Coercion in psychiatry and the fight against forced treatment are two of the main topics in the mental health service user/psychiatric survivor movement worldwide. At the same time, our own user-led or survivor-controlled research in this field is almost nonexistent. This chapter explores some of the structural obstacles to including service user/survivor perspectives in psychiatric research on coercion. Without aiming to provide a systematic or complete review, in the first part of the text we take a closer look at several psychiatric studies on coercion, and discuss their overall approaches and the methodologies applied. Our standpoints are informed by our own research practice, by our activism in the international movement of psychiatric survivors, and by our personal experiences of forced or coercive
treatment. This contribution aims to extend the debate on the ethics of coercion beyond the notions of ‘treatment effectiveness’ and ‘perceived coercion’ by raising questions about how coercive methods impact individual lives. The second part of the text will outline some of the principles and values that we consider essential for comprehensive and responsible research on coercion.

13.1 Limitations of psychiatric research on coercion

Legislation and policy are certainly not informed by research outcomes solely, but they do aspire to be evidence based. Human rights monitoring of different psychiatric settings, which has become a requirement under the UN Convention on the Rights of Persons with Disabilities [1] that ‘expressly stipulates that civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process’ (Article 33.3) [2]. In contrast to this requirement, scientific research on coercion is still dominated by the psychiatric approach and mostly undertaken by clinicians themselves. We think that the lack of independent research on coercion contributes to the outcomes of psychiatric studies being taken for ‘the evidence’, reinforced by the medical authority behind them. One systematic review of 18 psychiatric research studies on coercion, for instance, reports that the percentage of patients who perceive their involuntary hospitalization as helpful can reach 81%, whereas the proportion of those who perceive no benefits or even feel harmed by the compulsory treatment can be as low as 6% [3].

We do not aim at any complete or systematic review of the up-to-date research on coercion, as such work would exceed the purpose of this chapter; however, we wanted to take a closer look at the nature of psychiatric research evidence, focusing on its inclusiveness of the perspectives, experiences and truths of persons subjected to forced treatment. We started with a small, non-systematic literature search of psychiatric studies on coercion both in institutional settings and in the community, mainly looking for those that we had already heard about. Our special interest was in some of the recent research on community treatment orders, because of its potential to inform current changes in legislation and debates around public safety and the extension of forced treatment from institutions into the community. We included peer-reviewed journal articles, about six quantitative [4–9] and about three qualitative research studies [10–12]; two systematic reviews [3,13]; and the online self-presentation of one randomized controlled trial currently being conducted in the UK [14]. The studies we included were conducted in the USA [4,7–9], the UK [6,12], New Zealand [5,10] and Sweden [11] in the course of the last 15 years. As researchers ourselves, we observed some major structural obstacles that stand in the way of service user/survivor knowledge of coercion entering these studies and forming their constitutional part. These refer to the language applied, to the understanding of what
constitutes a ‘sample’, and to the research questions and methodologies applied. We consider these aspects of the research process to be decisive in shaping study outcomes, and think that their illumination must come before any debate about the findings of psychiatric investigations of coercion. We therefore focused primarily on the research process and tried to avoid discussion of the outcomes reported.

The perspective we take and the issues we raise are directly informed by both our background in user-led and survivor-controlled research and our experience in collaborative projects and participative methods. We also share the view that there is no such thing as a value-free investigation of social reality, and that transparency and attentiveness to the investigator’s own standpoint are critical for the whole research process, starting from its design. Discussing the notion of ‘evidence-based medicine’, Alison Faulkner and Phil Thomas say:

No matter how ‘scientific’ we aspire to be, clinical decisions always will involve value judgements and it is a serious mistake to pretend otherwise. [15]

Similarly, regardless of how ‘objective’ they aim to be, current studies on coercion in psychiatry are informed by the biomedical approach which directs their design and their outcomes. Systematic reviews of such studies from service user/survivor perspectives could be a way of moving towards informed and sound dialogue amongst different parties, in accordance with Mary O’Hagan’s claim:

The stakeholders who dominate this debate, such as mental health professionals, politicians and families tend to support and promote the legalised use of force. Their views are well known, well documented and well reflected in laws around the world that allow for compulsory intervention. But the views of users and survivors who want to see less or no force are relatively marginalised. As yet our views have not exerted any major influence on thinking, legislation or practice. This needs to change. [16]

Our attempt to briefly tackle some of the main limitations of psychiatric research on coercion in this chapter can certainly not replace such already overdue process.

