Anne-Laure Donskoy's paper for the Prevention of depression and suicide conference, Budapest, December 7th, 2009:

I will start with a statement from the European Network of Users and Survivors of Psychiatry (ENUSP):

 When ENUSP was first invited to take part in the preparations for this conference over 6 months ago, it quickly became apparent, despite best intentions, that seeing the first person voice take a prominent place was always going to be difficult. Ordinary user and survivors should be keynote speakers, or be more visible and audible at the high table of plenaries, or be leading parallel sessions rather than find themselves in mere 10 minutes response time slots. Independent networks of users, independent of the pharmaceutical industry and of the medical profession that is, should be able to have a greater say on who the experts in the field are, so that a good mix of perspectives is really represented. We have had panels of experts but we too are experts of our lived experience of depression and attempted suicide. And some of us are here to tell the tale.

My presentation will be in two parts. First looking at the importance of user research, followed by two examples of how user research, grounded in experience, can help advance the debate.

The supporting document to this Thematic Conference notes the lack of user involvement in research which would reflect the "appropriateness [of research] to those who have contact with services". This is one of those beautifully vague statement that is meaningless because it so obviously lacks commitment.

In effect, user involvement can take many aspects. In practice, it is often taken to mean "consultation" rather than full collaboration as research partners, or as user researchers with full control over the research process. How can one achieve good quality research and data while there is a lack of clear and genuine commitment towards user involvement in research or when conventional research chooses to ignore data from experience-based knowledge? It only serves to perpetuate a state of staleness in research and a status quo of perspectives.

We have heard a lot in the last couple of days about evidence-based clinical models. But what evidence are we talking about? Evidence-based medicine starts from a very specific and not necessarily scientific epistemology; and the political and cultural frameworks for health that support it chose to ignore that there are other ways of knowing and constructing our knowledge of the world.

User research is now over 25 years old and is recognised for its validity and the added value that it brings to the construction of knowledge. With user research, there is a paradigm shift not only in the way that knowledge is constructed through its epistemological and ontological positions, and in the type of outcome produced, itself grounded in lived experience. This is what I call "service users taking over the research asylum". Yet, many conventional researchers, as well as public and private funders, are starting to realise the potential of this untapped source of knowledge. The coming of age of user research is also attested by the

publication this year of two books on user research in mental health and I would urge you to look at the information which is being made available at this conference.

User research allows the first person voice and experience to be properly taken into account, not dismissed or derided as anecdotes...... and researched as aspects of a complex truth. Others amongst my esteemed colleagues of the user research and survivor worlds regularly eloquently speak about it, or from it. Amongst them, and on the subject of this conference, is David Webb, who has explored the experience of suicide in a truly unique way. He is acclaimed way by experts, including from the field of suicidology, such as Michael Dudley who has authorized me to give his official support for David's work.

I will now give you two examples to illustrate how user research can help advance the debate. The first comes from self-harm, which apparently defies all logic and certainly carries with it a degree of fear and taboo.
The literature on self-harm is still largely full, including in the supporting document to this conference, and despite some notable shifts in attitude in some quarters... as well as evidence ... of phrases which purport to and therefore reinforce, a quasi automatic link between self-harm and suicide. Worse still, they assimilate link and cause.

 But first I am going to give you a glimpse of the background:

Research in self-harm does not start before the beginning of the 20th century and does not really become a reality before [Karl] Meninger in the 1930's with the first attempts at classifying self-harm behaviours. There is a real lack of historical perspective on self-harm research, which would allow at least a critical analysis of the context in which it is taking place. There has been some but not enough. Naomi Shaw's meta-analysis of 2002 is a notable exception.
She notes cycles and periods of interest and activity in self-harm research since the 1950's; and periods of inactivity. The constant dominant though is the need for clinicians and academics, such as Armando Favazza more recently, to categorise self-harm behaviours, as if categorizing was enough to shed real light and create appropriate responses.

When research is active, history shows that the same stale approaches and perspectives are recycled. Things change for the worse in the late 70's when self-harm is progressively absorbed by suicidology, with a strong emphasis on behaviourism and deficiency of functioning. It is at that point that self-harm, as a coping strategy, pretty much falls off the conventional research agenda. If suicide prevention is a priority, and no one doubts this, it also drives huge amounts of research funding which pushes the rest to one side, if not oblivion... which means that just over one hundred years on from the first clinical writings on self-harm, we are not really better advanced. And self-harm resists. It resists an alienating psychiatry's attempts to make sense of it, as well as habitual research paradigms.

