

TALKING POINT PAPERS 3

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Through the eyes
of the observed:
re-directing
research on
psychiatric drugs

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Biography



Jasna Russo is an independent survivor researcher and consultant based in Berlin, Germany. She is a long-term activist in the international mental health service user/psychiatric survivor movement. Jasna has an MA in clinical psychology and is approaching completion of her PhD at Brunel University London. She has worked on both survivor-controlled and collaborative research projects, including several large-scale international studies.

Her articles have been published in anthologies and journals in Germany and the UK. Together with Angela Sweeney, Jasna is the editor of *Searching for a Rose Garden. Challenging Psychiatry, Fostering Mad Studies* (PCCS Books, 2016).

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About the talking point series

About the McPin Foundation

The McPin Foundation are a mental health research charity. We are committed to improving the quality of mental health research so we need to know more about what works to improve the mental health of communities everywhere. We champion experts by experience to be involved in all aspects of research as we believe people directly affected by mental health problems have unique and valuable expertise that can be utilised to improve the relevance and impact of mental health research.



Almost everything to do with mental health has been, or is, sharply contested. From understanding health experiences, diagnoses, appropriate treatments and approaches to managing distress to the language used to describe mental health problems has often sparked strong debate. Mental health research is no exception.

The majority of the discussions in mental health research are framed from the point of view of professionals and academics. We welcome these views, but are keen for discussions to broaden engagement in research, particularly with service users and carers. We have therefore commissioned a series of Talking Point papers to encourage people to consider key issues in mental health research.

The funding for the Talking Point papers is from the McPin Foundation. However, the views expressed in the papers are the author's own. We are keen to hear from others who would like to contribute to the series – you can email ideas for topics to contact@mcpin.org.

We are very pleased to present the third Talking Point paper by Jasna Russo, which looks at public involvement in psychiatric drug research.

You can join the discussion on this issue through our Facebook page or Twitter, using the hash tag [#PsychDrugDebate](https://twitter.com/psychdrugdebate).

Talking point papers give people with expertise from experience the opportunity to discuss and debate under-discussed or particularly difficult issues in mental health research. We hope that these papers and the discussion around them will aid us in our mission to 'transform mental health research'. The funding for the Talking Point papers is from the McPin Foundation, but the views expressed in the papers are the authors' own.

Introduction

Psychiatric drug prescriptions are still the prevailing answer to the multitude of problems that cause people to seek or receive professional help. When in contact with mental health services in the Western world, hardly anyone can get around being offered, prescribed or forced to take psychiatric medication. Dilemmas and decisions around medication are central to the lives of people diagnosed with a mental illness or psychiatric disorder.

At the same time, the official knowledge production about psychiatric drugs carries on with minimal consideration of the accumulated knowledge of people who have first-hand experiences with these substances. In distinction to some other areas of mental health research characterised by increased efforts towards public and patient engagement – research on psychiatric drugs remains the most conventional in its overall approach and its understanding of roles in research. In mainstream research scenarios – which are most often randomised controlled trials (RCT) – the designated role of people with psychiatric diagnoses is usually that of bodies to receive medication, or a placebo.¹ We are being recruited on the basis of our diagnoses and randomly assigned to different treatments in order to compare their effectiveness.

Our role in knowledge production about psychiatric drugs is reduced to providing genetic material, giving demographic information (about our gender, age, education, etc.) and ticking boxes in different questionnaires and scales. Such fragmented and partial insight into our lives can hardly touch on our many realities and the complexity and relevance of our experiences on and off medication. Survivor researchers worldwide are disrupting that tradition and working towards establishing our place in official knowledge making:

“Science has too often been about patients without their involvement. Some of the most important topics to us, such as how psychiatric medications affect our lives, are neglected in the research. Together I believe we can change that.”

Will Hall (1)

“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 of people involved with psychiatry experience.”

Lauren Tenney (2, p. 15)

Fundamental criticisms of RCTs as a method of ‘evidence’ making in psychiatry can be found in the first paper in this series written by Alison Faulkner (3). Expanding on that paper, I specifically focus on drug research and explore some possible avenues of transforming both the dominant research agenda and the conventional ways of generating knowledge in this field.

1. Placebo is a substance having no pharmacological effect but given merely to satisfy a patient who supposes it to be a medicine (from www.dictionary.com).

Treatment with psychiatric medication, as well as related research, continue to be scrutinised and criticised from many different angles, including some clear voices from the psychiatric profession itself (4-12). In addition to that comprehensive and well-documented body of work, this paper closely focuses on the gap between the realities of those who use, refuse or are forced to take psychiatric medication on one side and the results of related official knowledge production on the other.

As we know – the latter informs policies, development of services, and professionals' training; the former remains individualised, anecdotal and occasionally added on as 'subjective' components.

This paper is grounded in the conviction that perspectives of people who have first-hand experience with psychiatric drugs should acquire a very different status. But it is also grounded in the view that such status cannot be achieved by selectively inserting our perspectives into current research frameworks.

Here I will unpack some of the constraints of biomedical research and how they stand in the way of centring research on first-person knowledge of psychiatric drugs. At the same time, I will explore some possible ways out of this trap towards comprehensive, transparent and responsible knowledge production in this field.



2. Preliminary notes: on language, representativeness and the scope of this paper

Knowing how language used can be contested and that the terms of preference of some people can be precisely the terms that put other people off – I prefer to provide this preliminary note to explain why I personally choose to use certain terms and avoid others. My use of language is not intended as any suggestion of right or wrong terms. Imperfect and always evolving, my choices in fact mirror my current positioning and express how I personally navigate the territory that borders powerful psychiatric discourse² on one side and fearful and negative lay people's attitudes on the other.

Even though I may interchangeably use 'psychiatric medication' and 'psychiatric drugs', I much prefer the latter as in distinction to 'medication', 'drugs' imply neither a related illness, nor its cure. Some of these substances, such as antidepressants for example, are often prescribed by general practitioners. However in this paper I refer more specifically to prescribing in the context of psychiatric treatment, both voluntary or coerced. Also I do not use terms such as 'mental illness' or 'mental disorder' because even though these terms are rather common, they carry the flavour and the heritage of the pathologising biomedical approach. It is important to remember that "the term mental illness is also problematic because it gives the appearance of scientific proof and medical consensus, which has not (yet) been achieved" (13, p. 5).

Like many other authors who do not subscribe to the biomedical model,³ I use madness and distress as terms of preference in our efforts to reclaim and de-medicalise these experiences and understand them in their social, economic and political contexts. At the same time, I am aware that in particular the term 'madness' is heavily loaded and often unacceptable for people facing additional structural discrimination and oppression – including above all, racism (for a detailed explanation, see 14). Nevertheless, I have continued to use the word 'madness' in an attempt to bring the expression of this experience back from its social exile and reclaim its human nature.

Also, I hope that we can reach a level beyond single terms, where the perspectives of people who have been psychiatrically labelled and treated connect in all their depth and difference. To me, searching for the right words is at the core of our infinite journey towards understanding ourselves and the world we live in.

