

## VETmh TuTo+

### Vocational education process in European tutoring for immersion trainees in the mental health sector

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Involving users of mental health services  
in the training of psychiatric and mental health professionals:  
a literature review



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## INTRODUCTION

The participation of users of mental health services in all projects that concern them is an important issue. Such participation is addressed here within the framework of the evaluation of the international project VETmh TuTo+ (2018-2021). This is a European training programme for tutors and trainers of tutors in psychiatry and mental health, focused on developing the skills of young professionals. The objective of this article is to perform a review of the literature, making it possible to: 1/ highlight what legitimates the participation of users of mental health services, 2/ identify what characterises a successful participation of users in international projects, and 3/ identify the specific features and mark out the formalisation of the participation of users in the evaluation of the training programme.

## METHODS

An exploratory review of the French-language literature was conducted using the databases of the *Banque de données en santé publique*, Base SantéPsy and Cairn.info:

## RESULTS

32 articles from scientific journals published between January 2015 and July 2020 were retained; 2 institutional documents (European Commission, 2005; World Health Organization, 2013) and the work relating to the TuTo project (2014-2017) were also selected.

This review reveals the necessity of involving the users, and makes it possible to identify relevance criteria that legitimate working in a partnership between the users and the other actors for evaluating a mental health training project, as well as quality criteria that should guide the concrete elaboration of this involvement.

## DISCUSSION

This work is a first step in the collaborative development of a protocol for evaluating the training programme VETmh TuTo+ (2018-2021). It also demonstrates the necessity of validating a practical tool intended to guide the formalisation of the participation of users within the framework of European and international mental health projects.



## INTRODUCTION

Funded by the European programme “Erasmus+, Strategic Projects”, the VETmh TuTo+ project (2018-2021) continues and supplements the TuTo project (2014-2017). The first strand consisted of a process of training and tutoring young European psychiatric and mental health professionals, offered via traineeships in European countries for several days a year over a period of three years, in order to become acquainted with different psychiatric and mental health work contexts. The second strand is a programme for training tutors and trainers, focused on the development of practical and relational skills and the evolution of the practices of young European psychiatric and mental health professionals.

While the first strand - the TuTo project (2014-2017) - was generally agreed to be a success - with 122 European professionals from psychosocial care and counselling, most of them between 20 and 35 years of age, travelling to participate in traineeships in 10 European countries, its final evaluation noted significant variation in the quality of the follow-up that the tutors gave their tutees (Fond-Harmant and Deloyer, 2017). Firstly, the surveys and interviews conducted amongst the trainees revealed that they had to some extent the impression that their tutors were not sufficiently familiar with the project, that they all found that the tutors had different levels of motivation, that they believed overall that the pedagogical follow-up and the link between the partners of the programme and the tutors needed to be improved and deepened, and that greater efforts had to be made to further involve the tutors. Secondly, the evaluation sessions bringing the latter together revealed a certain confusion on their part regarding their role and tasks. A significant number of them admitted that they hadn't found their place as tutors vis-à-vis the trainees.

This finding led to the project's second strand: the VETmh TuTo+ project (2018-2021), a training programme for tutors and trainers of tutors. Concretely, European psychosocial care and action professionals wishing to become tutors are firstly recruited on the basis of voluntary participation by hospitals that are partners of the project, then addressed to the project leaders. The engaged professionals take part in a training cycle of three-day training sessions organised once a year over the course of three years. The different modules of this training course are conceived and dispensed – by teachers with experience in the fields of mental health and psychiatry – in such a way as to be simultaneously useful, complementary and flexible. Beyond a training content and a toolbox, it is more a matter of an andragogical approach aimed at raising the tutoring skills of the referents, starting from



their own abilities and getting them to try the emancipatory approach that the tutees and tutors in training will be led to experience.

Mid-way through this project, the World Health Organization Collaborating Centre for research and training in mental health (WHO-CC) of Lille - the project's French partner - conducts an evaluation of this training programme for tutors and trainers of tutors in psychiatry and mental health. One of the tasks of the WHO's Collaborating Centre in France is to help the World Health Organization (WHO) to promote the participation of users of mental health services in all actions that concern them, whether in the areas of care, research or education. In coherence with the values and working methods of the WHO's French Collaborating Centre, as well as with the international and European guidelines on the involvement and engagement of affected persons (WHO, 2013; EU, 2005), this mid-term evaluation was conceived in a joint construction dynamic in order to facilitate the full participation of users of mental health services in this phase of the project. With regard to global recommendations, the WHO recommends that users be given the means to participate in research and evaluation in the mental health field (WHO, 2013, p.10).