13.2 Language

The terms which are used in psychiatric debates to describe persons subjected to coercive measures are ‘patient’ and ‘service user’ or ‘consumer’. We find these terms both contradictory and inappropriate to the context of coercion: ‘patient’ implies the healing potential of coercion, while ‘service user’ or ‘consumer’ imply that coercive measures are one option amongst many mental health services on offer, which are to be freely chosen and used. Free choice is a false concept in psychiatric settings because of the very limited number of available alternatives to pharmacological treatment.
Choice is even less applicable to coercive methods since they are not chosen at all in the way the words ‘user’ or ‘consumer’ would suggest. The language of psychiatric studies on coercion represents one of the fundamental obstacles if the investigation of this topic is ever to open up to the perspectives of persons subjected to forced treatment. We wonder how a person can be considered a user (or consumer) of services which are imposed on them. How can restraint, seclusion and forced medication or electro-convulsive therapy (ECT) be understood as ‘mental health services’?

In the context of researching coercion, we find the term ‘patient’ to some extent more appropriate and more honest, although being a patient is only one aspect of a person’s identity, usually a temporary one. If the impact of coercion on a person is to be investigated, then persons must be perceived as more than treatment-responders, as Faulkner and Thomas suggest:

> Although EBM [evidence-based medicine] may be valuable in discriminating between the claims made by advocates of different treatments, patients are left feeling that their concerns are forgotten and that they are little more than a disease being treated. [15]

If research aims at inclusion and understanding of our perspectives, then the first step is to invite and welcome these perspectives instead of structurally excluding them with political terminology. This is, however, never simply a matter of the words applied, but rather of the concepts they stand for. What remains implicit in psychiatric research on coercion is the notion of research subjects. Either reduced to the role of passive patients or misleadingly reconstructed as ‘service users’ or ‘consumers’, the participants in research are perceived and treated as ‘subjects’. This tradition remains implicit and persistent in psychiatric studies on coercion and stands in the way of acknowledging a person being subjected to forced treatment. This very fact pre-defines what is possible and restricts what is open to question and exploration in psychiatric research. If they are to enter an equitable dialogue, persons subjected to forced treatment must be seen as capable of reflecting upon their experiences and providing general judgements.

At present, the necessity of coercion seems to be taken for granted, and the main issues remaining to investigate concern the effectiveness of its different modalities. When the ‘subject’s’ perspective appears on the research agenda, it remains reduced to a perception of coercion. The translation of the real coercion exerted and experienced into the reductive term ‘perceived coercion’ so common in psychiatric research [4–7] masks the actual incidence of coercion and its profound impact. As coercion is certainly not just a matter of perception, we fail to understand how such a construct can take a central role and guide investigations of coercion.

Psychiatric research has also so far failed to acknowledge the political organizing of people with psychiatric diagnoses and the fact that a large portion of participants in
this movement define themselves as ‘survivors of psychiatry’. The notion of a survivor is certainly not value-free; it is obviously disturbing as a working term because of its strong implication that psychiatric treatment is something to survive. But as the terms ‘patient’ and ‘service user’ (consumer) applied in psychiatric research on coercion are in no way neutral either, we plead for the acknowledgement and inclusion of uncomfortable survivor perspectives. We are convinced that these perspectives are directly relevant to research on coercion and that they should find their place in knowledge production, and constitute evidence.

13.3 Composition and perception of the ‘sample’

Very often clinicians and other professional staff are the first ones to decide about their patients’ capacity to take part in research on coercion. The process of obtaining participants’ informed consent starts after the first selection has already taken place. This type of recruitment seems to be embedded in research studies in such an automatic and natural way that it is rarely even described. It is usually briefly mentioned, in some cases also providing information about the number of patients left out, but normally without any reflection on the possible impact this might have on creating a sample bias:

Initially, personnel at the mental healthcare centres... were asked to select patients suitable for an interview. [11]

The key workers (or case managers) of those patients were then approached, with an initial request to assess the patient’s capacity to participate in the research, in consultation with their psychiatrist. [10]

The exclusion criteria for participation in the study were... patient incompetence to participate as determined by the patient’s “responsible clinician” and primary nurse... [5]

Clinicians will identify patients and ask them if they will see the researchers. [14]

Just one amongst the nine reviewed studies provided a detailed ‘recruitment and follow-up flowchart’ [6]. Its focus was on involuntary hospital admissions, and although it just aimed to present the reasons for patients’ nonparticipation or dropping out of the research, this rare chart, in our opinion, provides closer insight into the role of the professional staff in determining the study sample. Of all the reasons reported for the failure to contact patients, just one related explicitly to those patients’ will – ‘patient refusing to see anyone’ (this reason related to 14 out of 136 patients whom the researchers failed to contact). The other five reasons included:
staff refused contact (too ill); staff refused contact (reason unspecified); staff refused to contact (too violent/dangerous/unpredictable); patient sedated; and patient sleeping [6].