On this journey, I believe it is more worthwhile to enlarge, rather than restrict our personal freedom to use the expressions that best fit our respective experiences and thoughts and to always give priority to what somebody is trying to say and what they mean, rather than how they say it precisely.

2. Discourse is a mode of organising knowledge, ideas, or experience that is rooted in language and its concrete contexts (such as history or institutions) – from www.merriam-webster.com.

3. The biomedical model understands experiences of madness and distress as the result of brain dysfunction or genetics that should be chemically or surgically treated.

Throughout this paper I will use the term 'mental health service users/survivors of psychiatry' (or simply 'users/survivors') even though I am conscious of the many limitations of this term. In distinction to terms such as 'patients', 'people with lived experience', 'experts by experience', 'peers', 'people with psychosocial disabilities' or 'mad' – the term 'user/survivor' is the term of preference in the organisations and groups that I have been a part of. Therefore, due to my personal background, I have retained 'user/survivor' as a working term in this paper.

People who have first-hand experience with psychiatric drug treatment differ in their experiences, as well as in their stances towards medication. And just like with anyone else – our positions are not written in stone, but change and shift with time and experience. However, when given a place at the table in official debates about our lives – we, people with psychiatric experience, often face the expectation to present a view that is representative of everybody else from 'our' group. While professional experts are not only allowed, but also expected to give their individual expert-opinion, the value of our views is often measured against the fictitious, anonymous, universal 'mental health service user' and our ability to represent them.

The accusation of not being 'representative' or too different from that imaginary 'average client' is often used to disqualify and downsize our contributions. In distinction to the over-emphasis on representativity, survivor researchers David Crepaz-Keay and Jayasree Kalathil stress the need to *balance* "the overwhelming majority of material written about those who are labelled mad by those who do the labelling and those who study them so that we can see a more balanced whole" (15).

This paper is a small contribution towards achieving such a balance, while many more are needed. Although this paper is built on published accounts, as well as the conceptual and political work of many people who have undergone treatment with psychiatric drugs (myself included), it certainly can hold no claim to speak in all of our names.

The main purpose of this text is to take a look at those questions regarding treatment with psychiatric drugs⁴ that are being insufficiently addressed or remain largely under-researched. Drawing upon my research, activist and personal experiences, I explore the implications of such omissions and problematise the ways in which the official knowledge on psychiatric drugs is being created. The issues I raise are not meant to constitute an exhaustive list.

The main intention is to foster further debate and demonstrate the centrality of experiential knowledge in this field. But as we know, experiential knowledge is diverse and the topic of psychiatric drugs is anything but neutral. The debate is usually framed for (pro) or against (contra) drugs, people easily become judgmental and this can lead to divisions not least within the user/survivor movement and organisations.

I have no intention here of reproducing or deepening such divisions. In my experience, purely ideological debates tend to omit complex truths and struggles of those who take or do not take these substances. So even though I cannot pretend to have no opinion on psychiatric drugs – rather than platforming my particular stance, I aim to open up some questions for research that can hopefully take us beyond pro and contra debates towards articulating what is missing from current knowledge production both in terms of topics and methodologies.

4. There are several classifications of psychiatric drugs. It is hard to find simple overviews of their ingredients and their main effects that are not provided based on the biomedical explanatory model. Going into a detailed presentation would exceed the scope of this paper. The five main groups include: antidepressants, antipsychotics, anxiolytics, depressants (hypnotics and sedatives), mood stabilisers and stimulants.

3. About the structure of this paper

This paper is divided into three main parts.

Part 1

Firstly I examine how treatment with psychiatric drugs stopped being a merely medical issue and got on the international human rights agenda. The emphasis here is on the implications for research in the light of recent United Nations' documents.

Part 2

This part features experiential knowledge of psychiatric drugs and provides a brief insight into user/survivor produced sources on this topic. In this part, I also explore the compatibility of our knowledge with the dominant research conduct and the prospects of 'experts by experience' taking on advisory roles in clinical trials.

Part 3

In the last section I move on to conclude with some suggestions on how to transform drug research.



4. Psychiatric drugs: from a medical to a human rights issue

The basic lack of free and informed choice in regard to treatment with psychiatric medication is one of the central features of mental health services. With the movement of global psychiatry, this trend is also rapidly reaching the non-industrialised world (16). Advocating for alternatives to medicalising madness and distress have been long-term claims of many organisations of mental health service users and psychiatric survivors. That we don't share one same stance on psychiatric medication is accurately described in one of the very first survivor-controlled studies on this topic:

“Twenty five years of being involved in the movement of service users or survivors of psychiatry has taught me that for every person who says their life has been ruined by psychiatric drugs there is someone who believes they have been saved by them, and many more who just don't know, who have been taking them for years and wonder if their lives would have been better or worse if they had been free of them.”

Jim Read (17, pp. 2-3)

Despite these differences there are a number of issues that we do tend to agree upon. One of those issues is the personal right to make free and informed choices. In order for those choices to be justly informed – responsible, comprehensive and accessible research on psychiatric drugs is indispensable. And in order to be able to talk in terms of choices at all there have to be other options than medication available, or at least the option not to take it.



One large-scale consultation exercise with service users from 15 European countries about their understanding of human rights has clearly shown that different forms of pressure to take psychiatric medication are experienced as a violation of fundamental rights (18). A research participant from the UK described the disproportional availability of medication in comparison to any other response to people with psychiatric diagnoses:

“We are all different and I totally respect everyone's right to take it [medication] or not take; you know it's not a case of drugs are good or bad, it's a personal choice but I don't feel we are allowed the right to not take it. It's very easy if you want it, you can have it by the shed load but if you don't want it it's very difficult.”

(quoted in 18)

4. Psychiatric drugs: from a medical to a human rights issue

The above consultation exercise was conducted in 2007, one year after the adoption of the Convention on the Rights of Persons with Disabilities (UN CRPD)⁵ (19). In the meantime the overreliance on psychiatric drugs and especially their use in the context of forced treatment are being increasingly recognised as human rights issues.

Ten years later, in his report on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, the UN Special Rapporteur⁶ (20) took an explicit stand on a person's right not to take medication:

“While psychotropic medications can be helpful, not everyone reacts well to them and in many cases they are not needed. Prescribing psychotropic medications, not because they are indicated and needed, but because effective psychosocial and public health interventions are not available, is incompatible with the right to health.”

Dainius Puras, UN Special Rapporteur (20, p.18)

The far-reaching implications of the dominance of the biomedical model on the lives of people with psychiatric diagnoses are increasingly being highlighted in legal debates and legal documents.

Together with a growing body of evidence of risks and harms caused by psychiatric drugs (4-12), these developments place clear demands not only on treatment but also on related knowledge production. One would expect that research on psychiatric medication would adopt a human rights framework and that systematic explorations of non-medical approaches to madness and distress would become a clear research priority. But this is not the case and apart from rare exceptions, drug research continues as part of biomedical research.