If the participation of users had not been formalised until then, this programme - since the initial strand - is in fact being implemented with their participation. Primarily since the partner health establishments who assume responsibility for receiving trainees work with representatives of the users of mental health services. Nevertheless, the formalisation of this participation within the framework of evaluating the training programme developed together with the users of mental health services raises questions: What legitimates the participation of users of mental health services within the framework of European and international projects concerning them? What characterises a successful participation of users in such projects? What points of vigilance need to be known and mastered? What methods appear to be the most relevant? And, within the framework of the VETmh TuTo project (2018-2021), how should this participation be formalised?

As preliminary step, this article offers a systematic review of the literature making it possible to answer the above-mentioned questions and clarify the reflections relating to the VETmh TuTo+ project (2018-2021). It is thus expected to be able to argue for 1/ implementing an evaluative approach that includes their participation, 2/ choosing the terms for participation, 3/ marking out its formalisation. From this perspective, the purpose of this review is to draw up an inventory of the participation of users of psychiatric and mental health services.



## METHOD

This paper is a systematic review of the French-language literature. The literature search was performed on three bibliographic databases: the archive of the *Banque de données en santé publique* (BDSP - the Public Health Database), Base SantéPsy and Cairn.info.

The inclusion criteria selected scientific articles published between January 2015 and July 2020, in French, dealing with the participation of users of mental health services. The search equations were developed by articulating keywords - first defined on the basis of dictionaries of synonyms and thesauruses - with the aid of the Boolean operators “ET” (or “AND”), “OU” (or “OR”) and “SAUF” (or “UNLESS” ), as well as truncation.

The exclusion criteria eliminated articles dealing with the participation of users outside the field of psychiatry and mental health as well as articles dealing exclusively with the participation of users of mental health services in their own care programme and rehabilitation process. In addition, texts other than scientific articles and editorials of scientific journals were not included.

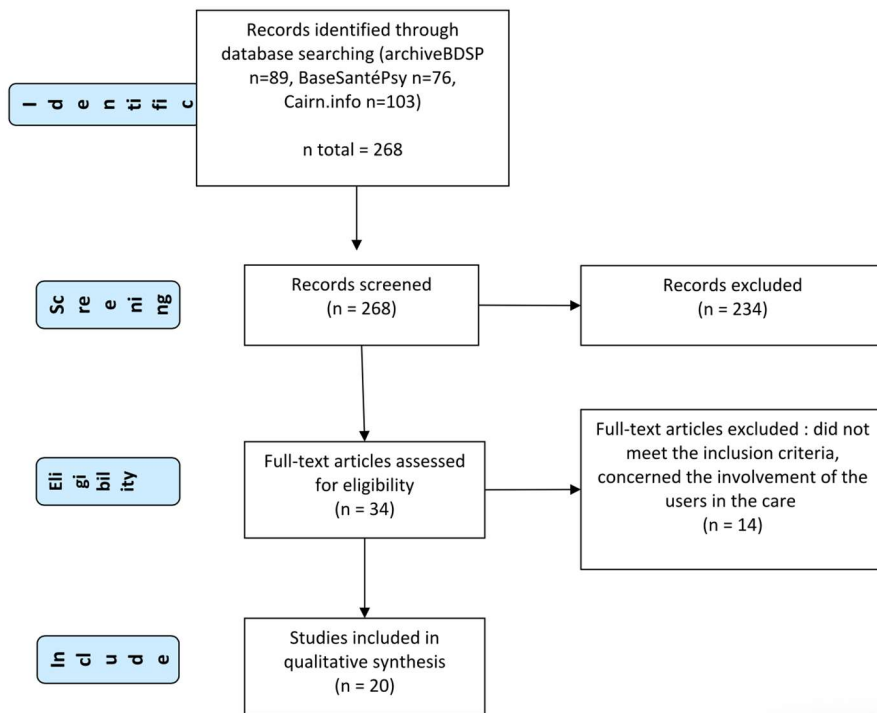
Table 1. Search method of the literature review.

database	thesaurus	search equation
BDSP archive	yes	(participation of the user) AND (mental health) OR (psychiatry) AND (mentally ill) OR (expert patient) OR (health user) OR (care consumer) OR (mental disorder) OR (psychopathology) OR (citizenship)
Base SantéPsy	yes	(participation) And (mental health Or psychiatry Or mentally ill Or expert patient Or user Or psychiatric pathology Or psychopathology Or citizenship)
Cairn.info	no	(“participation”) AND (“mental health” OR “psychiatry”) AND (ill OR patient OR user) AND (mental illness OR mental disorder OR psychopathology) AND (democracy OR citizen*) UNLESS (handicap*)



## RESULTS

Figure 1. Flow chart of the literature review.