Further on, we observed that psychiatric studies on coercion are limited to persons currently being subjected to forced treatment or who received it relatively recently. The usual follow-up period does not exceed one year [3]. This also refers to studies investigating compulsory treatment in the community. In the sample of one qualitative study which reports patients’ generally positive attitudes to community treatment orders (CTOs), 52% of participants were still under the CTO at the time of the interview [10]. Despite such an outcome, the same study reports:

Many service users who were still under the CTO at their interview wished to be discharged from the order, and the majority of those already discharged were pleased with their voluntary status. [10]

Given the fact that the possibility of forced treatment profoundly affects every person with a psychiatric diagnosis, we don’t think that the investigation about its impact should be reserved only for those immediately affected. We consider this to be a serious restriction to comprehensive research on coercion, which is why we fully agree with the following remarks by survivor Peter Campbell:

I do not intend to argue either for or against the use of legal compulsion in treatment. But the fact of its existence has repercussions for all service users, and these must be recognised.

That an individual can be compelled to receive psychiatric treatment affects each in-patient regardless of whether his stay is formal or informal. It is hardly possible to be unaware that you are being cared for within a legal framework that allows for treatment against your will. [17]

The context in which psychiatric treatment happens, and its potential to turn into forced treatment, means that the legal definition of coercion is much narrower than the coercion actually exerted and experienced. In support of some of our statements, we will quote from a recent consultation exercise with service users/survivors across 15 European countries about their perspectives on human rights, which one of the authors was in charge of [18]:

I see it less as a process of the legislation because coercion works on so many levels. Yes, there’s the level of the legislation where you know people are sectioned against their will but then there’s so many other little things you see in hospitals, you know people told – well unless you do this then this will happen and you know and that’s not, that’s not a legal process. [18]
Psychiatric patients don’t have to be legally compelled in order to find themselves in situations of having no other choice but to adhere to treatment and to institutional or community psychiatric rules.

And then I remember one, one thing that stuck into my mind that suddenly a male nurse comes to say to me that now – you have to take a shower that well, now if you don’t take a shower, well, by that and that time, we will come all male nurses and wash you in the shower and I was totally terrified, that oh my God, what is this and first they fixed the deadline to eight o’clock and said now you must take a shower but then they made it quicker, I had to take a shower by six o’clock. [18]

Without seeking to equate forced treatment with voluntary treatment, what we want to emphasize is the coercive potential of psychiatric treatment itself. This is what restricts freedom of choice when undergoing psychiatric treatment to begin with; it is also what extends coercion far beyond what is captured by its legal definition. Inside a system based on the option of using force, the question of whether a person is legally coerced or not may become a side issue on an experiential level. Nevertheless, the patient’s legal status as voluntary or involuntary remains what most psychiatric studies on coercion focus on; they don’t investigate what exactly comprises the coercive treatment [4–7,9–11,14].

Some psychiatric research studies showed no significant differences in ‘perceived coercion’ between voluntarily and involuntarily admitted patients [19–21]. We also encountered recognition of the fact that ‘coerced hospitalisation or treatment may occur in the absence of legal involuntary status.’ [4] But further investigation of possible causes for such outcomes focused on demographic and clinical characteristics of patients [4,5] rather than any exploration of the treatment that they were actually experiencing.

In our opinion, an approach truly aiming to investigate coercion and understand its impact on both voluntary and involuntary patients – that is, the way it affects people’s lives – requires a radically different perception of research participants. We are aware that the term ‘perception’ is reserved for patients only and never applied to clinicians and researchers because the only ‘perceived’ thing is coercion. No one mentions ‘perceived treatment outcomes’, ‘perceived treatment need’ or ‘perceived psychiatric disorder’. We argue that even if never addressed, there is a perception of patients or research subjects inherent to psychiatric research which narrows its potential for ample investigation of coercion. To overcome this constraint, patients would need to be seen as capable of making reflections and judgements which reach beyond their individual and immediate situation, in the same way as all the other stakeholders. As long as we remain perceived as study subjects only, we will not be encouraged to reflect and will be forbidden to generalize, unlike everybody else involved. By the nature of our designated role, we will also not be invited to take part.
in dialogue, as no authentic dialogue can take place via psychometric scales. Hiday et al. report:

In trying to understand causes of perceived coercion, negative pressures, and process fairness, our three dependent variables, we expected sociodemographic characteristics to be important because these characteristics place individuals in groups that experience legal and medical authority differently. Age, gender, racial, and socioeconomic groups vary in their norms and experiences which affect others’ reactions to them and their own interpretations of the commitment process. [4]

This might be true (and proved true to a certain extent within this particular study), but we ask: how can such an investigation improve the understanding of the complex reality of coercion which does not take place only at a perceptual level or only as a correlate of sociodemographic characteristics?

Research on coercion needs to question, rethink and change researchers’ perceptions of participants, as well as to move beyond attempts at approaching our lives as an interplay of dependent and independent variables.