This means that the highly contested biomedical explanatory model of madness and distress defines the initial questions and the development of research protocols, it also guides the interpretation of outcomes. The necessity and helpfulness of psychiatric medication form the unquestioned presumption of the vast majority of studies in this field and the most frequent topic of research is the effectiveness of different substances. This is slowly beginning to change but prevailing drug research ignores a large group of people who are poorly served by current mental health services and leaves their needs completely unmet, as described in the following accounts from Denmark and the UK:

“To defend oneself against psychiatric mistreatment in my country means to get no professional help at all when you go out of your mind.”

Karl Bach Jensen (22, p. 303)

5. The Convention on the Rights of Persons with Disabilities (CRPD) is an international human rights treaty of the United Nations. The CRPD was adopted in 2006 with the aim to protect the rights and dignity of persons with disabilities, including people with psychosocial disabilities or with psychiatric diagnoses. Since then, this treaty has been ratified by more than 170 states including the European Union as a whole. The UK ratified the Convention in 2009 which implies a legal obligation to implement it. States Parties are required to report regularly to the body called the UN CRPD Committee which examines the implementation of the Convention in different countries in turn. The UK was subject to such examination for the first time in August 2017. See more at <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

6. The title 'special rapporteur' refers to individual experts working on behalf of the United Nations (UN) who have a specific thematic mandate from the United Nations Human Rights Council (adapted from https://en.wikipedia.org/wiki/United_Nations_special_rapporteur).

“It’s almost like walking up to the nurse wearing wet clothes, and the nurse treats you for a cold. The nurse then lets you walk out without changing your clothes. When you return the next day, the nurse wonders why you still have a cold. Similarly, I’m walking around as a product of emotional and physical abuse, broken relationships, no meaningful employment, stressful housing – and I’m taking a tablet for the symptoms.”

Pete Shaughnessy (21, p. 22)

The restriction of scientific research in mental health was emphasised in the above-mentioned report issued by the UN Special Rapporteur this year:

“Scientific research in mental health and policy continues to suffer from a lack of diversified funding and remains focused on the neurobiological model. In particular, academic psychiatry has outsize influence, informing policymakers on resource allocation and guiding principles for mental health policies and services. Academic psychiatry has mostly confined its research agenda to the biological determinants of mental health.”

Dainius Puras, UN Special Rapporteur (20, p.8)

It must be admitted that there is no evidence to support this premise that psychiatric disorders are biological conditions (23, 24).⁷ Even the Chair of the task force responsible for producing the *Diagnostic and Statistical Manual of Mental Disorders* (5th edition) (DSM-5) has confirmed that no biomarkers⁸ of any single psychiatric diagnosis have been identified. He explains: “We’ve been telling patients for several decades that we are waiting for biomarkers. We’re still waiting.” (24). Yet, the biomedical research in this field continues to attract large portions of public funds. This is not to say that madness and distress do not exist or that people do not go through all sorts of crises and altered states of mind that can temporarily be eased by psychotropic substances. As Rimke (13) accurately summarises:

“The cumulative pain and suffering due to inequalities takes its toll on individual minds, hearts, bodies, communities – and far more on some social groups than others.”

Heidi Rimke (13, p.9)

However, it is clear that these phenomena can neither be explained nor adequately treated as biological diseases. So why does the related research continue as if this were the case?

Here are two descriptions of how transformative research is stifled and frustrated in practice. Coming from different angles, both of these accounts are applicable to many national research funds and their policies, as well as to the research programmes of the European Union. The first one is from critical psychiatrist Peter Stastny from the US (25); the second, from survivor researcher Angela Sweeney from the UK (26):

7. For a thorough explanation of the implications of the lack of biological evidence for the DSM, see open letter of the American Psychological Association (2011).

8. Biomarker is an abbreviation of the term ‘biological marker’. This term refers to measurable indicators of biological states or conditions. Biomarker is a distinct biochemical, genetic, or molecular characteristic or substance that is an indicator of a particular biological condition or process. It is a biologic feature that can be used to measure the presence or progress of disease or the effects of treatment (adapted from explanations on www.wikipedia.com, www.dictionary.com and www.medicinenet.com).

“In the US, any type of system-transforming research must be administered by the very system it is designed to change. This immediately creates a conflict of interest for researchers who are at once beholden to their administrators and to the transformative research agenda.”

Peter Stastny (25, p. 70)

“If I had the chance to have a second career, I would try harder not to follow of the fashion of the herd. The mistakes I have made, at least those into which I have insight, have usually resulted from adhering excessively to the prevailing orthodoxy.”

Robin Murray (28)

“[C]urrent systems for funding research are biased in favour of mainstream treatments and approaches. This means that mainstream researchers can add new therapies or services to existing services and then explore the differences between the new therapy or service and ‘treatment as usual’ – a self-perpetuating system. Given this, how can survivors generate funding for meaningful and in-depth transformative research?”

Angela Sweeney (26, p. 223)

Within mainstream psychiatry there are more and more voices being heard about the ambiguity of their own approaches. For example, the editorial team of one of the leading psychiatric scientific journals stated that “one could view psychiatry as a medical specialty for people who are not sure they are right” (27). Another example comes from a well-known UK psychiatrist critically looking back at his 40-year engagement with ‘schizophrenia’ research:

Statements like the above indicate that things are starting to change. But at the same time, they raise many legitimate questions and leave a bitter taste for those whose work remains marginalised. Here in particular, I mean scholars, who due to their theoretical background and research approach face structural barriers and discrimination when trying to enter ‘scientific’ competition and who might choose not to speak their minds at all due to the potential impact on their careers.

It seems that while some are allowed to experiment further even though they are not sure that they are right, or are resourced to make mistakes for many years – the others who are not ‘adhering to the prevailing orthodoxy’ continue to be systematically denied means and access to official knowledge production. Given the many failures of biological psychiatry – the fact that this research paradigm⁹ is still clearly favoured at the cost of all other approaches certainly raises issues related to the responsibility of ‘biomedical gatekeepers’ (20) when it comes to the distribution of research funds and scientific credentials.

The biomedical model of mental illness has channelled drug research for decades in one direction only and limited its overall reach. Therefore, the first and most urgent task of any transformative research in this field is to break the vicious circle in which the biomedical model signifies both the departure and the arrival point of the research process. There is more than one way

9. A paradigm is a set of assumptions, concepts, values, and practices that constitutes a way of viewing reality; also a model or pattern.

to disrupt that circle and to establish drug research on a different ground, but that would require a strong commitment to change in mental health research governance.

One can say that the individual right *not* to be formally or informally coerced into treatment with psychiatric drugs has its equivalent in the right to generate non-medical knowledge of madness and distress. The latter is not being explicitly denied as of right but the ruling research establishments effectively force researchers who don't want to stay on the margins to either subscribe to the dominant biomedical paradigm or to at least bring their research proposals in line with it.