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit [www.prisma-statement.org](http://www.prisma-statement.org).

The search made it possible to collect 268 texts. The manual sorting based on the inclusion and non-inclusion criteria led to 20 references being retained. Some of them being journals, ultimately 32 scientific articles and editorials of scientific journals were included in the literature review. Each of these documents was carefully read and analysed.

The reading and analysis of this corpus made it possible to identify relevance criteria that legitimate the participation of users of mental health and psychiatric services beyond their care plan and their rehabilitation process, as well as points of vigilance that should guide the formalisation of the participation of every user or ex-user of psychiatric and mental health services.



## ANALYSIS

### **Relevance criteria**

#### **Getting persons with a lived experience of mental health disorders to participate in order to help society evolve**

Firstly, the literature presents the participation of persons with their experience of life and their experiential knowledge of mental health disorders as a lever for combating stigmatisation, discrimination and social exclusion. One of the articles recalls that stigmatisation is defined as “*the reaction of a group or of a society against different or underprivileged persons or minority groups (...) consisting of attributing a label that categorises them as deviants*” (Goffman, 1975 in Alary, 2016). In this sense, certain authors evoke the stigmatisation, firstly, to which psychological disorders are subjected and, secondly, to which persons affected by these disorders fall victim (Rhenter & Carbonel, 2015; Alary, 2016; Loubières et al., 2018). Also evoked is the stigmatisation suffered by professionals who support and accompany these persons (Alary, 2016). Professionals from the healthcare and psychosocial sector, particularly psychiatrists and psychologists, are notably concerned here.

Certain authors describe a Western society in which socially-constructed negative representations persist. Historically, for many years, a *process of exclusion of the mad, the insane, those who don't make sense, those who appear to no longer be aware of their actions* (Foucault, 1972 in Caron, 2015); and culturally, whatever the country, madness and danger have long been associated (Loubières et al., 2018). In fact, in the Western collective imagination of today, a person directly affected by mental health disorders is simultaneously perceived as disturbing or even dangerous (Alary, 2016) and presumed to be unable to defend his interests (Troisoeufs and Eyraud, 2015) or even supposedly unable to think for himself or even work or live independently (Rhenter and Carbonel, 2015). These negative received ideas have harmful consequences for any individual suffering from psychological disorders. Indeed, access to housing, employment and leisure activities as well as the building of intimate relationships of love or friendship or the exercise of parenthood are all made far more difficult for persons with psychological disorders than for others (Loubières et al., 2018). In addition, these negative prejudices can have another harmful impact for individuals suffering from mental disorders, i.e. they can become trapped in a vicious circle of self-stigmatisation (Loubières et al., 2018). Self-stigmatisation occurs when the person concerned interiorises this set of negative prejudices,





which can reduce or even destroy his self-esteem and have a harmful impact on his everyday life and rehabilitation process.

The authors mention that actions are being taken, more or less formally, to combat stigmatisation. One of them is to renew the terms used in order to speak of psychological disorders and individuals affected by these disorders. New terms are thus used to speak of them *without* participating in stigmatisation. For example, to evoke a person experiencing mental suffering, the expression “psychologically ill” replaces that of “mentally ill”, itself preceded by the terms “alienated”, “mad” and “insane” (Alary, 2016). But this type of intervention - like most of the actions recommended for combating such stigmatisation - supposedly has little impact and is not particularly long-lasting (Loubières et al., 2018). The fact is that terms from clinical psychiatry and the mental health field are used in everyday language to mock or insult (Alary, 2016). The effectiveness of this type of intervention is all the more relative since, at the same time, the negative social representations are regularly reinforced by the way mental health questions are dealt with in the media, as well as by how persons with psychological disorders and psychiatric and mental health professionals are represented in films, on television and in the media generally. In fact, this treatment and this representation arouse emotions that tend to strengthen firmly-anchored negative social representations (Loubières and al., 2018).

The authors also explain that the participation of persons directly affected by mental health disorders is more likely to make a genuine contribution to the process of deconstructing received ideas, in other words to effectively combating stigmatisation (Loubières and al., 2018). In particular since this makes it possible to reinject the human aspect into mental health questions. The fact that an individual affected by psychological disorders speaks out to tell a part of his own history relating to mental disorders can permit others to put a face to these diseases and to envisage them via a singular experience. This is an opportunity to put an end to the dehumanisation and generalisation intrinsic to the mechanisms of stigmatisation (Loubières and al., 2018). It is also an opportunity for the individual who participates to break out of the vicious circle of self-stigmatisation.