Comprehensive research will also have to reach beyond persons being currently or recently subjected to forced treatment and their relatives or the professionals involved. Research on coercion needs to include the larger community of service users/survivors and build on their experiential knowledge, not just on their observable characteristics and the scores they produce on numeric scales. It also needs to radically redirect its focus from ‘perceptions of coercion’ towards an all-inclusive investigation of actual coercion capturing the range of modalities of its incidence.

13.4 Research questions and methodologies

The quantitative studies that we reviewed focused on measuring patients’ perceptions of coercion and placing them in relation to their legal status [5], their sociodemographic and clinical characteristics [4], their adherence to treatment [7], their service evaluation [8] and factors associated with treatment outcomes [6,9,14]. Of the three qualitative studies that we included in this review, two aimed at understanding patients’ experience of involuntary hospital admissions [11,12] and one explored patients’, family members’ and mental health professionals’ views on community treatment orders [10].

In contrast with the detailed descriptions of the patients’ socio-demographic and other characteristics, hardly any article provided even minimal information about the researchers’ profiles and their background. Of the studies reviewed, the only exception to this rule was the one that reported and reflected on the collaborative nature of the investigation that included co-research with mental health service users [12]. One review of the 18 quantitative studies of involuntary hospital
admissions states that ‘most involuntary admitted patients show substantial clinical improvement over time.’ [6] The fact that two-thirds of the studies used interviewers responsible for patients’ treatment is mentioned when describing the methodological quality criteria for this review. However, the way this potentially influenced the outcomes goes entirely ignored.

We argue that the closeness of the research on coercion to the psychiatric treatment context reduces the ability of these studies to achieve a reliable and true picture of the topic under investigation. Some of the typical mechanisms applied include clinicians preselecting the sample, employing researchers who are part of the treatment team, conducting interviews and assessments at the same venues where persons receive psychiatric treatment, and recruiting participants who are still under forced treatment, or have been subjected to it very recently.

This problematic proximity between compulsory treatment and its psychiatric research is also reflected in the research questions guiding most of the studies. Too often we encountered quite an explicit and straightforward concern solely to identify factors that could predict patients’ perception of coercion [4–9,14]. There also seemed to be a strong interest in making patients feel better about being subjected to forced treatment rather than searching for alternatives to it.

Improving the percentage of patients stating that the admission was justified might be a sensible aim for both policy and clinical practice. [6]

Approximately two-fifths of our sample reported little or no negative pressures and little or no process exclusion in their hospital admission. These findings suggest that involuntary admission to a mental hospital can permit patients to feel like they have voice and validation, and can avoid force even in the absence of choice. The challenge is to try to extend to all patients at the time of their admission a demonstration in word and action that they are persons with opinions, desires, rights, and dignity, and not just mental patients in an acute crisis. [4]

How to predict the way patients will feel about the coercive measures imposed on them seems to be a far more challenging question for modern psychiatric research than investigating possibilities for rethinking and replacing treatment based on force with something different.

Even those studies which attempt to explore the outcomes of compulsory treatment take a predominantly clinical perspective when defining those outcomes. The findings of these studies differ, showing that involuntary treatment may have negative, positive or no significantly different outcome in comparison with voluntary treatment, but what they have in common is the nature of the outcome measures applied. Besides measures like hospital re-admissions [6,9], arrest or homelessness [9], in six of the nine studies we reviewed, the attempt to understand the impact
of coercion took place through asking patients to rate items on different scales or to assess a number of pre-formulated statements as ‘true’ or ‘false’. Most of the articles we included do not describe the instruments that they applied in detail, but their technical and quantitative nature is clearly implied by their names: Perceived Coercion Scale, the Negative Pressure Scale and the Voice Scale [5]; true–false items of the MacArthur Interpersonal Relations Scale [4]; Client’s Assessment of Treatment Scale, Global Assessment of Functioning, Brief Psychiatric Rating Scale [6]; Lehman Brief Quality of Life Interview [9]; subscales from the Therapeutic Limit Setting Measure, Modified Admission Experience Survey, Session Impacts Scale, the Working Alliance Inventory, Short Form [8]. Four of the six quantitative studies applied the MacArthur Perceived Coercion Scale [4,6,7,9]. This obviously popular and respected measure consists of the following five items which can only be assessed as either true or false and scored accordingly [4,7]:

- ‘I felt free to do what I wanted about coming to the hospital’;
- ‘I chose to come into the hospital’;
- ‘It was my idea to come to the hospital’;
- ‘I had a lot of control over whether I went into the hospital’; and
- ‘I had more influence than anyone else on whether I came into the hospital.’