This situation means that even though the overreliance on treatment with psychiatric drugs has increasingly and irreversibly climbed up the list of issues on the human rights agenda, people coming

into contact with mental health services will actually not be able to make use of their proclaimed right to alternatives to drug treatment unless those services start acquiring fundamentally different approaches.

When the UN Rapporteur stated that “[p]sychosocial interventions, not medication, should be the first-line treatment options for the majority of people who experience mental health issues” (20), it is clear that such an elementary change of practice cannot be introduced solely by law.

In order to enable a consistent transformative process in service provision, systematic explorations and advancement of social responses to madness and distress are vital. This leads to the question as to whether it is sufficient for clinical trials to broaden their research questions and include ‘experts by experience’ in their designs as they are starting to.



5. Experiential knowledge of psychiatric drugs

One possible avenue for transforming drug research is Moncrieff's (8) well-argued proposal to distinguish the drug-centered from the disease-centered model in drug research. Moncrieff decouples the effects of psychiatric drugs from the idea that psychiatric disorders are brain diseases that can be healed with these substances.

Similar to older psychiatric methods such as insulin coma and electro-shock – treatment with psychiatric drugs does not reverse the 'underlying disease' as the term 'antipsychotic' medication would suggest, but rather, creates an abnormal neurological state (29, p. 156).

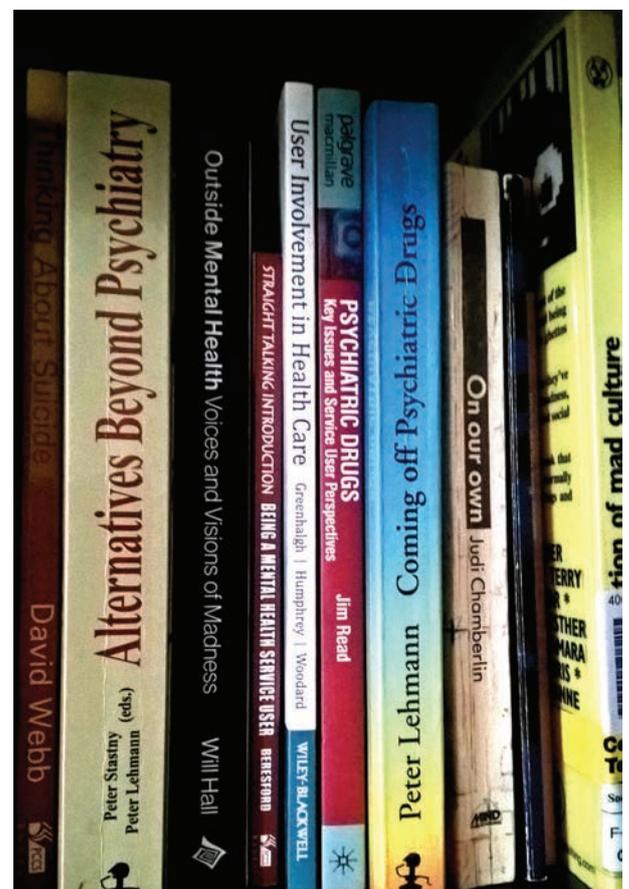
According to Moncrieff's drug-centred model, "it is the subjective experience of taking a drug that determines whether it might be useful or not. [...] Therefore, it is down to the user of psychiatric drugs to decide whether the effects of a drug are likely to be useful to them in their own unique circumstances." (8, p. 106). Moncrieff's claim to emancipate psychiatric drug research from the biomedical model of mental illness holds the potential to substantially improve both prescription practices and related knowledge production.

However, in this paper I will further explore the role of (intended) psychiatric drug recipients in this whole enterprise and our possible contribution to taking this important research topic out of its current individualised medical framework into a larger societal and political context.

Despite the fact that we form a hugely diverse group – unlike the dominant players in the realm of official knowledge production on psychiatric drugs – we know these substances from our own experience.

Our own inquiries of those experiences and efforts towards sharing our knowledge have taken forms of initiating self-help groups, publishing personal accounts, undertaking our own research and starting our own initiatives to support each other when coming off psychiatric drugs. The topic of medication appears to a more or less important extent in most of the works authored by people with psychiatric experience.

A systematic exploration and compilation of this diverse and vast body of knowledge could significantly inform and aid the creation of respectful and supportive responses to madness and distress, in addition to further guiding research in this area.



The following list entails a very brief, chronological outline of some user/survivor produced sources that specifically focus on psychiatric drugs:

- In 2004 a team of psychiatric survivors/service users coordinated by Jim Read conducted research into the ways people cope with coming off psychiatric drugs (30). Commissioned and funded by the UK mental health charity *Mind* this study comprised 204 short and 46 in-depth interviews with service users. In relation to people's reasons for coming off psychiatric drugs as well as their sources of support throughout that process, there is a significant overlap between the findings of this study and the outcomes of the most recent user-controlled research on this topic (31).
- This same year saw the publication of an international anthology of personal accounts of withdrawal authored by people who successfully reduced or came off psychiatric drugs and their supporters (32).
- Building on his work in the *Freedom Center and Icarus Project* – survivor led initiatives in Western Massachusetts, Will Hall wrote the first edition of *Harm Reduction Guide to Coming Off Psychiatric Drugs* (33). Since its publication in 2007 this guide has been translated into 15 languages.
- In 2009 a comprehensive “book about psychiatric drugs written from a fresh perspective; that of people who have taken them” (17) was published in the UK. It includes and extends the findings of the *Coping with Coming Off* study from 2004.
- Erick Fabris published findings of his academic research into chemical incarceration under community treatment orders in Canada (34). Describing the nature and the scope of his inquiry, Fabris stated: “Rather than using their [*survivor*] lives as data for argumentation, this book begins from personal knowledge as most important to questions of coercion.” (34, p.7)
- At the time of writing of this paper, the results of the first withdrawal study in the United States that “was led by current and former users of psychiatric medications with professional training in research and clinical practice” were just published (31). This web-based survey with 250 participants demonstrated among other things, the frequent lack of medical support for people coming off psychiatric drugs.

As already stated – the experiential knowledge of psychiatric drugs is documented in many other sources. In works that specifically focus on this topic – as the above list shows – the issue of coming off drugs appears to be of central importance. This issue is now generally attracting more attention and is also coming onto the agenda of psychiatric research. But the inclusion of first-person perspectives in mainstream research often goes hand in hand with the diminishment of our role and influence on the overall process.

In their accurate analysis of such developments, Jones et al. emphasize that this is “not merely because of academic researchers’ actions, but

because of myriad macro- and micro- cultural and institutional forces that constrain and proscribe those actions” (35). These survivor authors also observe that “in the fields of psychiatry and mental health, there has never been real consensus regarding the importance of user/survivor participation” (35).