In this logic, all situations involving persons affected by mental health disorders speaking out participate effectively in the struggle against stigmatisation and forms of discrimination, as well as for social inclusion.



Several articles also mention the healing power of social inclusion (Haliday, 2018). The participation, by helping to fight for the integration of individuals affected by psychological disorders, would also facilitate the rehabilitation process of the user who speaks out.

Secondly, the literature presents the participation of persons with a lived experience of mental health disorders as a way to effectively realise democracy in the field of health. One of the articles recalls that health democracy is defined, in France - by the *Agences Régionales de Santé* (ARS - Regional Health Agencies) - as “an approach that strives to associate all of the actors of the health system in the development and implementation of health policy, in a spirit of dialogue and consultation” (Arveiller & Tizon, 2016). In sum, this involves citizen participation in health policies (Arveiller and Tizon, 2016).

While Canada is presented as being a country that has taken the lead on such questions of health democracy (Arveiller & Tizon, 2016), some authors paint a more mixed picture of health democracy in the French psychiatric and mental health landscape in recent years (Alary, 2016; Arveiller and Tizon, 2016). On the one hand, the “mentally ill” became a “psychiatric patient”, then a “user of psychiatric and mental health services”, as more and more rights were attributed to him (Alary, 2016); but on the other, the ideal of health democracy - which was being built up simultaneously in the field of political democracy and social democracy (Alary, 2016) - was given short shrift, notably with respect to persons having mental health disorders (Brière, 2016).

Indeed, certain authors address the fact that the stigmatisation of which individuals directly affected by psychiatric disorders fall victim leads to discriminations, including with regard to citizenship (Loubières and al., 2018). The way society looks at mental disorders, and at the persons affected by them, as well as how other citizens treat these individuals, participate in the construction of a “second-class” citizenship for users of psychiatric and mental health services (Loubières and al., 2018).

From this perspective, the participation of persons with a lived experience of mental health disorders can contribute to achieving genuine health democracy (Chambon, 2015). The fact that an individual affected by psychological disorders is regarded as a citizen per se and that his words are heard and listened to fits perfectly within the ideal of health democracy.



Moreover, certain authors believe that this battle for the full citizenship of users of mental health and psychiatric services – which is supported by their speaking out – not only represents a fight for respect of the rights of persons with psychological disorders, but is also a struggle for respect of the dignity of these persons (Deutsch and Dutoit, 2015). Other authors go beyond merely encouraging users of psychiatric and mental health services to speak out in a perspective of full citizenship and transformation of the health system. They promote the expression of these users in a combined perspective of full citizenship, transformation of the health system as well as therapeutic transformation. It then becomes an issue of civic recovery (Pelletier et al., 2015 in Lierville et al., 2015). Participation, by contributing to the fight for full citizenship of individuals affected by psychological disorders, also facilitates the rehabilitation process of the user who speaks out.

### **Getting persons directly affected by psychological disorders to participate in order to improve their state of health and quality of life**

This literature review emphasises the positive impact that participation can have on health – both physical and mental – as well as on the quality of life – notably social – of the person who shares a lived experience of mental health disorders.

On this subject, the literature on the participation of persons directly affected by psychological disorders often uses the English term *empowerment* (Laval, 2015; Deutsch and Dutoit, 2015; Arveiller and Tizon, 2016; Alary, 2016; Letailleur, 2016; Gagné, 2016; Launay & Maugiron, 2017; Loubières et al., 2018; Trémine, 2018; Desmons, 2018; Haliday, 2018; Demailly, 2020; Troisoeufs, 2020; Loubières and al., 2020; McCluskey and al., 2020). A number of French translations have been proposed, notably in France and Canada: “*empouvoirement, empuissancement, capacité de dire et d’agir, appropriation du pouvoir d’agir, pouvoir sur sa propre existence, autonomisation, émancipation, etc.*” (Laval, 2015; Haliday, 2018; Desmons, 2018). Today, experts have come to agree that the English term *empowerment* has something untranslatable in French (Haliday, 2018; Desmons, 2018); nevertheless, there is a lack of consensus about exactly how *empowerment* relates to the participation of persons directly affected by psychiatric issues. For example, some authors emphasise the notion of *empowerment* as a positive and necessary element of the rehabilitation process, while others see it as part of a deleterious imposed imperative of autonomy (Alary, 2016; Trémine, 2018).