Aside from noting that this measure is an oversimplified and therefore inappropriate tool to explore any aspect of coercion, we would like to raise two issues around its trustworthiness. Firstly, the answers on this scale relate only to the circumstances of hospital admission and hold no information about the person’s perspectives on coercion from that moment onwards. Secondly, the scale ignores the fact that people may hold themselves ultimately responsible for most things in their lives; this does not mean they are unaware that force has been imposed over them.

Research on coercion obviously uses an approach similar to that of diagnostic tests and different instruments of psychiatric assessment. Psychiatric survivors, like Louise Pembroke, argue that this is a way of systematically depriving people of their experiences and the meanings these hold:

I have come to the conclusion that people are not studied by psychiatry and psychology, merely categorised and described. That their rigid frameworks serve only to fragment people, turning a break-up into a breakdown. In categorising the distress the distress itself is not acknowledged. The individuals’ right to own the experience has been stolen. [22]

Research on coercion needs to become interactive and engage in a dialogue with different protagonists instead of celebrating one-way assessments. But this is hard, if not impossible, within a biomedical framework which perceives people as passive
respondents to treatment and is traditionally based on observing and measuring them rather than engaging and attempting to understand and share their realities.

Coercion primarily takes place between people (and not as an isolated internal process) and so that is how and where we think it should be explored.

Qualitative methodological approaches in psychiatric research can certainly come closer to the complexity of persons’ experiences, and we agree with Johansson and Lundman that ‘using a narrative method increases the possibility to study coercion identified by the patient’ [11]. Despite our critical stand on their method of recruiting the interviewees (through asking the personnel from mental health centres to ‘select patients suitable for an interview’), we do appreciate the approach they take when trying to understand what coercion means for patients:

A primary way of giving meaning into experience is to make stories of it. This is especially relevant when dealing with changes in life and trauma. [11]

This study, together with another qualitative one which was conducted in collaboration with mental health service users [12], we consider to be of the highest quality amongst the selection of nine which we reviewed for the purpose of this chapter.

But we want to stress that we consider neither service user involvement nor a qualitative approach as such to be guarantees of good quality research on coercion. When service users are employed just for data collection that takes place via quantitative clinical instruments alone, the experiential knowledge they bring will not have much influence on the whole process or enrich and reshape the research [23]. Similarly, the research topics and questions of qualitative studies can still be dictated by the same clinical/biomedical paradigm. In concluding their review of five qualitative studies on coercion, Katsakou and Priebe write:

Although the perceived impact of involuntary treatment is fairly clearly described, differences between distinct patient groups are not examined. Future research should investigate such differences in order to inform relevant policy decisions for particular groups. [13]

Qualitative research can also remain driven by narrow attention to finding answers within the individuals or their ‘particular groups’ rather than broadening the focus to the larger treatment context in which coercive measures are applied. Despite the availability of participants’ original quotes from qualitative research, some authors and reviewers feel free to draw conclusions which obviously reflect their own views rather than any evidence they encountered:

Overall, people suffering from mental health problems are particularly sensitive against any intrusions into their autonomy and privacy. Coercive interventions are often viewed as an attack on their overall ability to self-regulate. [13]
We are not aware of any studies in which academic researchers, clinicians and others ‘not suffering from mental health problems’ were subjected to coercive measures for the sake of experiment and comparison. If we were to positively argue for randomized controlled trials, then these could be applied to test the statement above. We would hypothesise, though, that the ‘others’ would react much worse to ‘intrusions’ than service users/survivors because we have already been exposed to psychiatric force and might have learned some coping strategies. But we are not suggesting an experimental approach to research on coercion, and want instead to draw attention to the statement above as an example of the interpretative freedom exercised in ‘scientific’ reviews. The concluding part of this review illustrates what we have already observed to be the either explicitly suggested or frequently implied direction of modern psychiatric research on coercion:

However, when patients feel that professionals genuinely care about them and offer them some degree of participation in their treatment, such interventions are viewed in a less negative light and do not have a negative impact on people’s sense of self-value. Thus, it seems important to enhance people’s perceived participation even when being treated involuntarily. [13]

As we don’t share this conviction, in the second part of this chapter we will try to outline some alternative principles and values for research on coercion.

13.5 Towards comprehensive research on coercion

As we have already said, we are aware that research outcomes are just one of the factors that inform mental health legislation and policy, and presumably not the most important one. Nevertheless, taking into account that the premises of psychiatric studies as well as the way they are designed and conducted inhibit comprehensive research on coercion, we think that their further funding should be scrupulously reconsidered. If this broadly relevant topic is to be seriously investigated, the research will have to take a new direction: forced psychiatric treatment is a human rights issue, and there is no reason for further investments in strictly medical studies of it. The first step that needs to be taken is to let ethical, legal and social perspectives enter the arena of the investigation of forced treatment.