One large study of public and patient involvement (PPI) in England and Wales reported that steering committee membership and reviewing patient information leaflets are the most common PPI activities (36). Some recent examples of service user involvement in research on psychiatric drugs (37, 38) confirm these findings. Our work

5. Experiential knowledge of psychiatric drugs

is often termed as 'helping' the research and the achievement of higher recruitment targets in clinical trials is highlighted as a provable measure of success of patient involvement in research (39).

This kind of 'utilitarian' approach to the scope of our involvement leaves core questions of research behind and raises rightful concerns that "it is not enough to take existing structures (and norms and expectations) and simply 'plug' those with lived experience into them" (40). Even though there is a strong rationale for engaging 'experts by experience' in knowledge production – a legitimate question emerges – whether current PPI activities promoted in countries like the UK are actually capable of *transforming* the contested nature of biomedical research and evidence making in psychiatry.

There is increased criticism of the implementation of PPI in health research in general, as well as calls to consider the highly-competitive climate in which research and academia operate. Madden and Speed warn that "experts by experience' are in danger of being reduced to another commodity, as an opportunity for professionals to consume affective individual testimony without the need to engage with wider publics or more contextualized forms of research" (41). These authors observe how PPI has become "a form of busywork in which the politics of social movements are entirely displaced by technocratic discourses of managerialism" (41).

When thinking about the prospect of PPI in research on psychiatric drugs we need to consider that this research field is emerging within an area of medical science which has a long and deep-seated history of involving patients solely as research subjects. Since its inception, drug research has operated with methods of experimentation, observation and measurement and up-to-date clinical trials remain its main methodology. Leaving aside the ethics of distressed people's random assignment to different interventions (even when they consent to being randomised) the core characteristic of this approach is that it emulates natural sciences despite having humans as its object of interest.

Even when genuine efforts are made to re-define and extend involvement of people with psychiatric diagnoses and engage us in advisory roles in drug research, the question is whether this amounts to an adequate and sufficient strategy to make first-person perspectives integral to research and treat them as legitimate, equitable and a valid source of knowledge. This in particular affects those first-person perspectives which explicitly seek answers beyond treatment with medication and are therefore hard to subsume under PPI activities in current drug research.

But whether we are searching for a better pill with less side effects or wishing to find a different way through madness and distress – all our lives are of a complex social nature and cannot really be explained as an interplay of easily identifiable, dependent and independent variables (42). Or as survivor researcher Laysha Ostrow argues – "focusing on one thing, one system, one issue (be it psychiatry, family systems, education, employment, or access to care) will not fix the multiple intersecting systems and the multiple intersecting problems they seek to address" (43).

When we take a closer look at the accounts of authors with first-hand experience of psychiatric drug treatment, it quickly becomes obvious that these substances do not only affect our bodies and minds – they enter our lives and shape our biographies. The following excerpts from Canada, the US and India speak to many of us who have undergone psychiatric treatment – regardless of whether we are pro or contra drugs:

"Sometimes I have this tremendous sadness because I think that I might be in a much bigger place than I am now. I'm happy with my life but I'm also 51 years old. I might have been where I am now twenty years ago had all this not happened. I figure I'm here in spite of the mental health system."

Kris Yates (45)

“Wandering aimlessly down the street one day, I realized that I felt as if I’d died and gone to hell. The bright, creative, joyous, promising young person I’d been the year before – the person I used to think of as ‘me’- had been crushed out of existence. In her place was a debilitated mental patient, gazing through windows at women who were slinging burgers or operating cash registers for minimum wage, wishing desperately that she could pull herself together enough to do that one day.”

Irit Shimrat (44, p.17)

“My life has shrunk before my eyes. I stare with detachment at my patient self. Dishes are cleared and washed, and the television is back on.”

Erick Fabris (34, p. 131)

“So when everyone else is busy doing age appropriate things, to be caught up in a psychiatric web of illness and medications is socially very disabling.”

Prateeksha Sharma (46)

Unlike these accounts, conventional studies – including recent participatory trials of psychiatric drugs – break down the question of treatment outcomes into a set of elements to be measured. Questionnaires that are commonly used include Positive and Negative Syndrome Scale,¹⁰ Work Productivity and Activity Impairment Questionnaire,¹¹ Work and Social Adjustment Scale¹² or Sexual Experiences Scale¹³ – to just mention a few that are freely available.

One of the first questions that these instruments bring to mind is whose criteria are being applied when measuring treatment outcomes and whose criteria ultimately matter. What on the outside might appear as a positive clinical outcome can feel rather differently on the inside. These scales can therefore miss the point of what they are supposed to measure as we can see from the following excerpts:

“I did not manifest any of my internal distress, because I did not show any evidence of internal life at all. This is not the same as the absence of madness. Yet it was the gauge by which the success of treatment was measured.”

Adam Smith (47, p.51)

“It’s definitely a challenge to find the right tool and still honour the individual. Recovery is not linear and you can go back and forth. You can be doing great for five years and then one blip...does that mean you have to start from scratch? How do we really measure it?”

(quoted in 48, p. 14)

10. <http://egret.psychol.cam.ac.uk/medicine/scales/PANSS>

11. www.reillyassociates.net/WPAI-SHP_English_US_V2.doc

12. serene.me.uk/tests/wsas.pdf

13. https://www.mirecc.va.gov/visn22/Arizona_Sexual_Experiences_Scale.pdf

5. Experiential knowledge of psychiatric drugs

The question is whether, as a matter of principle, treatment outcomes can and should be measured according to any external, third-person criteria given the fact that they relate to an entire life of a person and the way that particular person feels about their particular life. These fragmentising approaches typical in drug research also overlook the intertwined nature of people's lives in which different parts intersect, connect and unfold into a unique whole. They turn a blind eye to our crucial social positionings in relation to race, class, gender and other as if achieving mental health or wellness were only a matter of individual, inner processes, which at the same time are supposed to correspond to third-party indicators.

Even those aspects of our lives that appear less complicated and easier to quantify such as whether a person is in employment or not – tell us nothing about the suitability of that employment for that particular person and how *they* feel about it, let alone about what they aspire. The systematic neglect of people's potentials, aspirations and dreams when making judgments about the quality of their lives is particularly unfair as vividly pictured by Sharma:

“We can easily make people into bonsai-s: miniature versions of themselves, whose ideas, wings, vitality or dreams are cropped, diminished and turned around to suit those others around who want them to grow in a certain way.”

Prateeksha Sharma (49)

Research on psychiatric drugs relies on a firm set of beliefs about what constitutes good or good enough 'outcome' for people diagnosed with a 'mental disorder'. Treatment success is being measured according to such standards and research focuses on clinical judgments about individuals taking drugs and their 'functioning'.

But if the attempts to separately define prospects for people with and without psychiatric diagnoses were given up and if we were to accept that we are *all* entitled to the same opportunities in life – then the very concept of 'treatment success' would require fundamental changes. Treatment would then be judged by its ability to support us in finding and realising those opportunities (50).