Likewise, when users speak out and participate in actions that concern them, they at the same time contribute to the struggle for their own integration and recovery of their full citizenship, thus



supporting their rehabilitation process (Pelletier and al., in Lierville and al., 2015; Haliday, 2018). In this sense, the participation of users is essential for their well-being (Chambon, 2015). Moreover, several teams of researchers and clinicians present the positive feedback shared by users of psychiatric and mental health services when they express themselves about their participation (Rhenter & Carbonel, 2015). Some users attest to the pride and satisfaction they derive from it (Lierville et al., 2015), others associate with it the fact of having social usefulness and contributing to social solidarity (Rhenter & Carbonel, 2015). One female user of psychiatric and mental health services makes the link between the participation and taking control of her own health (Gagné, 2016).

The literature thus establishes a connection between the participation of an individual with his experiential knowledge and a possible benefit for his health - notably mental. However, the potential harm for his health is also touched on (Chambon, 2015). Indeed, if engaged for purposes of public display or without knowing the points of vigilance that govern this participation, it can prove not only ineffective but even pernicious for those involved. This is one reason why it is important to formalise the participation of users of mental health services, and all the more so in international projects, which often find themselves at the intersection of scientific and cultural issues.

### **Getting persons with experiential knowledge of psychological disorders to participate in order to improve (public) health interventions**

With regard to the participation of users of mental health and psychiatric services, virtually all works refer to the acquisition of an experiential knowledge inherent to the experience of a mental disorder (Jouet, 2000 in Lierville and al., 2015; Letaille, 2015; Launay and Maugiron, 2017; Desmons, 2018; Loubières and al., 2018; Cloutier and Maugiron, 2016; Lamadon, 2019; Schweitzer, 2020; Demailly, 2020; Troisoeufs, 2020; Loubières and al., 2020; Niard and al., 2020). This knowledge is closely linked to the facts, firstly, of having been ill, secondly, of having been a user of services and, finally, of having recovered (Demailly, 2020). These life experiences linked to mental disorder give the affected individual a certain amount of knowledge and abilities (Cloutier and Maugiron, 2016). Here one mentions e.g. the experience of being diagnosed, knowledge of the feeling of being overwhelmed by intense emotional suffering or symptoms that are “stronger than oneself”, knowledge of stigmatisation, or even self-stigmatisation, understanding of the life problems resulting from the mental problem in connection notably with precarity, the experience of being hospitalised, possibly without consent, the experience of being medicated, understanding of the effects of drugs (including secondary ones), understanding of relations with professionals, the experience of having come



through the entire process, understanding of the obstacles, of the re-adaptation approach and the rehabilitation process, as well as self-disclosure, empathy, tolerance, flexibility (Cloutier and Maugiron, 2016; Lamadon, 2020; Demailly, 2020). These abilities and knowledge transform themselves or are converted – in the event that the individual participates in training – into competencies, in part by raising the awareness of the individual concerned (Demailly, 2020).

Such experiential knowledge that is built up in the experiences of life with a mental disorder - despite being neither scholarly, academic, scientific or learned - appears to be valuable, since it is a “know-how” that can make a useful contribution (Demailly, 2020). In practice, from the person who joins a health care team (Cloutier and Maugiron, 2016; Launay and Maugiron, 2017) to the individual who becomes part of a research team (Godrie, 2015; Mccluskey and al., 2020), without ignoring those who participate in the organisation and planning of health services (Laurent, 2015) or in the training of psychiatric and mental health professionals (Lechopier, 2015), the added-value of the participation of a user of psychiatric and mental health services has fundamentally to do with the sharing of this experiential knowledge, since that permits its expression. This knowledge contrasts with or complements the more academic forms of knowledge and the experiential knowledge of the professionals and researchers (Chambon, 2015; Loubières and al., 2018).

Thus it is the fact that the user of psychiatric and mental health services has lived with a mental disorder, and thereby acquired an experiential knowledge, that legitimates his speaking on questions relating to mental health and to persons living with psychiatric issues. Moreover, users of psychiatric and mental health services - who in France are called “peer helpers” - are called “experiential experts” in Belgium (Schweizer, 2020) and “experts through experience” in England (Langlois and al., 2017).

Besides this experiential knowledge constructed through the experiences of life with a mental disorder, the users of psychiatric and mental health services also have - like any other citizen - other types of knowledge linked to their earlier domestic, university, professional or associative lives (Lamadon, 2019; Demailly, 2020). Not to mention that the users who regularly participate in a given framework can also have other knowledge connected with their participation per se (Demailly, 2020). While this is also - in cognitive terms - experiential knowledge, to avoid confusion with the knowledge linked to the experience with mental disorders, knowledge linked to the experience of participation itself is called “action knowledge” (Demailly, 2020). While these types of knowledge deriving from earlier experiences and this action knowledge are not those which in the first place lend legitimacy to



the user of psychiatric and mental health services speaking out, they will benefit from being mobilised and make a contribution within the framework of his participation.