This has started to some extent through the work of bodies like the Committee for the Prevention of Torture [24] or the UN Special Rapporteur on Torture [25], but despite their considerable importance, short monitoring visits to places of detention cannot substitute for systematic explorations of coercive treatment, its incidence and its impact. Such visits are also not applicable to exploration of forced treatment outside of institutions.
Trying to envisage ample research on coercion, we agree with Mary O’Hagan that we should first of all encourage and listen to the perspectives of those people whose voices are stifled by forced treatment.

In recent decades users and survivors have found their voices after centuries of virtual silence. You simply cannot engage in a fair and full debate on force with us, unless our voices lead the way. [16]

There is a growing body of available texts authored by people who identify themselves as mental health service users/psychiatric survivors. We consider these to be an invaluable source of guidance when developing questions of relevance for research on coercion. Referring to some of those texts, we will now let our voices lead the way by raising a few issues that we consider important when investigating coercion. As with our small-scale review of psychiatric studies on coercion, however, the following suggestions give only a snapshot of the work required to develop a comprehensive and socially responsible framework for research on coercion.

### 13.6 Importance of independent research

We are convinced that any sound research on coercion must take place completely independently from the provision of psychiatric treatment. As long as clinicians in charge of forced treatment are the same ones making decisions about the research, there will be no chance of a true and complete investigation. We have already criticized the method of recruiting study participants through clinical staff. We have also criticized the research on coercion being conducted by members of the treatment team, since it entirely ignores the power imbalance in the coercion situation, which we consider to be a matter of common sense.

I had to learn not to express anger and frustration towards what felt like torture. I could not express my pain and anger to the people who were controlling every aspect of my life. [22]

Many written accounts by service users and survivors confirm that honesty cannot be expected in a coercive context and that a person needs to have sufficient distance not only physically but also in terms of time in order to freely report their experiences. We doubt that statements like the one below could have been obtained at the time when treatment was taking place.

I signed the consent form because I hoped at the time that I would die under the anesthetic. This was the view that informed many of my future signatures on ECT and
over the next six years I received approximately 60, each justified by continually changing labels which ranged from psychotic depression to schizophrenia. [26]

Any research studies aiming at all-inclusive investigations of coercion will have to develop alternative ways of approaching potential participants, earning their trust and obtaining informed consent from them. Furthermore, the researcher should not be obliged to brief the clinician on the outcomes. There are parallels to attempts at investigating guardianship [27] while having to obtain guardians’ consent to even talk to the persons in custody. Research ethics committees need to carefully consider such vicious circles and set different rules. Independent research on coercion must be demanded and allowed. The intimate link between the conduct of forced treatment and research about it will have to be broken in order for the topic under investigation to be brought out of the individual treatment context and become subjected to different perspectives.

13.7 Redirecting the research focus

Judgements of the ‘effectiveness’ of coercion, which remain the focus of most current research, should only come 

after 

a thorough explanation of coercive measures and how they take place. If something proves effective, this doesn’t mean that it is good and acceptable. The fact that weapons are effective in fulfilling their goals does not mean that they should be recommended. Perhaps the goals themselves need to be brought into question. Even if there are people who anecdotally report that coercive measures have saved their lives, research should still be able to tackle the quality of those lives and continue raising questions about how things can be done in a better way. It is a matter of not assuming that because a practice is long established, this means it is necessary and right and unchallengeable. Many routine practices such as child labour, slavery, foot binding and forced marriages have been changed and even prohibited as new generations begin to see their inherent inhumanity.

In order to make complex judgments, everybody should be entitled to a detailed and comprehensive picture of what coercion looks like and what it consists of. Such topics are almost excluded from the current research on coercion. The fact that somebody is involuntarily committed or is under community treatment order does not say anything about the treatment they receive. One user-led study of experiences of hospital admissions confirms:

... the coercion of being detained was not attributed to the legal process involved but rather to coercive events that service users were subject to as a consequence of detention. [28]

There is a lack of communicable knowledge of what ordinary psychiatric treatment imposed on a person looks and feels like.
What we are experiencing is a hierarchy of disempowerments that stretches from the psychiatrist’s consulting room to the queue for bread and jam at bed time. It is interlinked and greater than the sum of its parts. In the end, it is sustained by our own suspicions that we are truly inferior. We come out of these isolating places and we are much too afraid to tell ordinary people what it was like. [29]

... the truth is that most of the interference with choice actually occurs in much more mundane, routine, noncrisis kinds of matters. Things like when we eat, when we’re allowed to use the telephone, who we can associate with, and what we do with our time. And while these issues don’t have the “glamour” of the high-risk situations we hear about, I really believe that that’s where the most of us have felt the most intruded upon and where the lack of choice has really been a burden to us over the years. [30]

The definition of coercion needs to be enlarged to include all the single occurrences where people are denied a choice about basic things in their lives. Researching coercion should focus on its incidence and the methods used; it should be able to answer how, by whom and with what kind of justification coercive methods are applied.

