative work, and Brookfield indicated how to proceed in practical ways, knowing that everyone had something to learn from the experience and this took time.

Health activism is usually concerned with specific health issues (Laverack 2012), led by national campaign groups, sometimes with local branches. Advocates may be connected with these groups, supporting individuals or advocating for strategic change, with tension around advocating *for* or *with* individuals, by professionals (Hubinette, Dobson, and Regehr 2015). The work of health professionals for social change is often seen as advocacy rather than activism (Laverack 2012). This research programme was connected to local activists and advocates, as illustrated in Table 1, and was focused on the experience of using mental health services in the long term. Beresford (1999) was influential in developing understanding of how to be an activist in the university setting, responsibly and inclusively creating opportunities for effective change in the local mental health services.

<Table 1>

Improving mental health care through activism

Mental health care differs from other health care settings. Rogers and Pilgrim (2003) have pointed out the relative weakness of knowledge in psychiatry, indicating the tension between social and medical perspectives. Historic underfunding has been identified as a cause of inequality and led to campaigns such the parity of esteem initiative in the UK (Royal College of Psychiatrists 2012). Unlike other health settings, compulsory treatment for mental health problems is sanctioned by law (the Mental Health Act 1983), imposing institutional restrictions on sectioned individuals, who then require advocates to safeguard their human rights. Advocacy is a term more commonly used in the healthcare literature (Kirsh 2015; Cage 2007; Evert 1995) because popular use of the term activism tends to relate to vigorous campaigning such as marches, boycotts, and sits-ins (Frank and Muriithi 2015). The practice context of most healthcare professionals may not permit these actions, because of local and legal codes of professional conduct (Pollard and Block 2017). However, activism has underpinned many improvements in how mental health services are provided (as opposed to interventions), such as the growth in community rather than institutional care.

In relation to mental health, activism takes different forms, reflecting different agendas. Since 2007, Time to Change has been a campaign to reduce stigma, started by a partnership between the government, charities and academics. Nearly £21 million funding was obtained from the National Lottery, Comic Relief and Department of Health and Social Care in the first four years (Henderson and Thornicroft 2013). The programme targets knowledge, attitudes and behaviour about stigma (Smith 2013), and has consulted service users about their experiences from the beginning. Consultation is different to leadership and reflects the different ways of being an activist. In contrast service users have, since the 1970s, led the international Mad Pride movement, challenging the dominance of psychiatry in understanding their experience and identifying social determinants (MacDonald, Charnock and Scutt, 2018). This has led to the more recent Mad Studies academic discipline, where service user voices are central, linking experiences with many other disciplines beyond psychiatry (Faulkner 2017). Occupational therapy is considered here to be a separate discipline to psychiatry.

Occupational therapy: origins and contemporary understandings

Occupational therapy prides itself in having a history of activism (Cage 2007) with historical roots in the Arts and Crafts Movement and the Hull House in Chicago, where occupation was a focus for social activism (Wilcock and Steeden 1999). Dr Elizabeth Casson (1881-1954), the founder of the first school of occupational therapy in the UK, was influenced by the Arts and Crafts reformers through her first employer Octavia Hill (1838-1912) (Darley 2010), and later, American occupational therapists, led by the Hull House pioneer Eleanor Clarke Slagle (Paterson 2014). Subsequently, activism and advocacy was polarised by Evert (1995), who described the national United States professional association undertaking political activism, to ensure occupational therapy was included in insurance agreements. In contrast, she viewed advocacy as a local activity, on behalf of people receiving professional services. Similarly, advocacy is what some therapists see themselves to be doing or called to be engaged in (Kirsh 2015). More recently, interest in activism has resurfaced within occupational therapy (Townsend and Marval 2013). However direct engagement in activism is not strongly evident in current occupational therapy literature, although there may be much action which takes place but is not published. There is interest in activism as an occupation (Fox and Quinn 2012; Frank and Muriithi 2015) and calls for more political activity to help people who use occupational therapy services (Maria Galheigo 2011; Guajardo, Kronenberg, and Ramugondo 2015). Alliances with disabled people, such as those in this research programme, have been described by others (Pollard and Sakellariou 2014) .

Challenges and opportunities in mental health research and education

Occupational therapists are educated to identify and address access and performance problems, facilitate participation and collaborate to create cycles of action in different contexts, until problems are resolved (Pentland et al. 2018). The focus of occupational therapy is on what people do, a simultaneously practical and complex focus, which does not sit well in services oriented to dealing with the impact of mental ill health through talking, tablets and constraint. Articulating knowledge about occupation, or doing, has been challenging: occupational therapy education has relatively recently entered universities (Paterson 2014), with research growing slowly in response. Funding for general health research puts occupational therapists in competition with powerful medical teams, or fosters unequal partnerships. Yet understanding real world experiences and issues is a priority for research funders (Wicks et al. 2018).