## **Quality criteria**

### **Monitoring certain elements in the selection of the user of psychiatric and mental health services willing to participate**

Firstly, several authors find that the participation of persons affected by psychological disorders takes the form, in part, of members of associations of users of psychiatric and mental health services speaking out. Although one of the authors affirms that these associations are now run by users themselves (Letailleur, 2016), others regret that, traditionally, they bring together more people who are close to individuals with an experience of psychiatric and mental health services than the latter individuals themselves (Brière, 2016; Alary, 2016). Indeed, these groups are generally composed of parents, brothers, sisters, children, spouses, friends and caregivers. In effect, privileging the representation of users of psychiatric and mental health services by their family and friends serves to maintain an infantile subordination of these individuals to their families (Alary, 2016). In addition, encouraging the representation of these users by representatives involved in an association tends to institutionalise the speech of the persons affected by mental health disorders (Alary, 2016). Thus, in order to give full meaning to the participation of persons affected by a mental disorder, it would be advisable to give priority to the participation of the individuals directly affected by these disorders themselves (Alary, 2016).

Secondly, several authors describe the negative impact that participation can also have on the health – physical and mental – as well as on the quality of life – notably social – of the person sharing a lived experience of mental health disorders.

The authors primarily highlight the stress that such participation can generate for this individual (Lierville and al., 2015; Godrie, 2015). For example, one of the articles tells the story of a person having experience of life with a mental illness and who intervenes as a peer-helper (Lierville and al., 2015). He notes that every occupation generates stress, and that this one – his participation as a peer-helper – is no different; and he points out that it is obviously more difficult to work on the basis of his experience. Thus such participation, as a potential source of stress, risks putting the individual's physical and mental health - as well as his socialisation - to the test.



The authors also evoke the array of negative emotions that participation is capable of stirring up in a person carrying experiential baggage of psychological disorders, and the emotional fatigue it can produce (Lierville and al., 2015; Godrie, 2015). Whatever framework he speaks in, the participant is, one way or another, led to rethink his experience in connection with the mental disorder. For example, one of the articles recounts the case of an individual with experiential baggage linked to mental disorders who takes part in a research project (Godrie, 2015). Within this framework, he is integrated into a team of researchers as peer research agent and assigned to analyse the stories of individuals having a similar experience to his own. One of his colleagues says that *reading a summary or listening to a recording would make him relive old memories, so that it was necessary for him to go out and take a walk or smoke a cigarette; it got so he couldn't sleep at night, it all reminded him of what he'd experienced and he was plunged into what had caused his suffering, or he was forced to face hard truths about his own existence*. Thus it appears that participation, because it can emotionally immerse the individual in memories linked to his own experience of mental health disorders and be a source of emotional fatigue, threatens to be physically and mentally exhausting and to have negative consequences on his socialisation.

In addition, the authors address the feeling of sham and betrayal that participation is capable of generating in a person with lived experience of mental disorders (Godrie, 2015). In line with the theory of double consciousness (Smith, 1990 in Godrie, 2015), individuals affected by mental disorders who express themselves regularly in one of the participation frameworks have the ability to see things from the point of view of the oppressed group - persons suffering from psychological disorders - and from the point of view of the dominant group - persons who are not suffering from them. From the perspective of integrated outsiders (Collins, 2004 in Godrie, 2015), individuals affected by psychological disorders are simultaneously *outside* the world of health care or intervention, because they belong to the group of mental and psychiatric patients who were not traditionally associated with it, and *inside* that world, because they nevertheless do have access to it and contribute the experiential knowledge they have acquired. Although it is precisely through this understanding of the two worlds - sometimes referred to by the term "bilingualism" (Lamadon, 2019; Schweitzer, 2020) - that the participation of users of mental health and psychiatric services is relevant in term of improving public health interventions, this can also generate negative externalities. Indeed, this ambivalence can not only engender a feeling of being a sham vis-à-vis the persons amongst whom the individual speaks out, as well as a feeling of betrayal vis-à-vis others affected by psychological disorders; but it can also cause a weakening of the identity or identity confusion. Moreover, this ambiguity can have the





consequence of changing his status in the eyes of some of his peers - persons affected by psychological disorders - who might make him feel that he no longer belongs to their universe. It thus seems that participation, because it can make the individual lose a part of his identity, risks having negative repercussions on his mental health as well as on his socialisation.