From the already mentioned large consultation exercise with service users/survivors around 15 European countries [18], we learned that a person can be locked up for a week in solitary confinement (Belgium); that the nurse in charge of close observation does not speak to a patient at all (Finland); that patients who are not allowed to leave the ward have to wear pyjamas at all times in order to be easily distinguished from the others (Austria). We learned that there is often no access to a toilet in the isolation room and that the patient can be forcibly cleaned with the same mop with which the floor is cleaned (Greece). We would like to see research on coercion capable of examining and documenting such situations and providing complete and unbiased data. We expect the research on coercion to disclose all treatment methods, providing accurate information about their use, the decision-making processes behind them and their therapeutic justification.

As psychotropic medication is what constitutes psychiatric treatment, coercive measures are predominantly used in order to assist with administering drugs. The already mentioned user-led study of hospital admissions [28] confirms this.

There was a strong link between medication and coercion. All physical restraints reported were followed by forcible injection ... [28]

The European consultation exercise with service users/survivors [18] about their perspectives on human rights has also shown that refusing medication is not really an option in psychiatric treatment, both in hospitals and in the community.

I see it as a right for people to choose to not take medication as well as taking it and I don’t feel that any country allows for that. . . We are all different and I totally respect
everyone’s right to take it 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 is very difficult. [18]

You can refuse chemotherapy if you have cancer even if you are going to die but it can be made impossible to refuse medication [18]

Comprehensive research on coercion will therefore have to include independent, reliable and accessible information about the drugs administered, explaining both their main and side effects. The fact that current research pays no attention to such explanations completely leaves out the most crucial aspect of coerced treatment:

I guess for me the worst human rights violation is the forcing of physical treatments – drugs and ECT because for some people they can cause lasting damage whereas mechanical restraints are not as likely to cause lasting physical damage. [18]

Ron Bassman writes that:

The spirit-breaking component of forced drugging is reflective of the rationale used to justify past psychiatric treatments. A review of the history of psychiatry reveals that spirit-breaking was an important first step in treatment and a major justification for the psychic and physical torture of patients. [31]

Investigations of coercion need to move their focus away from subjects’ perceptions and reactions, as these never take place in isolation. We would like to see research that reflects on the traits of clinical staff, their values and beliefs, while documenting the possibilities of monitoring their work.

Furthermore, the process of granting consent to treatment is well worth investigating in the psychiatric context, and studies should therefore never be limited to involuntary patients only. The fact that a person agreed to treatment does not guarantee that they have made a free and informed choice.

When I signed my consent form for ECT it was completely lacking in information. Nobody told me what the possible side effects would be, nobody told me that I might have memory loss. The information sheet didn’t mention that, you know – so under what circumstances was I giving this consent? [18]

Studies of coercion should be designed to bring light to concrete practices, the entities in charge of them, and the whole interaction process. Before judging
the outcomes, one should be able to explore and understand from multiple perspectives what constitutes the system of coercion and how this system operates.

While there is no space for a full discussion in this chapter, we believe that systematic investigations of the values, principles, practices and achievements of alternatives to coercive psychiatric treatment [32] should be called for as a necessary component in informed public debates about this issue.

13.8 Rethinking treatment outcomes

The outcome of coercive treatment cannot be quickly assessed from an outsider perspective. The impact of coercive treatment on people’s biographies has to be tackled in terms of those biographies, as their owners are in the best position to report what happens in their lives. The notion of effectiveness of coercion as applied in psychiatric research remains just one amongst the variety of ways to think about treatment outcomes.

Much of the research on outcomes involves time specific snapshots measuring recidivism and symptom reduction while ignoring the demonstrated non-linear path of recovery. Funding decisions that favour research to find ways to improve drug taking compliance limit the prospect for studies that reflect the richness and the complexity of the human condition. [31]

When service users/survivors talk about the impact of forced treatment, they seem to be thinking in terms of their whole lives. The first encounter with the psychiatric system usually marks a turning point in a person’s biography [33], and forced treatment is often seen as incompatible with healing.