These are just some of the difficulties that come up when thinking about how to insert first-person knowledge into clinical research. Another issue is the unequal access of black people and people from ethnic and other minorities to involvement activities (51, 52) and systematic exclusion of seldom-heard and non-conforming voices (53). The exclusivity of PPI activities is certainly worth further exposing and addressing. But besides the difficulties of implementation of genuine and diverse user involvement, it might be worth examining the very project of our physical inclusion into structures and epistemologies¹⁴ that hardly leave space for first-person knowledge because of precisely the way they have been defined and established.

What can we actually contribute once we enter such unequal terrain? In their reflections on transformative research, Jones et al. emphasize the centrality of “ongoing critical questioning of often unspoken assumptions about power, truth, and science” (34) as well as user/survivor leadership. The need to move on from the concept of involvement towards *leadership* of experiential knowledge is being voiced more and more often.

14. Epistemology is the theory of knowing; it is the field of philosophy concerned with the question of how we get to know things.

The following two excerpts both point to dominant structures in mental health research and service provision being too narrow and too pre-determined to meaningfully accommodate experiential knowledge and foster development of its full potential. The first one is from Staddon's (54) conclusion from her edited volume on service user involvement in mental health research; the second is from this year's Manifesto of the UK National Survivor User Network (55):

“[w]e will need to consider how to ‘take over the factory’, the means of production, rather than be consulted as to the kind of machinery it is best for others to use. (Marx 1967).”

Patsy Staddon (54, p. 172)

“It’s time for service users and survivors to start leading the agenda, rather than responding to it.”

National Survivor User Network (55, p. 2)

In the remainder of this paper I will try to outline some research topics and approaches that are hard or impossible to channel into PPI activities in studies that predominantly focus on improving treatment with psychiatric drugs.

The most important question remains – how can we shift knowledge making in this field and change what disability theorist Mike Oliver (56) terms ‘social relations of research production’?



6. Inverting the research gaze: from assessing people to re-thinking treatment

Limiting the omnipresent treatment with psychiatric medication or replacing it with something else is not a minor task for mental health services. It is unlikely that drug treatment will step down from its long-standing position of being the number one response to madness and distress without completely reconsidering how we understand these human experiences. US survivor researcher Nev Jones points to the multifaceted and profound nature of the task ahead of us:

“Change is urgently needed. We need to transform not only in the way we approach psychiatric problems and distress, but also the way we evaluate interventions, train clinicians and researchers, and critique research methods and the power hierarchies they often perpetuate.”

Nev Jones (57)

When the need for change is of such a fundamental nature, it is impossible to make technical, easily implementable suggestions for improvement. Fostering social responses to madness and distress is a project for entire societies and cannot be carried out either by the psychiatric profession itself or by its narrow research paradigm. This change requires joint efforts from many different players, as well as the comprehensive and multidisciplinary generation of knowledge.

It also requires inclusive and dialogical methodologies which are able to disrupt the medical and pharmaceutical monopolies and open up new avenues for research, theory and practice.

In relation to drug research, my suggestions are grouped around three issues that I see as matters of principle. These are the call to thoroughly inquire and monitor drug prescriptions, to explore and foster social approaches to madness and distress, and to merge research and practice rather than further divide them.

A call to inquire and monitor prescriptions of psychiatric drugs

So far research on psychiatric medication has primarily focused on people taking drugs. Peoples' reactions to these substances are also at the centre of studies that are critical of drugs. Perspectives guiding research are predominantly those of experts who typically have no direct experience with the psychiatric medication they are researching. Leaders of drug trials are usually clinical academics, which means that they are not only researchers but also prescribers.

It is therefore not surprising that compliance and adherence to treatment for example are frequently researched topics. Even when some prescribers claim that they have tried 'certain pills', such mini experiments under controlled conditions cannot compare with the reality of life on psychiatric medication.

I am aware of only one anthropological study where the researcher took antipsychotic medication for six weeks in order to come closer to the population that she was researching (58). When describing her decision to do so, Estroff reported: “Interestingly, the psychiatric professionals had the most reservations [...]” (58, p.30). Discussing the overall quality of that particular study would exceed the scope of this paper and I certainly am not recommending here that researchers should take the drugs that they wish to research.

As explained earlier, drugs do not operate in a social vacuum and artificially-produced, temporary identities and situations for the purpose of experimentation can never substitute for life learning. It would therefore be crucial for research

to leave its dominant perspectives behind and use as a starting point the experiences of people taking, refusing, discontinuing, struggling and/or feeling ambivalent about drugs. Such counter points of departure would move the research focus from the person taking drugs as the sole object of investigation towards illuminating the far less researched territory of prescription practices and the broader social and economic structures and environments in which they take place.

Research regarding the prescription of psychiatric drugs usually stops at a descriptive level. It mostly informs about patient demographics and rarely goes into investigating hows and whys. Some already established research findings raise important questions about prescribing practices but are rarely followed up on.



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Here are some examples from different countries that seem relevant across borders and which urgently deserve further investigation and *monitoring*:

- Several US studies have reported significant differences between drug administration to African-American and white patients both in types of medication (59, 60) and dosages (59, 61, 62). Kreyenbuhl's et al. investigation of 344 outpatients reported that "African-Americans were three times more likely to receive depot antipsychotic medications [...] compared to their Caucasian counterparts" (60). Another investigation conducted in emergency services (N=442) reported that "[c]linicians, most of whom were Caucasian, prescribed more psychiatric medications to African-Americans than to other patients and devoted significantly less time to their evaluations" (61). These outcomes, confirmed by several other studies call for deeper insight into prescribing practices and for much closer monitoring of drug administration. However, this is rarely suggested as a direction for future research. For example, a study that determined "that minority individuals are more likely to be prescribed dosages in excess of the recommended range" proposed that "further research should examine how patient characteristics and institutional factors influence medication use" (62), but mentions no need to eventually investigate prescribers' attitudes and biases.
- The Swedish National Board for Health and Welfare receives data about all cases "where a person has committed suicide while undergoing health care, or up to four weeks after their last health care visit" (63, p.2). Using the Freedom of Information Act, the investigative reporter Janne Larsson analysed the available data for the year 2007 on treatment that people had received prior to their suicide. Her findings show that 86% were treated with psychiatric medications in the year of their suicide; 77% received antidepressants and/or neuroleptics (63, p.5). On average people were being prescribed four different drugs; 11% of those who committed suicide were prescribed one drug only (63, pp. 7-8). Further information that this unique report provides is that none of the cases were reported to the "registry for drug adverse events at the Medical Products Agency", nor "did the responsible doctor (in most cases psychiatrist) consider that the tragic result could have been caused by the psychiatric drug or that the drug was a suspected contributory factor for the fatal result" (63, p.12). Larsson's report clearly demonstrates how important it is to consider suicide in connection with treatment as its possible outcome and not just as an ultimate proof of the severity of the 'illness'. Establishing suicide registers and making the information about treatment received publicly available for different kinds of analyses could certainly extend the knowledge base of the effectiveness of psychiatric drugs far beyond information reported from clinical trials.
- A pilot study conducted in Berlin (64) clearly demonstrated that there is far less monitoring and control of the prescription of several medications at once (known as polypharmacy) and of dosages prescribed in community psychiatric services in comparison to hospitals. There is a need for social workers and other non-medical staff to acquire basic knowledge of psychiatric medication and to intervene when they notice that people are excessively medicated.
- Prescribers and their social positioning, beliefs and values – are rarely a topic of research, let alone their feelings and personhood. One recent qualitative study from New Zealand examined the barriers to de-prescribing to older people as experienced by primary care physicians (65). Even though this research was not performed in the field of psychiatry, this inquiry offers valuable insight into the realities of GPs who experience de-prescribing as "swimming against the tide" for a variety of reasons:

“De-prescribing isn’t really something that’s been talked about from the get-go. It’s not something that’s come up. As a GP trainee, it’s not something that we’ve had a session on.”