The literature thus establishes a link between the participation of an individual with an experiential knowledge of psychiatric issues and the risk that he decompensates and relapses. Although participating can, in some cases, be salutogenic for the user involved – notably in terms of his mental health – in other cases it can be harmful. In order to minimise the risks of decompensation and relapse, it would therefore probably be wise to favour participation by those who are well along in their rehabilitation process. Moreover, several authors offer possible definitions of rehabilitation (Davidson and al., 2005; Loubières and al., 2020; Beetlestone, 2010 in Loubières et al., 2020; Niard and al. 2020; Whitley and Drake, 2010 in Niard and al., 2020), that goes beyond stabilisation and distinguishes itself from cure - a term that relates more to the development of the disease than to the development of the person. In brief, rehabilitation can be defined as a non-linear process of transformation or changes, simultaneously internal and external, which fundamentally consists of passing from “doing poorly” to “being better” and which is manifested by the “individual’s recovery of his ability to act and his capacity to enjoy life”. Rehabilitation is simultaneously clinical, functional, social, physical and existential.

Likewise, although the literature shows that it is desirable to leave the talking to individuals having direct experience of life with a mental disorder and who are at an advanced stage in their rehabilitation process or even fully recovered, it also indicates that it is preferable to give the word to users of psychiatric and mental health services who are not already too much in demand, notably in order to guarantee representativeness (Lierville, 2015).

Moreover, several authors address the fact that users of mental health services undergo self-development through the participation itself. The main types of training courses accessible to French users of mental health and psychiatric services are recalled (Gross, 2020; Troisoeufs, 2020; Niard and al., 2020). For example, the “Peer Health Support Workers” programme sponsored by the WHO-CC and integrated into the Health and Social Sciences course at the University of Paris 13 is presented (Gross, 2020; Troisoeufs, 2020; Niard and al., 2020). For some, it can prove relevant, depending on the context, to favour the participation of these trained (ex-)users of mental health and psychiatric services. For other authors, in certain participation frameworks, it can prove just as relevant *not* to





recruit only trained users (or even not to allow trained users to participate at all), precisely in order to guarantee representativeness. In the final analysis, the important thing is to get “*good representatives of users of mental health services*” in terms of *a priori* objectivised characteristics (Chambon, 2015).

### **Assuming one’s organisational responsibility notably vis-à-vis the user of psychiatric and mental health services who participates**

Certain authors evoke the organisational responsibility that is incumbent on any institution that gets persons who are living or have lived with mental health disorders to participate (Lierville et al, 2018). They explain that the structure can be guilty of shortcomings in the exercise of this responsibility and so it is up to the institution to organise, through various measures and according to different terms, the participation within it of persons living or having lived with psychological disorders. From the same perspective, some authors identify elements that were able (or which threaten) to compromise the participation of users of mental health services (Godrie, 2015; Letailleur, 2016), while other authors formulate recommendations to avoid such stumbling blocks (Haliday, 2018).

It therefore appears not only necessary to take a certain number of measures vis-à-vis the user who is willing to participate in whatever framework, but also indispensable to set rules with regard to the individuals who will interact with the participating user, notably when this participation is anticipated to be long term.

Firstly, it would be appropriate for every user of mental health or psychiatric services who participates to be taken on according to a formalised recruitment process, and that the reasons for his selection be explained to him (Godrie, 2015; Letailleur, 2016). A formal recruitment process makes it possible not only to guarantee the adequacy between the needs inherent to the participation framework and the user’s different types of knowledge, but also to reinforce the legitimacy of the user to participate - both in relation to the individuals that he will be led to interact with and vis-à-vis himself.

Then, it would be fair for a user of mental health and psychiatric services who participates to be compensated - indemnified in the case of a one-off participation (Godrie, 2015; Letailleur, 2016). This demand is made notably by users of mental health services (Gagné, 2016). A fair compensation makes



it possible simultaneously to give recognition to the expertise contributed by the individual (Letailleur, 2016) and to help mitigate the situation of precarity.