Research has been regarded as the highest form of advocacy (Al Wazni 2017) to generate useful knowledge. Flood, Martin, and Dreher (2013) argued that academia can be a site for activism through knowledge generation, teaching and learning; and for challenging and reconstructing power relations. However, challenges for academics involved in activist research include: negotiating the different models of recognition (academic community versus general public); and navigating the ethical boundaries of one's role between activism and research (Couture 2017). For research based in mental health services, these challenges become more complicated. Obtaining ethical and institutional approval can be difficult in the face of ignorance about mental health, how services work and how to engage with the varying vulnerability of people with severe mental health problems.

Collaborating with people who use mental health services, to evaluate and investigate the services they receive, can overcome some of these problems, although Rose and colleagues point out that survivor knowledge and research is not equally valued as a separate entity (Rose, Carr, and Beresford 2018). Cottrell (2005) suggested strategically using opportunities like key government policies and court rulings, to underline the relevance of proposed research. The issues discussed so far shaped the research programme as it developed, drawing on experiences of working in and using mental health services, and recognising that understanding of these experiences and issues would evolve in time, with more knowledge, more experience and greater resources.

The research process

The research was a programme of nine different projects, and further details are in Table 2, where relevant publications are referenced, so that project findings can be accessed. The people involved had user and professional networks across mental health services, non-statutory services and

universities. Several postgraduate students collaborated to lead elements of the projects, successfully gaining their MSc. Some of the projects were used for the impact statement for the Research Excellence Framework, the formal assessment of quality of research outputs from universities. Impacts on services and researchers are emphasised here, rather than findings.

<table 2>

The research programme lead (first author) had no concept of a *research programme* at the outset: this was an academic term, not used within her profession of occupational therapy, nor in mental health services. She was more familiar with evidence-based practice, on researching effectiveness of the services, but this was framed in terms of informing commissioning and professional decision-making (Ballinger and Wiles 2001). In retrospect, the idea of a *research programme* was helpful, to understand the values which meant some projects were rejected and others were pursued.

Briefly, these values can be summarised:

a) People with direct experience should be the core focus of research
b) Experiences of services should be investigated, so that action can be taken
c) Powerful agents should be exposed and engaged with (processes, people, beliefs)
d) Research should involve naming, creating and producing artefacts as evidence of experience

The first author also drew on prior personal experiences of using health services and activism to sustain it. She had not used mental health services but had long term experiences of other health services as a user and a carer. These experiences served as a critical point for reflection, especially when working with the service user researchers in project 3 (see Table 2). She had given up environmental activism to pursue postgraduate study, yet increasingly she understood the collaborative approach to research as a form of activism, with similar challenges and opportunities. There were pressures to shape the research to attract more funding to increase income for the university. Yet it was difficult to compromise on priorities, knowing the issues in local mental health services affected peoples' lives. Collaboration, although time-consuming and complicated, was more important than rushing through half-thought grant applications and publications.

The research programme started in 2002 with focus group research (project 1), evaluating the mental health day and accommodation services in the local borough (Bryant, Craik and McKay 2005). Politically, there was great interest in social inclusion, and these services were increasingly seen as socially exclusive. Local NHS managers were under pressure to modernise the services and wanted to gather opinions, so they invited tenders to conduct the research from local universities. The letter inviting tenders was brought to a teaching session at the university as an example and the

first author, undertaking her MSc as a mature student, immediately asked to be involved. Students
had been discouraged from undertaking research involving service users as participants, because of
the bureaucratic work and delays associated with getting NHS ethical approval. However, by doing
the project in partnership with local managers and senior academics, it proceeded without delay.
The findings were used to justify implementing a new anti-discrimination staff training programme.

For the second project, a new NHS manager was appointed to modernise the mental health day
services, drawing on the findings of the first project. She was also an occupational therapist,
experienced in bringing people together to work for change, and set up a forum of service users,
volunteers, local agencies and staff. The first author was invited to join and senior academics
encouraged her to start her PhD. The doctoral research was designed collaboratively with the forum,
aiming to identify and ultimately protect the aspects of the services which were helpful. Even though
this research pre-dated the austerity era, there was a persistent fear that the day services would be
cut to save money, a fear that was sadly realised as the research progressed. However, long term
capital funding was secured for one of the day services, justified by the findings of the PhD.