(65, p. 343)

“Most guidelines are suggesting you add medicines rather than take them away.”

(65, p.344)

“It’s harder to access other services. Non-pharmaceutical options are often a lot harder to access than medications.”

(65, p.344)

The above examples certainly go beyond the borders of their countries and point to many questions that are being neglected in current medication research. Including and especially centring experiential knowledge in research is not a matter of simply adding more researchers with personal experiences of the topic under investigation. Including perspectives that have been absent for far too long means letting those perspectives design and lead the research process beyond the usual questions that focus on characteristics of ‘patients’ detached from their day-to-day lives.

Furthermore, experiential knowledge is not the property of certain groups only. Prescribers might not have experiential knowledge of taking drugs but they certainly have first-person knowledge of prescribing. It is about time to invert the research focus towards them and their characteristics as well as the nature of helping relationships that are mediated with drugs.

Exploring non-medical approaches to madness and distress

A participant in the above-mentioned study on coping with coming off psychiatric drugs (30) describes a feeling known to many people who are taking psychiatric medication long-term:

“I wish there could have been two of me; one that took the road without Seroxat and one with Seroxat; because I want to know if it has had a positive influence on my life or been a burden.”

(quoted in 30, p. 3)

The latest survivor-controlled study on withdrawal (31) reports that the reason that almost half of the participants (48%) decided to discontinue psychiatric medication was “wanted to know who I am” (31, p.3).

In the report of her journey through user/survivor groups in the US, the UK and the Netherlands, Mary O’Hagan quotes a survivor from the US who explains how experiences that might help us grow get interfered with when you take drugs:



“We don’t know how to get to the other side because we are never allowed to go there.”

(quoted in 66, p. 10)

All of the above statements – in different ways – voice one same craving for those unexplored options that we are basically denied in a system that medicates madness and distress.

The central and most pressing question for services is how to approach these experiences at all, if not with medication. This is an immense question and at the same time, an area where the knowledge of people who ‘reached the other side’ and their supporters has a unique and leading role to play.

Here I don’t mean people who have recovered according to any clinical or any other third-person definition of recovery, any ‘peer’ role models or similar. I also don’t mean any universally applicable and replicable receipt of care or another form of professional help or technique. What is needed is a profound, ongoing collective learning process about how to accept madness and distress as part of our lives, how to keep looking at what they mean and where they come from and how to alter our relationships in order to support each other through the necessary changes that these experiences are obviously calling for.

The accumulated knowledge of people who are dealing with madness and distress without continuous use of drugs is vast, diverse and also (partially) documented. But because of its chronic inferior status, our collective knowledge proves to be unable to inform policies and services. This unique body of knowledge deserves to be



advanced and explored on its own rather than being utilised to selectively inform and enrich the dominant paradigm.

If our societies are ever to treat madness and distress with respect and dignity and seek to understand and accommodate rather than control and eliminate – then we need to admit that we don't know how to do that and also accept that the task of knowing cannot be delegated to one profession only. Research could have a powerful role in such a process, but not just any research. As Mike Oliver puts it:

“Research as production requires us to engage with the world, not distance ourselves from it. [...] Thus research is not an attempt to change the world through the process of investigation but an attempt to change the world by producing ourselves and others in differing ways from those we have produced before.”

Mike Oliver (67, p. 116)

Truly engaging with people who are currently prescribed psychiatric medication might lead us well beyond the question of 'right' medication or 'right dosage'. In his collection of many interviews with psychiatrised people and their professional and other allies, Will Hall comes to the conclusion that “[t]o solve mental health problems we have to think outside ‘mental health’ terms.” (68, p. 382). This might also be a way forward for research on psychiatric medication: in order to understand the long-term effects of drugs we might need to think outside of ‘drug paradigm’ and invest in exploring many different ways of ‘reaching the other side’.

Merging research and practice

Finally, I wish to point out the need for research capable of transforming practice, rather than continuing as a separate enterprise. Recent calls for a visible and measurable research impact seem to have more effect on competition for research funds than they do on actually bringing research closer to the realities of those who are its supposed beneficiaries. Peter Stastny problematises “slowness of science and urgency of need” (25) and vividly describes the contrary pace of official knowledge-making on one side and people's lives on the other:

“[O]ne of the most fundamental problems I choose to mention [...] is my impatience with the slow and unpredictable progression of scientific inquiry while facing evermore pressing needs, embodied by an endless succession of people coming through the clinic doors. The gaping chasm between the evidence that is being created for interventions (and perspectives) that might improve the lot of user/survivors and their broad availability is revealed to me every day by the wounds, disparities, stigmatization and lack of opportunities faced by users/survivors of the system.”

Peter Stastny (25, p.70)

At the time of writing of this paper, a large-scale randomised controlled trial is being conducted in the UK aiming to “to evaluate if reducing and possibly stopping antipsychotic medication helps people to live more independently” (37). Participants are being randomly assigned either to treatment with ‘antipsychotic’ medication as usual or supported throughout a process of reducing medication.

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The very fact that reducing or stopping 'antipsychotic medication' rarely makes it onto the mainstream research agenda means that this study is a sign of progress. But if we take the liberty to think in terms of the speed of progress, we can't overlook the fact that the main question this experiment will answer in five years' time has already been answered in publicly-available works authored by service users/survivors.¹⁵ However, this answer does not count as 'scientific' evidence and is therefore not considered good enough to inform policy and practice. These first-person sources clearly show that there will always be those of us to whom drugs are helpful and those to whom they are damaging. Furthermore, even for the same person – there may be times when drugs are helpful and times when they are not and something else is needed. That 'something else' remains a big open question mark for research, legislation, policy and practice of services.

So why do we need more investments in an attempt to establish which of the two options is generally helping people to live more independently? Why do we need another one-size-fits-all answer when we know that one answer will never fit all? Why don't we explore how to listen to people in need of support and base services on *listening* rather than on providing answers that have supposedly been 'scientifically' established as 'right' answers? Even as science slowly discovers that psychiatric drugs do not "help people to live more independently", how long will it take until such outcome reaches service provision and who will educate providers to work differently?

