



This document has been written as a companion piece to the National Involvement Partnership 4Pi Standards for Involvement. It aims to introduce readers to the language of mental wellbeing by providing an overview of terms that have been, and continue to be used in this area.

The Language of Mental Wellbeing

**‘Nothing about us
without us’**

The Language of Mental Wellbeing

1. What is the purpose of this document?

This document has been written as a companion piece to the National Involvement Partnership (NIP) 4Pi Standards for Involvement. It aims to:

- 1) introduce readers to the language of mental wellbeing by providing an overview of terms that have been, and continue to be used in this area; provide a resource, alongside the Service User Involvement in Policy and Carer Involvement documents, that enables readers to use it for reference purposes;
- 3) report on the findings of a recent survey of 103 NSUN members with regard to their preferred terms;
- 4) provide a basis for informing NSUN's future work on this topic.

Language defines and shapes our understanding and has been used to wield power. As such, it has been used to pathologise, dominate, and discriminate against people who have lived experience of mental distress. Language is also connected to understandings of personal and collective identity. The words we use to describe our own emotional wellbeing are inextricably linked to how we understand ourselves and make sense of our experiences. In addition, words have different meanings for different groups and communities, and the ways in which we talk about mental wellbeing is affected by these diverse cultural contexts. This is an emotive topic and there are many differences of opinion. It is not possible to reach a consensus on this issue. However, NSUN is working towards having a greater contextual understanding of these terms and without being prescriptive we seek to find alternatives to the medical model of mental illness.

2. The Language of Mental 'Health' and 'Illness'

The language of mental wellbeing is complex, diverse, and sometimes confusing. Language is not static or fixed. It arises from, and changes in response to, different social and historic contexts often reflecting or challenging political policies or movements. The words we use to describe mental wellbeing have

changed dramatically over time and are continuing to develop. The following section aims to briefly assess the current language of mental wellbeing and provide a context for many of the terms used by NSUN.

Mental health is sometimes referred to as '**wellbeing**' or '**emotional health**'. Wellbeing has been defined in many ways but tends to include areas such as life satisfaction, self-esteem, having a purpose, a sense of belonging and support. It is a combination of physical, mental, emotional, spiritual and social health.¹ For example, Mind defines wellbeing as a state where:

You care about yourself and you care for yourself. You love yourself, not hate yourself. You look after your physical health – eat well, sleep well, exercise and enjoy yourself. You see yourself as a valuable person in your own right. You don't have to earn the right to exist. You exist, so you have the right to exist. You judge yourself on reasonable standards. You don't set yourself impossible goals, such as 'I have to be perfect in everything I do', and then punish yourself when you don't reach those goals.²

A 'mental health problem' can range from the worry and anxiety experienced by most people, to more serious long term conditions. A mental health problem is described in the No Health Without Mental Health strategy (Dept of Health, 2011) as:

an umbrella term to denote the full range of diagnosable mental illnesses and disorders, including personality disorder. Mental health problems may be more or less common and acute or longer lasting, and may vary in severity. They manifest themselves in different ages and may present as behavioural problems (for example in children and young people.)

The reference to 'diagnosable mental illnesses and disorders' indicates that the Department of Health positions itself within the dominant discourse of the 'medical model of mental illness.' Beresford (2009) states that this approach is framed within terms of:

1. <http://www.nhsinform.co.uk/MentalHealth>

2. http://www.mind.org.uk/news/4504_what_is_mental_health_and_mental_wellbeing

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- an emphasis on the inclusion of individuals in particular, medicalised diagnostic categories
- ideas of 'treatment', care and 'cure' for such illness
- medicalised responses to 'mental illness' which are still centred on medicalised roles, hospital provision, and admission for long-term problems
- 'treatment' consistent with a medical model that is predominantly based on drugs and mechanical treatments;
- mental health legislation that is increasingly focused on the extension of restrictions to people's rights.

Although the No Health Without Mental Health strategy appropriates the language of the medical model, the glossary acknowledges that 'some people object to the use of terms such as 'mental health problem' on the grounds that they medicalise ways of thinking and feeling and do not acknowledge the many factors that prevent people from reaching their potential' (p.88.) Although these concerns are recognised in the document, the strategy states that 'there is no universally acceptable terminology that we can use as an alternative' (p.88.) The term 'mental health problem' continues to be used as a generic term by mental health charities such as Mind, Rethink, Together and the Mental Health Foundation, although they also use terms such as 'mental distress,' 'mental health issue' and 'mental health condition.'

The term '**mental illness**' has been used by the Department of Health to refer to 'more serious mental health problems that often require treatment by specialist services. Such illnesses include depression and anxiety (which may also be referred to as common mental health problems) as well as schizophrenia and bipolar disorder (also sometimes referred to as severe mental illness) (p.88) However, the Mental Health Foundation (amongst others) has highlighted that 'some diagnoses are controversial and there is much concern in the mental health field that people are too often treated according to or described by their label.' This can have a profound effect on their quality of life.³

NSUN's position is underpinned by the social model of disability (Beresford, 2009.) The model draws a

distinction between impairment and the disabling social response to people seen as impaired. As such, disabled people are disabled because of oppressive and discriminatory responses within society. Although there is ongoing debate about this model, it moves away from understandings of disability as the result of individual deficiencies that need 'curing' and instead focuses on the social barriers and discrimination that people face. Similarly, mental distress is still predominantly understood in terms of 'illness' or 'disorder.' The 'medical model' is the dominant approach that continues to define and shape language and understanding in this area. This model routinely pathologises people and leads to labeling, stigma and discrimination.