Towards the end of her PhD, the first author reflected on its limitations. The drive to modernise day
services had been imposed on local service users, and she decided to initiate project 3, where the
focus of the research could be determined by mental health service users themselves. Her
professional knowledge and experience of mental health services extended across many areas, so
she could imagine many possibilities and welcomed the opportunity to develop the research focus
collaboratively. This evolved, from 2007-13, into the Living with Psychosis project (Makdisi et al.
2013). Unlike the other projects, meetings about this research took place solely at the university and
a local non-statutory mental health service hosted the focus groups to gather data. An approach of
involving NHS staff and university students was used, and the project generated many opportunities
for collaborative presentations, writing and teaching (Bryant et al. 2012). Two of the group have
subsequently enrolled for PhDs. Towards the end of the joint work, the group reflected on psychosis
and medication, as this had been the only aspect the first author had been reluctant to pursue,
feeling it might be difficult to manage as a focus. However, it was felt to be a legitimate focus for
future research, exploring how service users experience psychosis being managed by medication and
the impact on their daily lives.

Meanwhile, occupational therapists based at one of the hostels (evaluated in the first project)
initiated project 4. They felt the hostel had lost its focus on rehabilitation, with fewer opportunities
for service users to do everyday activities independently. There was no research funding available,
so the first author gained support from the university by stressing the importance of the partnership.

There was a practical aspect to this, for the occupational therapists hosted regular student work placements. The first author also saw an opportunity for two students to undertake the research, just as she had done, gaining experience of user involvement and challenging beliefs about NHS ethics being too difficult. Inspired by experiences of user involvement in her PhD, she worked with the occupational therapists and students to involve a service user as an advisor in the planning and review meetings. The project design evolved so that current and recent service users of the hostel participated in photo-elicitation interviews (Notley et al. 2012). The project recommendations were used to structure a staff review day, agreeing on how to refocus on individualising rehabilitation programmes. The service remains focused on people's strengths, with service users setting their own goals for rehabilitation (personal communication, 26th September 2018).

Meanwhile, the university was preparing for the next formal national research assessment exercise, measuring the quality of research, and a new research centre was set up to promote evidence-based practice. Occupational therapists from local inpatient mental health services came to an event in 2009. They approached the first author, as they wanted to know more about what service users thought about their service. They had already considered extending the contract of a temporary member of staff to work on the project, using underspend money. At the time, the first author was more involved with another research centre focused on citizen participation, but could not resist the opportunity to undertake a project in acute services. By this time, NHS ethics approval was not viewed so much as a challenge, although the work involved to obtain it was steadily increasing. But the constant staff changes in the unit and security concerns were a challenge. However, the project was completed, involving service users as advisors as well as participants in interviews and focus groups (Bryant et al. 2016). Occupational therapists focused on improving their communication with ward staff. This project formed the basis for project 8, the Whiteread project (see below).

Then the number of postgraduate students increased dramatically and more research projects were needed. The first author was interested in how reviewing literature was difficult to do collaboratively, yet potentially very powerful for developing critical perspectives and robust projects. Projects 6 and 7 involved small groups of service users and occupational therapists, doing qualitative metasyntheses together, led by students under academic supervision. There were challenges for the students in developing leadership within a collaborative approach, but the opportunities for mutual learning were rich and exciting (Major and Savin-Baden 2012). The students brought articles to the groups, using a cyclical process of discussion and reflection to refine the metasynthesis. Project 6 was less successful in involving service users, but project 7 involved the occupational therapist from

project 4, who was experienced in creating and supporting opportunities to get involved. Two people from the hostel joined the group at the university.

The Whiteread project

The most recent phase of this research programme involved two projects, which were named Whiteread and Oulton after women artists. This reflected the first author's resistance to naming projects with acronyms, a practice which has military origins. It also reflected a desire to indicate the artistry of project design which she believed was more helpful for collaboration in mental health research. The Whiteread project is shared here as an example of where the research programme has led to. There is a detailed account in the report prepared immediately after the research (Bryant et al. 2015). The Oulton project is still underway. Both are concerned with user and staff experience of acute mental health settings.