And the truth is, you can’t heal me without my cooperation, you cannot. There’s no such thing as forced healing. [34]

... people who have recovered are people who have made choices on their own. Choice is an integral part of the healing process. It’s not just something that we can tack on to treatment when we feel it’s convenient. If choice isn’t available, then healing cannot occur. [30]

There seem to be historical disagreements around the question of whether ‘healing’ is at all amongst the intended goals of psychiatric interventions [35], including forced ones. Psychiatrist Peter Stastny distinguishes between medical practitioners respecting the Hippocratic Oath ‘First do no harm’ in contrast to those ‘who practice social control under the guise of psychiatric treatment’ [36].
The understanding of the scope of psychiatric intervention is closely connected to the question of who should define its outcomes and against which criteria. Many service users/survivors share demands such as those articulated by Lauren Tenney and Ron Bassman:

Recovery is no longer the exception. Recovery is the expectation. [37]

... it is imperative that you see the individual and value that special individual by engaging in a collaborative search to find understanding, meaning, and connection in this person’s unfolding life narrative. [38]

If psychiatric intervention is intended to help and heal, and if recovery and achieving a life worth living belong amongst its goals, then the outcomes of treatment need to be measured against the fulfilment of these goals. But such goals must also be articulated and revisited by persons themselves. The two treatment outcomes described below might have achieved a positive assessment if judged by any outside criteria.

Introverted, dazed and abused by forced feeding and vast cocktails of tranquillisers, anti-depressants and sleeping pills, life had no meaning, no reality – no hope – even my dreams, all I had to live for, had been brutally shattered at my feet, I was imprisoned in a cage where no-one could reach me; even myself. [39]

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. [40]

Even those outcomes which appear ‘objective’ and easy to define, such as ‘employment’ or ‘maintaining work’, give no information about their appropriateness for actual persons measured against their individual abilities and aspirations. We can’t judge the realization and the fulfilment of somebody else’s life without taking into account that person’s unique criteria and expectations, their aspirations, capabilities and desires together with the way these developed within their life history. Peoples’ ambitions usually get downsized in the course of psychiatric treatment [33], and no simplified outcome measures will capture such decisive outcomes.

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. [41]
When I got out of the hospital I felt hopeless. Even though I was only twenty one years old, I felt like my life was over. [42]

Comprehensive research on coercion would need to develop criteria for judging treatment outcomes which go beyond adherence to treatment or any single quantitative data like the number of hospital re-admissions. The latter is, for instance, used commonly to assess the outcomes of community treatment orders. Interestingly enough, the possibility of suicide is never mentioned amongst the descriptions of treatment outcomes. Even just the simple numbers of suicides committed following psychiatric treatment, or in the course of it, are not publicly available. Judgements of treatment outcomes need to include suicide as well. Outcomes of treatment refer to peoples' lives and therefore cannot be of a technical nature. Their definition needs to be individualized, able to capture people’s lives and the way they feel about them. We are aware, however, that such an approach would challenge the understanding of the purpose of psychiatric intervention, measuring its outcomes against the criteria of a fulfilled life. Investigators would need to give up their ambition to separately define what constitutes a good prospect for a person with a psychiatric diagnosis and accept that we are all entitled to the same opportunities in life. Psychiatric interventions would then be judged by their ability to assist individuals in the process of realizing those opportunities. If adopting such outcome criteria seems too ambitious or even utopian, our minimum expectation of all studies is that they become clear and transparent about the perspective they apply when judging the outcomes of coercive treatment.

13.9 Closing remarks

In both our review of psychiatric studies and in our attempt to come up with some principles and suggestions for comprehensive research on coercion, we have focused on empirical research as a source of knowledge. We are aware, however, that empirical research is just one form of knowledge production, and we would like to stress the importance of using other available sources of knowledge and letting them become part of what constitutes evidence. It should also be recognized that coercion in psychiatry has at no point been an evidence-based intervention. From the origins of psychiatry, coercion and actual force have been a given aspect of the incarceration and treatment system and have remained so. In the interests of genuine scientific research, as well as ethical, moral and values-based approaches, there should be an opportunity to take a step back from the assumptions and received wisdom that coercive psychiatry is ‘natural’ or inevitable.

If people with a psychiatric diagnosis are not to be ‘objects, imprisoned with and without walls, cut-off from a meaningful dialogue’ [43], then our experiential knowledge of madness, distress, treatment and force needs to find its place on equal terms with other types of knowledge.
Experiential knowledge takes more forms than those of testimonies and narratives, and nowadays includes advocacy, research and conceptual work done by mental health service users/psychiatric survivors.

We see ourselves and many of our peers in Louise Pembroke’s words:

Something was very wrong with the treatment but I didn’t have the language or the analysis to articulate it beyond refusing to cooperate with it. [22]

For those of us who have experienced forced treatment, it usually takes years until we come to terms with our lives, until we comprehend what happened and find a way to integrate that experience and deal with it. It takes even longer until we complete our interrupted education and achieve formal requirements to take part in organized knowledge production, often in the form of research. We wish for service user/survivor knowledge to find a shorter and more direct way to enter and inform public debates. We are convinced of its potential to reshape mental health legislation and policy towards fostering quality improvement in services instead of merely extending coercion.

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References