Finally, it would be relevant for the participating user to be adequately prepared and accompanied in order to successfully implement the various activities deriving from his involvement (Letailleur, 2016; Lierville and al., 2018). For example, in certain participation frameworks, courses on speaking in public are offered for users who are interested (Guézennec and Roelandt, 2015). Also, it would be relevant that the professionals who work with an (ex-)user of mental health services are also themselves prepared for the participation of the user and accompanied throughout this participation. Indeed, several authors explicitly describe how a user of mental health and psychiatric services can experience participation in research work done by professionals from psychiatric departments in hospitals (Mccluskey and al., 2020). One trend (amongst others) is identified and presented: destabilisation. Professionals can be destabilised by the participation of a user for several reasons. For example, because they do not know the user in question and his experience, or because they consider that the knowledge acquired from the lived experience with a mental illness is not of equal value to other forms of knowledge. It would therefore appear essential to prepare the professionals for the participation of a user and also to accompany them throughout this participation. It is important to enable professionals and users to meet and get to know one another (Langlois, 2017) - and for the professionals to listen to and hear the words of the users, despite the fact that they may be demanding, defensive or oppositional (Loubières and al., 2018). Indeed, the freedom of users of mental health and psychiatric services to get their voices and their experiential knowledge heard depends on the position that other actors adopt vis-à-vis them and the relations they establish with them (Clément, 2011 in Letailleur, 2016).

Besides the introduction of these measures and modalities which fall under the organisational responsibility, it appears essential that all institutions involving persons who are living or have lived with mental health disorders ask themselves about the meaning that they give to this participation and respond to this question collectively (Loubières and al., 2018): why do we adopt this approach, what do we imagine is to be gained from it, what are we expecting from it, how far are we willing to go with it?



## DISCUSSION AND CONCLUSIONS

With regard to the European and international projects for the promotion of mental health - and notably the training programme VETmh TuTo+ (2018-2021) - this summary of the literature makes it possible to highlight relevance criteria that legitimate the involvement of users of mental health services, outside of any legal obligation. Indeed, the active participation in these projects of persons directly affected by psychological disorders is said to be relevant in several regards. Firstly, because it contributes to the evolution towards a European and international society that is more inclusive and democratic. Secondly, since it could improve the state of health and the quality of life of European and world citizens who participate in these projects. Finally, because it would help to improve the (public) health interventions implemented in Europe and the world, with the ultimate goal of improving the state of health and quality of life of individuals affected by psychological disorders. Besides these relevance criteria, this summary of the literature at the same time makes it possible to identify quality criteria that should guide project leaders in permitting the involvement of users within the framework of European and international mental health projects. Thus, within the framework of formalising the participation of directly affected persons in this type of project, it appears important to carefully monitor a certain number of criteria when selecting users, but also to assume the organisational responsibility which is incumbent upon institutions that undertake in work that they wish to be conducted in partnership with persons affected by psychological disorders. In this sense, a collective reflection on the meaning of the participation of users of health services in the project in question, formalisation of a process for recruiting users willing to participate, the remuneration - or indemnification in the case of a one-off participation - of participating users and the preparation and accompaniment of these users and of individuals with whom they will interact are all elements that will facilitate a successful participation.

On the basis of the lessons drawn from this review of the literature - and notably the relevance and quality criteria identified - and in light of the international and European recommendations (European Commission, 2005; World Health Organization, 2013), it firstly appears highly important, and even urgent, to formalise the participation of users of mental health services in the mid-term evaluation of the VETmh TuTo+ project (2018-2021). From this perspective, it is important to think about the modalities of participation in the evaluation, developed together with users. In a second step, it seems opportune - for example, for the continuation of the VETmh TuTo+ programme (2018-2021) or within the framework of elaborating a third strand of the *"TuTo project"* - to reflect on an even more active participation of (ex-)users of mental health services. Users with a lived experience of mental health



services and psychological disorders might take part in the programme as trainers of the tutors - alongside teachers having experience in psychiatry and mental health. They might also take part in this project as co-tutor - in support of the young professional trainee in psychiatry and mental health, and complementary to the experienced professional tutor in those areas.

In addition to following the European and international recommendations on the involvement of users of mental health services in projects concerning them, this would make it possible to verify and support the quality criteria that this preliminary work has identified. This could serve as a basis for developing a practical tool to guide the formalisation of the participation of users within the framework of European and international actions or projects to promote mental health. The project leaders could therefore refer to it: respect of the recommendations in the implementation of their projects would make it possible to ensure an efficient participation of users in the field of mental health intervention.

This literature review presents certain limits that should be explicitly mentioned. Firstly, a very wide range of terms are used to speak of the participation of users of mental health services. Consequently, and although the work on constructing search equations from the dictionaries of synonyms and thesauruses strove to take this reality into account, this paper cannot claim to be exhaustive. Secondly, only documents in French were included, so the international scope of this review is relatively limited.



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# VETmh TuTo+

## Vocational education process in European tutoring for immersion trainees in the mental health sector

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