When looking back at decades of research on social determinants of health and also her own involvement in research with homeless people (69) a long-term Canadian homeless activist Cathy Crowe (70) writes: "Homeless people have been studied to death. It's now time for action." The same can be said about psychiatric patients. Canadian sociologist Arthur Frank reminds us of the "shift that seems paradigmatic of our times – from needing more knowledge to needing values that allow us to take a stand with respect to what we know." (71, p.363).

So much is already known about psychiatric medication, both from experiential perspectives and from the scientific research that has delivered no evidence of the healing potential of drugs. A variety of non-medical approaches to madness and distress also exist as the UN Special Rapporteur acknowledged:

“There are already promising initiatives in place throughout the world, including in low- and middle-income countries, which challenge the status quo. Creating the space, through strong political leadership and resources, to enable those practices to take shape in communities is a powerful means to promote and advance the changes needed.”

Dainius Puras, UN Special Rapporteur (20, p.19)

For research on psychiatric medication, this would imply giving up ambitions of making new 'discoveries' and turning with due respect to knowledge sources that have largely been subject to epistemic exclusion.

Responsible and inclusive research could facilitate full and true incorporation of first-person knowledge in the development and provision of services.

15. Please see the sources listed in the section *Experiential knowledge of psychiatric drugs*.

7. Summary

The issues I raise in this paper regarding redirecting research on psychiatric drugs are in no way an exhaustive list. In the hope that some of my questions and suggestions will be taken forward and considered in future research, here is a summary of what I believe are the key points:

- There is a vast disproportion between the central role of psychiatric drugs in lives of people diagnosed with a mental illness or mental disorder on the one side and the marginality of our perspectives and our knowledge in related research on the other. In distinction to other areas of mental health research that are characterised by increased efforts towards service user involvement and co-production, research on psychiatric drugs largely employs the methodology of clinical trials and remains quite traditional in its understanding of the roles in the research process – ‘experts’ on the one side and passive research subjects on the other.
- The prevailing drug research compares the effects of different substances and neglects the fact that these don't only affect people's bodies and minds, but influence our entire lives and shape our identities. Furthermore, the various definitions of ‘positive treatment outcome’ are not developed by persons whose lives are at stake. The conclusions about ‘treatment success’ are based on scores obtained from different questionnaires that provide fragmented information limited to describing the levels of people's functioning and can therefore miss the point of a whole which is always bigger and more complex than its parts. Furthermore, these kinds of assessments do not take into account a person's potential, aspirations and dreams. This raises the question of whether, as a matter of principle, treatment outcomes can and should be measured according to any external, third-person criteria given the fact that they relate to an entire life of a person and the way that particular person feels about their particular life.
- People treated with psychiatric drugs have a variety of experiences and approach and understand their experiences in many different ways. We do not share one single stance either when it comes to psychiatric drugs, or as regards the explanation of mental disorders as physical illnesses. Yet precisely, it is this impossible mission – to represent everybody else from our ‘group’ – that is often expected of us, when we get a chance at all to have our say in knowledge making and policies directly concerning our lives.
- The attempts to include perspectives of people with ‘lived experience’ in drug research projects have been subject to many limitations imposed on such projects. The most fundamental of those limitations is the obvious expectation of all drug research to be conducted within a biomedical explanatory model of ‘mental illness’. This applies to everybody working in this field of research, including researchers critical of the mainstream ideology that presents psychiatric drugs as a ‘cure’ to an underlying physical dysfunction. The fact that to date there is no scientific evidence for the latter does not prevent large portions of public funds from being invested in biomedical drug research. The separation of drug research from the concept of ‘mental illness’ as suggested by some scholars would be a great step forward.

5. What did I find?

- Since the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) in 2006, the human rights discourse has once and forever entered what had up until then been solely the medical realm. For people diagnosed with mental disorders, the CRPD means protection of our personal rights and freedoms. This international treaty ratified by 175 countries guarantees us the right to free and informed choices about psychiatric treatment, including the right to refuse medication. This provision calls for a giant shift in mental health care practices that cannot be achieved on a legal level only. Among other requirements, comprehensive and responsible research, capable of informing and guiding such change is very much needed.

We cannot make use of our right to non-medical responses to madness and distress unless different approaches and practices are in place. This is where the accumulated knowledge of people who have found ways to integrate extreme emotional and spiritual crises and go on with their lives without ongoing reliance on highly contested pharmacological treatment can acquire a crucial role.

- There is a considerable body of published sources by authors who know madness and distress and the corresponding medical treatment from the inside and are committed to breaking the circle of psychiatrisation. Their work opens up important avenues for developing radically different approaches to these human experiences. These sources range from personal narratives, research reports, different academic and non-academic papers to concepts of alternative crisis support. In works that particularly focus on psychiatric drugs, the most frequent topic is withdrawal.

This topic has recently been put on the official research agenda as well, but the established patient and public involvement activities (PPI) are usually too narrow to allow for substantial contributions from service user/survivor researchers and scholars. Furthermore, the official knowledge making in this field does not sufficiently consider the existing user/survivor produced sources despite their relevance, quality and significant transformative potential.

- The inclusion of experiential knowledge in drug research is not a matter of people with 'lived experience' taking on specific tasks in clinical trials. The genuine inclusion of our perspectives would mean letting those perspectives become departure points that direct the research. This would enable a much needed change of current research focus – from patient reactions and patient characteristics to prescribers' characteristics, their values and belief systems, prescribing practices, relationships and broader socio-economic contexts in which administration of psychiatric drugs takes place.

Re-directing the research focus from our reactions to drugs to assessment of treatment quality would allow for much needed closer investigations of already established research findings such as over-medication of people of color, lack of prescription monitoring, the prevalence of antidepressant drugs in suicides etc.

- Finally, already so much is known about the dangers of psychiatric drugs and the potential damage they can cause especially when used long-term. There is not so much need for further investigations of new and old substances as there is for finding ways to effectively incorporate what is already known into mental health care practices. Inclusive and responsible research based on dialogue with different parties could acquire a leading role in the process of upcoming policy and legislation changes.

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We champion experts by experience in research so that people's mental health is improved in communities everywhere.

- We deliver high quality user focused mental health research and evaluations
- We support and help to shape the research of others, often advising on patient and public involvement strategies
- We work to ensure research achieves positive change

Research matters because we need to know a lot more about what works to improve the lives of people with mental health problems, their families and communities. We believe better mental health research is done by involving experts by experience. We work collaboratively with others sharing our values.

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Talking point papers are written by people with lived experience of mental health problems. Each paper is focused on a particularly under-discussed or difficult issue relating to mental health research. We hope that each paper will spark a constructive dialogue between a very wide range of people. We also hope that the Talking Point papers will influence the development of future research. The funding for the papers is from the McPin Foundation but the views expressed in the papers are the author's own.

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