By 2012, when the Whiteread project was first proposed, some of those involved in the research programme had gained up to ten years' experience of collaborative research. Service user advisors and occupational therapists believed that a deeper understanding of service users' experience of acute mental health occupational therapy could be gained, with another method such as Photovoice which the first author had used in a local day service (project 2). A small research grant was awarded to the first author and service lead from an external funder, following a competitive process. Being very specific about the purpose and method, building on the previous research, was helpful in writing the proposal and gaining ethical approval. The project was named after the artist Rachel Whiteread, for the reasons stated above, and to signify the visual interest in spaces usually unobserved in everyday life. Photovoice is a participatory approach (Lal, Jarus and Suto; 2012), used in this project to explore user experiences of an occupational therapy department within the local acute inpatient mental health unit.

Learning particularly from the previous Photovoice project, the larger doctoral project and the Living with Psychosis research, service user participants were involved over a number of weeks and could negotiate their involvement according to their own capabilities and interests. Through negotiation, this research design enabled people who were acutely unwell to be involved. Two facilitators, a service user researcher from the Living with Psychosis project and an occupational therapy researcher (fourth author), worked with five service users who were recently discharged or current inpatients over 10 weekly sessions to carry out the project. Together they captured with photographs how the physical, social and occupational environments worked as a resource, during their admission.

The previous projects had achieved an emancipatory purpose for some service users, who took up opportunities to get more involved in the research programme and take the findings forward. The Whiteread project had a slightly different impact, with three of the five participants using the project report to actively promote the findings for the benefit of other service users in the unit and to local staff. Similarly to those involved in other projects, they felt more confident about being involved in research, reflecting on the personal benefits of participation as they emerged from an acute episode of ill-health.

Reflections

The research programme involved many people in the nine projects over several years. Reflection was embedded in the process, as part of the collaborative approach, to engage with different perspectives on what was happening and what could happen next. The reflections here were part of the process of creating this article, drawn from the four authors and two researchers. The authors and one of the researchers each wrote a short reflection, responding to the questions in Table 3.

<table 3>

All four authors read all the reflections and developed themes to compare and present here. This was not a formal qualitative analysis: the aim was to capture the essence of some of our experiences, knowing the process would trigger further reflections as if we were meeting in a hall of multiple mirrors. The first author synthesised the themes which were scrutinised by all the authors and the second researcher, who also contributed verbal reflections. Our perspectives are drawn from being service users, academics, clinical occupational therapists, PhD/MSc students and independent researchers. Each of us has taken part in one or more projects in collaboration with the first author and service users.

The themes were concerned with: identity; shared values; challenges; and working together, learning together.

Identity

People's identities evolved throughout the research programme. Being involved shaped how they viewed themselves, their experiences and their own capacities. Not everyone identified themselves as an activist. But one author felt they became an activist through taking part in the research:

"My two hats as an academic and occupational therapist combined with my PhD experience have shaped me in that I have become in a small way, an activist."

The combination of being an occupational therapist as well as an academic was identified as important, for choosing participatory action research as a method that supports activism. Some identified themselves as activists prior to being involved in the research programme:

"I began to think of my activist self, having been involved in NHS union protests, women's organisations and local environmental groups…… Participatory action research with mental health service users was the only way forward."

Another identified that being an occupational therapist could involve being an activist, when working with people in mental health settings:

"My occupational therapy role supported people to overcome these inequalities and support them to continue to challenge inequalities."

The theories that informed occupational therapy practice also applied to doing participatory action research, which could be framed as activism:

"I knew that engaging in occupation, inherently involves action and doing, which can lead to change for the individual and wider community. I found that research, if seen as an occupation, meant the findings could identify areas for potential change."

Action and change were a shared focus of occupational therapy, this research programme and activism.

Shared values

One person did not immediately agree that activism was part of the research programme. However she observed that the direction of the programme was informed by shared values about research influencing change, but not all the work that took place was visible. She described the first author:

"like a swan, gliding along, with your legs pedalling like crazy."

Others were drawn to working with service users as researchers:

"I valued this experience as my first opportunity to collaborate with service user researchers… I felt collaborating was the right thing to do."

For most people involved in the research programme, it was their first experience of collaborative research. These people identified the benefits:

"the phrase "nothing about me, without me" sprung to mind- how do you explore users' views? By working with users to answer the question."

"I felt this approach could help make the research more relevant to research participants"

Service users therefore had to be part of the research team as well as the more usual role of participant, for maximum impact:

"the research meant the potential for change for a stigmatised, oppressed and marginalised group of people in society."

There was a shared interest in doing relevant purposeful research for local change:

"I take pride that I can be involved in research that helps to improve services"

Engaging in the research however, had its challenges, considered next.