It resists because something is missing. It is missing because of the way that scientific research constructs knowledge and, more particularly, makes

epistemological choices that exclude certain types of investigation and data, with a strong emphasis on <u>looking for</u> and finding causal links.

It is also missing because scientific research and the medical world have immense powers over the pathology, the behaviour and the functioning of the subject as patient. Coming from experts this seems legitimate. However, these experts have such a power over language, over the experience of the person and over the construction of knowledge, that it leaves virtually no room for anything, or anyone else, as the literature on self-harm demonstrates.

Thinking for a minute about the concept of the black box in physics, self-harm experts have become technical experts of the box, interested mostly in behavioural aspects. In other words it is interested in what is observable, expecting self-harm "behaviours" to fit into models and diagnoses, while rejecting the core of the person's complex internal mental states, i.e. the inside of the box. Hence often inappropriate treatment and approach responses; including in terms of research.

User research can help deconstruct and demystify the quasi-automatic link between self-harm and suicide which has come about largely because of psychological suicide autopsies. These pose a problem since, by definition, they work backwards and may find, at some point, evidence of self-harm. Data collected at that point is not very sophisticated, mostly because the individuals it is collected from are no longer alive to tell the full story and there may not be enough or good enough clues left behind. This has two consequences.

The first is that this leads to all forms of self-harm being lumped into one, and self-harm then becomes an "indicator of suicide", a "suicidal behaviour", and in some quarters, a link effectively becomes "a cause of suicide". The consequence of this emphasis on suicide prevention is that self-harm is considered an illness whereas self-harm is a human response to an often intolerable situation.

The other consequence is the way some users are treated by mental health services which, under suicide prevention, often create more problems. For instance so-called "zero tolerance" contracts on wards despite plenty of evidence which shows they are counterproductive; or the forced admission of patients, in particular in cases of repetitive self-wounding, even if the person clearly does not intend to commit suicide through self-harm or even if their life is clearly not in danger. There is very clearly an issue of human rights violation here, in the name of suicide prevention.... Once they are forcedly admitted, they are effectively potentially at greater risk of attempting suicide; they also become very creative at finding the means to self-harm. Sometimes, they may go on to commit suicide. But, <u>not</u> because of their self-harm; but because they did not get the <u>timely</u> and <u>appropriate</u> attention and care that they needed.

In order to understand self-harm better and rather than start from the end point of suicide, user research looks at self-harm in how it helps us live and survive, rather than kill ourselves. This is difficult for most conventional researchers and clinicians to accept. User research denounces the detrimental link between self-harm and suicidality and the over simplification of complex mental states. In self-harm and self-wounding, the person is as much the victim as the perpetrator of the act. User

research attempts to disentangle the different levels of meanings and experience that an individual with the experience of self-harm expresses.

There are many missing pieces in the self-harm research puzzle. The study of the first episode of self-wounding in particular is one of them. There has been a lot of research done on what leads a person to self-harm, on patterns of repetition, on methods, on treatments, on attitudes etc, but none at all that focus specifically on the first episode, which is what I am doing in my own research. The first episode is a point of transition between a before and after when subsequent episodes will never be the same again as the first time. Precisely because I am someone with the experience of self-harm, and because I have taken part in conventional self-harm research which left increasingly frustrated by what I saw were rarely the right questions, or not asked in the right way, I decided to conduct my own research into it. In this instance, the subject of the first episode **IS** obvious for anyone with the experience. Because it is a point of transition between "the before and the after" and when all subsequent episodes represent totally different experiences from the first.

The second example concerns the prevention of suicide more directly. Some of our colleague users and survivors have been looking at the suicides induced by neuroleptics, in particular in people diagnosed as suffering from schizophrenia and which no one talks about. There is nothing either in the consensus paper or in the supporting document, or at this conference that even points out to those deaths which could potentially be prevented. Users and survivors have been saying for a long time that there is a need to develop proper forensic research in suicides, sudden and other deaths when neuroleptics were prescribed.

In conclusion,
Current research on suicide and depression, which includes self-harm, largely follows a medical and biological model which rests on the premise that suicide is, and I quote the so-called consensus paper, "primarily an outcome of untreated depressive illness", therefore a condition that should be approached primarily following the bio-medical model... which is extremely restrictive.
Policy needs more qualitative research and a different, more grounded, type of evidence. Because user research asks the question which conventional research does not ask, is not interested in, or does not ask in the right way, it is an essential tool in the exploration and understanding of users and survivors' lived experience. It helps combat the stigma, ignorance, fear and taboo still associated with mental distress and psychosocial ill health.