Challenges

Collaboration meant being thoughtful during the research programme, to respond sensitively and negotiate when researchers and participants struggled with their commitment. This had to be emphasised when seeking institutional approval each time, as perceived risks of involving service users as researchers and/or participants were considered:

"From an NHS ethics perspective, we were always doing research with vulnerable people, because of their mental health issues"

There had been conflicts with ethics committee members, overcome by pointing out how service users and occupational therapists as mental health professionals had been involved in developing the projects. Challenges from one of the universities were also encountered, limiting institutional support:

"Favoured research attracted large amounts of funding, international partnerships, and generated findings with commercial potential."

The first author pursued participatory action research nonetheless:

"challenge of finding ways of doing the research that fitted with prevalent agendas"

Being creative and determined in making that fit was required:

"My experiences changed my approach in that I became more persistent when faced with challenges."

These challenges from the universities were not perceived by everyone, because there were important resources available which enabled and supported the collaborative work.

Working together, learning together.

The reflections describe how working together with service users, clinicians and researchers meant growing and learning:

"my experience, knowledge and confidence grew with this research"

"I have become more critical, questioning and political regarding academia and occupational therapy."

"So we learnt together and built up a shared understanding of what we were doing"

"Gradually the service user researchers became more vocal and contributed more and more to the running of the sessions as well as answering the research question."

"I learnt from [name removed] as an experienced therapist and academic."

This highlighted the value of researching with others with more experience of participatory action research. The collaborations led to further projects together:

"long term and possibly lifelong professional networks and relationships are formed".

Thus, opportunities for future collaboration are fostered. The advisory group set up to plan and oversee the Whiteread project was identified as vital to working together. It consisted of service users, the grant holder, the NHS trust research and development lead for occupational therapy, occupational therapists and two professors. The group worked together on equal terms:

"the service user being as expert as the professor"

This project fostered respect for each other's views and ideas, and taking them on board, which then influenced the next project. The cycles of action and reflection, intrinsic to participatory action research, could be perceived in the research programme as a whole.

Finally, working together extended beyond those directly involved, to those who could access the findings of the projects. One person shared this story of the impact of the Whiteread project:

"The hospital manager at this site was proposing to use the [therapies] space as offices for staff, with implications that service users would no longer be able to access therapies off the ward. I was immediately able to respond to the service manager and inform him that we had formally researched evidence undertaken within our organisation which demonstrated the benefits of service users being able to access an 'off ward' environment which aided their recovery, and helped them in their discharge from hospital. Less days in hospital for a service user is better not only for them, but ultimately is more cost effective for the health service. The change proposed did not happen and service remains as having a 'Step down' approach with an off ward therapies centre four years later."

Discussion

This research programme involved activism, in the local mental health services and in the university setting, but the activism was not necessarily perceived as such by those involved or outsiders. This is understandable because of the militancy traditionally associated with activism (Chatterton and Pickerill 2010). However, it raises the issue about whether it is important to know who we are, when engaging in collaborative research to give voice to experiences of mental health services. Knowing who we are could enable us to reach a consensus about what we want, or the aims of our joint work. This in turn raises the question about who cares, and do they care enough to support or inhibit our collaboration? Therefore this discussion considers these questions, like a chant from a protest march: who are we? What do we want? Who cares?

Who are we?

From project to project, identities changed as people developed new roles through being involved in this research programme: into researchers and activists, but also into people who could work

together to design, refine, implement and present research projects. Forenza and Germak (2015) explored the process for becoming an activist, for social workers, suggesting that it was useful to refer to socio-political stages identified by Kieffer. As people got involved, formed collaborations and saw outcomes, they became more committed. Similarly, Kramer-Roy (2015) observed the emancipatory potential of participatory action research. From her perspective, the emancipatory disability research paradigm was an important reference point, to support work for practical outcomes and the use of the social model to understand experiences of disability. However, there are additional challenges because of the difficulty of knowing who we are in relation to madness, or mental ill-health. This is not so much to do with whether people accept the word "mad" but, as Russo (2016) pointed out, because it can be difficult to agree a common focus drawing on experiences of life with a long term mental health problem, which can combine and intersect with many difficulties and inequalities.

The difficulty of finding a common ground was a primary reason for focusing on the settings for mental health service use in this research programme. This could be seen to primarily reflect a health professional agenda, especially as project 3 contrasted with the others, with a broad focus on psychosis defined by the service user researchers. However, the collaboration between service users, clinicians, students and academics could not work without a shared identity, of being researchers aiming to give voice to direct experience of services. Using Freire (1996) as a primary influence to recognise the potential for everyone involved to oppress each other, reflection and careful honest discussion were central to the projects. There were individuals (professionals, academics, students and service users) who found this difficult and did not stay long. Rose (2018) critically analysed the challenges of participatory action research, suggesting that reciprocity was important for addressing power differences. However, our experience suggests that reciprocity has its place at different stages: sharing experiences at the beginning of a study leads to the development of experiential knowledge. This term is described by Beresford (2016) and Faulkner (2017) to indicate the knowledge that can form the basis for research and activism. Experiential knowledge can be questioned, by doing research involving other users. Identifying as researchers meant we could focus on participants' experiences, to further develop the experiential knowledge we had already developed together. Beresford (1999) indicated that support is important, from practically enabling access to research resources to actively supporting each other through distress and stress. This is also fundamentally important for sharing experiences and developing experiential knowledge. In this research programme, the potential to change services for the better was readily understood, so that while people might not have identified as activists, they were empowered by sharing their experiences. They could see the value of the research and the importance of

supporting each other to achieve the study aims (Forenza and Germak 2015). It is possible that there was common ground between service users and occupational therapists because occupational needs (apart from paid employment) can be marginalised and misunderstood in mental health services, yet are a central focus to everyday life. Self-advocacy is also important (Beresford 1999): who is representing who, and what can they say? Responses to this do depend on knowing who you are. Identifying who was who in the research programme was increasingly complex: people could define themselves in relation to specific projects but, for some, involvement was over multiple projects in different roles. Freire's theory of dialogic action was influential, where people come together "to name the world in order to transform it" (Freire 1996, page 148). This was experienced in practical terms, naming the projects, but also in the efforts to find a common understanding of experiences. This did involve naming ourselves, at times, a process which was easier when seeing research as an occupation, and identifying ourselves by what we were most interested in doing. For example, using photography helped to focus on researcher roles and specific user experiences in projects 2, 4, 5 and 8.

It is possible with the growth of Mad Studies as a separate discipline (Russo and Beresford 2015), collaborative research programmes will be more frequently led by service users in the future. The issue of who leads research is important for understanding its credibility and power to transform services. Research led by health professionals could be seen to have more impact, because there are more resources available such as funding, and findings are often communicated in conventional ways, which are accessible to service providers and commissioners. But user-led research can have more credibility, being drawn from direct experience without being compromised by professional agendas (Russo 2016). Polarising the issue in this way can mask the complexities of partnerships, where leadership could be negotiated and membership evolves. Beresford (2013) indicated the importance of addressing the distance between researchers and people being researched. This research programme suggests that this is a process as much as a goal, which reflects how activists bring issues to the attention of those who can implement change. Raising awareness can be achieved in many different ways, to encourage people to fill the gaps in their understanding.

What do we want?

People may have wanted many things from the research programme, but two main aspects are discussed here. The first was to create research findings which could change how services were provided, and protect the aspects they valued, for example the safe space in the day services (projects 1 and 2) or a separate space from an acute ward for therapy (projects 5 and 8). Generally the research process was helpful in specifying and agreeing aims and actions. The second aspect was

what we wanted for the research programme to thrive. We wanted space, time, power and respect for our research focus.

Pollard and Block (2017) observed the importance of a neutral space for activists. For four of the projects (3, 4, 5, 7), planning meetings took place at the university. Service users and occupational therapists from the local mental health services saw the university as a potentially neutral space which valued learning and critical discussion, separate from the pressures of service provision and professional expectations (Pollard and Block 2017, Bryant et al. 2012). The researchers in project 3 developed their understanding of the need for space to include time, suggesting a "warp factor" where the ideal future is lived in the present, also observed by Chatterton and Pickerill in their study of everyday activists (2010). By allowing sufficient time and space to work together, a future vision of equality and mutual respect was experienced in the present (Bryant et al. 2012).

This was an ongoing process, as part of knowing *what we want* was to explore differences in opinion and differences in experience. The positions of relative power between service users, students, academics and therapists were suggested in the theme of shared interests from our reflections. This theme indicated the positive aspects of collaboration, for example steering group members getting along, with no comments about the challenges due to power differences. This could be because of the questions for reflection (Table 3). In contrast Rose (2018) observed, in her reflections about user-led research, that one participant forgot the user-researchers were not mental health professionals, possibly because of the power associated with expertise in leading research. However, a more significant issue of power was related to gatekeepers – the professionals who recruit participants for research, exerting judgements about who can be included (Rose 2018). After an issue with coercion in project 1, much care was taken to challenge this power, by holding open events with refreshments and information so potential service user participants could find out more (projects 2 and 3), bypassing professionals altogether in non-statutory services (project 3) and working with service user volunteers and co-researchers to recruit from the acute unit (projects 5 and 8). These approaches demanded clear explanation to gain ethical approval (discussed further below) and were developed in collaboration before the formal ethical approval process started.

If collaboration could take place before funding and approvals were gained, at first often people did not know what they wanted to specifically research, other than to come together and explore shared interests to start the process (Forenza and Germak 2015). This meant sharing experiences, being open to different forms of knowledge, and being inclusive about what knowledge was valued. The idea of experiential knowledge would have been helpful to discuss, as a more inclusive way of understanding of what constitutes knowledge and its generation was important (Faulkner 2017).

Knowledge transfer funding was obtained for project 3, once it was explained clearly what the knowledge was, how it was being created collaboratively and how it could inform local service improvements and capacity for further research. An inclusive view of knowledge is important to occupational therapists because of their focus on what people do, which is simultaneously simple and complex. This focus involves considering where, how and by whom knowledge about doing or occupation is created, in relation to time and place, and political and socio-economic influences (Guajardo, Kronenberg, and Ramugondo 2015; Pollard and Sakellariou 2014).

Pollard and Sakellariou (2014) argued that focusing on occupation is something people have to learn to do to raise consciousness, naming it occupational literacy. They gave the example of a toothbrush: an everyday object which enables participation. Critical discussion about the impact of using a toothbrush can range from how having fresh breath enables social contact, to the politics of plastic toothbrush manufacture and disposal. In this research programme, everyday activities were similarly valued: gardening in the strawberry patch (project 2), walking down the alleyway leading to the resource centre (project 3), sitting in the chair by the hostel entrance (project 4) and drinking from a china rather than a plastic mug in the therapy kitchen (project 8). Occupational literacy could be developed further by connecting with the phenomenon of everyday activism, described as a messy and pragmatic evolution of activism from a militant past, localised and practical (Chatterton and Pickerill 2010). It is possible that these ideas could inform future developments of the research programme.

Who cares?

The question of who cares is relevant, for discussing who made the projects happen and who inhibited their progress, and what this reveals for collaborative research in general. Many of the facilitators have already been discussed. The university had important resources for the research programme (people, spaces, access to information), so it was important to comply with required processes for approval. Compliance often meant compromise because of the institutional pressures on the academics to produce research outputs (Couture 2017). The mental health settings also had important resources (sites for research, participants, real world problems) which required approval for access. Mutual misunderstandings were difficult to overcome, especially in relation to ethical approval.

The irony was that having learned so much about how to navigate the NHS research ethics processes, the Whiteread project was nearly derailed completely. This was not because of fears about photography taking place in an acute mental health unit, but because of a disagreement

about ownership of the project, and consequently who would bear the blame if the project went wrong. The NHS side saw the project as low risk, but the university was unfamiliar with the idea of service user researchers, the method and the setting, and consequently risk adverse. The first author resorted to a protest tactic, sitting in the offices of those who had the power to sign the projects off, until they did so.

One of the fears was based on ignorance of mental ill health and capacity. This was important to openly discuss in all projects, for issues did occur during several of the projects. A planned and considered response could be made because of the discussions which had already taken place. Rose (2018) suggested capacity issues can be used by gatekeepers to prevent research participation, but also recognised that ethical issues are complex in mental health research. Clear protocols can protect vulnerable people. Academics may have to act as interpreters for institutional processes and pressures, being mindful of institutional preferences for income generation (university) and direct service provision (health services).

Faulkner (2016), a service user researcher, considered how important it is to care about the differences between consultation, collaboration and control. Service users did not start to get involved in defining and designing research until project 3 in this programme. Until then initial decisions were not open to users: not just who decided what, but what decisions were made. The Researching Psychosis Together group spent significant time throughout their work together discussing this issue (project 3), as views were different about priorities and significance. Faulkner (2016) describes "colliding worlds", where different perspectives come together. This is also echoed in one of our reflections about wearing different "hats" – the different perspectives can reside within one person as much as between different individuals. Time and tolerance enabled the personal, political and professional perspectives to be teased out.

Flood and colleagues (2013) distinguished between academic publications and activist publications, stressing the importance of the latter in achieving social change, but also hinting at the conflicting messages about "impact". When impact statements were introduced in the formal monitoring of research quality in the UK, locally the research programme was viewed as very promising because of the strong partnerships and response from local services, but then reframed as small-scale because of the low amounts of funding involved. This conflation of impact and income generation was misleading and unhelpful to the research partnership, and could have inhibited further development. Involving students in projects meant that research had to be tailored to fit student deadlines, compromising some aspects of collaboration and activism (Couture 2017). But students were an important resource for this research programme, which often aligned with their own values

and hopes for the future. Finally, services cared very much about this research as can be seen from the ongoing support, involvement of staff and service users, and the impacts from implementing the research findings.

Conclusion

People can be marginalised by institutions (universities, health services): bureaucratic processes take precedence because people can be, and are, replaced. Yet human experiences direct and disrupt the processes. This research programme resisted marginalisation by persistently focusing on the processes (service delivery), producing findings from direct experience and presenting them in unarguable forms recognised by the university (reports, presentations, articles). Townsend and Marval (2013) recognised the importance of communities working together for change, proposing that occupational therapists could form communities of "activist practitioners". For these projects, communities were formed, but research was emphasised rather than activism. This programme and our reflections suggest we do not always know who we are, what we want or who cares about research outcomes, but it is helpful to embrace the potential of activism, to energise and focus people for positive action, wherever they are based.

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Table One: Links between the research programme and community activists	
Type of activism	**examples**
Health activist organisations	The local branch of Mind were involved throughout: promoting the research, recruiting people, hosting events, sharing findings & resourcing implementation of recommendations
Individual activists	Involved in promoting research participation, using findings to pressurise and inform MP and commissioners, working closely with research programme leader to share potential audiences
Local user-led activism	Campaign to keep local resource centre open – research programme leader took photographs and wrote supportive report, using initial research findings
User-led activism in the university	Centre for Citizen Participation: a university research centre with a user advisory group
Advocates	Involved in supporting recruitment and participation in first focus group study

Table Two: Summary of research programme 2002-current			
initiated by	driver	participants	method
1. Evaluation of day and accommodation services for mental health users (2002)			
Managers at NHS trust	Local service development	Service users, carers, staff, managers	Focus groups
Bryant, Craik and McKay (2005)			
2. Social networks in mental health day services (2003-8)			
Manager at NHS trust	National modernisation policy	Service users, staff, voluntary partners	Participatory action research (Photovoice, survey, interviews)
Bryant et al (2010), Bryant, Tibbs and Clark (2011)			
3. Living with psychosis (2007-13)			
Partnership emerging from social networks project	Academic wanted to host user-led research at university	Service users	Focus groups
Makdisi et al (2013), Bryant et al (2012)			
4. User perspectives on accommodation services (2008-11)			
Staff at NHS trust	Local service development	Service users	Photo-elicitation in individual interviews
Notley et al (2012)			
5. User perspectives on acute mental health services (2009-11)			
Staff at NHS trust	Local service development	Service users	Individual interviews and focus groups
Bryant et al (2016)			
6. Service user perspectives on groupwork in acute mental health services (2011-12)			
NHS occupational therapist	Evidence-based practice, new method	None (all involved were researchers)	Collaborative qualitative meta-synthesis
Unpublished MSc dissertation.			
7. Perspectives on self care in mental health services "Scallop" (2012-13)			
Partnership from accommodation project	Evidence-based practice and new method	None (all involved were researchers)	Collaborative qualitative meta-synthesis
Unpublished MSc dissertation			
8. Service user perspectives on acute mental health services: "Whiteread" (2012-14)			
Partnership emerging from 2011 acute services project	Local service development	Service users	Photovoice
Bryant et al (2015)			
9. Environmental factors in acute mental health care "Oulton" (2012 –current)			
NHS occupational therapists	Local service development	Service users, staff	Participatory action research (survey, mapping)

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Table Three: Questions for reflection
How did your experience of collaboration between service users, the mental health setting(s) and the university change your approach to research and service development?
What prompted you to get involved? Do you see yourself as an activist, a person who works for change?
What was your experience of being involved? What happened? What do you remember most?
Why do you think that memory has stayed with you? Does it link back with what prompted you to get involved originally?

Points of interest

- Doing participatory action research brought us together for this research programme (mental health service users, occupational therapy students, health professionals and academics). We asked what users had to say about mental health services and living with mental health problems. We did nine projects from 2002 onwards.

- We saw ourselves develop as researchers and/or activists at different times. Knowing what we wanted to achieve was something that developed as we gained experience. We needed space and time to do this well.

- For this paper, we've asked: Who are we? What do we want? Who cares? This last question shows who helps and who stops research. We have shared some of our experiences, to encourage others to work together and do research.