The French philosopher Michel Foucault introduced the idea that there is a social context to the labeling and identification of mental illness. He argues in his classic text *Madness and Civilisation* (1967) that the scientific disciplines of psychiatry and psychology have attempted to measure, sort and categorise individuals according to a spurious, socially constructed 'norm.' Those who fall outside of the category of the norm have traditionally been classed as 'deviant' or 'risky' individuals who need to be confined and 'cured.' This process of labeling and categorisation continues to be pervasive and can have a stigmatising effect.

'**Stigma**' has been defined as having three distinct elements:

The problem of knowledge – ignorance

The problem of attitudes – prejudice

The problem of behaviour – discrimination
(Thornicroft, 2006).

Stigma can operate at an institutional level or within social groups, where people endorse and perpetuate stereotypes about mental illness. It can also be experienced at a personal level, where individuals internalise stereotypes and lose self-confidence, or avoid seeking help in order to avoid a negative label. The Young Minds (2010) report states that:

3. <http://www.mentalhealth.org.uk/help-information/an-introduction-to-mental-health/what-are-mental-health-problems/>

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the stigma connected to mental health is pervasive, but how people experience it varies from person to person. This is connected to factors such as people's cultural beliefs, their knowledge and beliefs concerning mental health, and whether they have had contact with others with mental health problems (p.14.)

For many people, their knowledge of mental ill health comes from the mass media, (Wahl, 1995. Cited in Young Minds, 2010.) Some newspapers, for example The Guardian, aim to be sensitive in their coverage and portrayal of mental wellbeing. Their style guide states that writers should avoid 'clearly offensive and unacceptable expressions... loony, maniac, nutter, psycho and schizo... because they stereotype and stigmatise.' However, recent studies have found that negative views and pejorative terms such as 'nutter' and 'loony' continue to be used in tabloid newspapers and UK television programmes (Social Exclusion Unit, 2004; Philo et al. 2010.)

As a move towards challenging stigma and discriminatory language, Mad Pride activists have been campaigning since the early 1990s to reclaim terms such as 'mad' in much the same way that the word 'queer' has been re-appropriated by some gay rights campaigners. This creates a further degree of complexity with regard to the language of mental health and illness, as a term such as 'mad' is not inherently 'unacceptable.' It may be used as a reclaimed identity or a derogatory insult. Understanding the context of production and use of these terms is therefore crucial and this is discussed in more detail in section 5.

With regard to the term '**recovery**,' there is no single definition of the concept. 'Clinical recovery' focuses on the reduction or elimination of symptoms. By contrast, the 'recovery approach' is now more frequently used by mental health professionals.⁴ The recovery approach originated within the US Civil Rights Movement (Chamberlin, 1978; Davidson et al. 2010.) It focuses on maintaining quality of life with or without ongoing symptoms, and is defined by the person experiencing mental distress.

4. <http://www.mentalhealth.org.uk/help-information/an-introduction-to-mental-health/what-are-mental-health-problems/>

Rather than just treating or managing symptoms, this model emphasises building the resilience of people through hope, acceptance, control, basic needs and meaningful activity.⁵ However, Gould (2012) has raised the issue that 'recovery' can mean different things to mental health professionals and service users. Some people, particularly those from marginalised communities, have raised the issue that their personal understanding of recovery does not fit with the recovery model of mental health services. Some mental health survivors have also drawn attention to the political colonisation of the recovery model by mental health services, commissioners and policy-makers. For example, the survivor-led group 'Recovery n the Bin' state:

"Many of us will never be able to 'recover' living under these intolerable social and economic conditions, due to the effects of social and economic circumstances such as poor housing, poverty, stigma, racism, sexism, unreasonable work expectations, and countless other barriers. We believe 'UnRecovered' is a valid and legitimate self-definition, and we emphasise its political and social contrast to "Recovered."⁶

3. The people who use mental health services

The terms used to refer to people who use mental health services have changed significantly over the past 30 years. Traditionally, the NHS has used the term '**patient**' or '**client**.' This has received criticism from those who argue that it incorrectly positions people who use mental health services (particularly those with long term conditions) as passive recipients of care (McLaughlin, 2009; Coldham, 2012).

The political context of the 1980s and 1990s with its emphasis on the growth of market economy saw a move towards the privatisation of mental health services (Rush, 2004.) Within this discourse, health and social care was viewed as a product. It led to the view that patients or clients should be viewed as

5. <http://rethink.org/living-with-mental-illness/recovery/what-is-recovery>.

6. <http://freepsychotherapynetwork.com/2015/03/11/recovery-in-the-bin/>

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‘customers’ or ‘consumers’ (Rush, 2004; McLaughlin, 2009.) Mental health services became commodities to be bought and sold and the ‘customer’ or user of services was positioned as someone who was able to choose between the different public, private and voluntary sector services on offer.

The terms ‘customer’ and ‘consumer’ have been widely critiqued for their emphasis on the notion of individual ‘choice.’ Choice is empowering if it genuinely enables a person to make decisions about their health and life. However, researchers such as Rush (2004) and Stickley (2006) have argued that within health and social care, ‘choice’ has been constructed within the context of neo-liberalism. Neo-liberal political regimes encourage individuals and communities to regulate themselves. Discourses of governance emerge which place great emphasis on personal choice, autonomy and responsibility. However, these notions of ‘choice’ are spurious and illusory when framed within the wider context of mental health legislation and Community Treatment Orders, the inherent power imbalance between practitioner and ‘service user’ (Cowden and Singh (2007.) and pathologising deficit discourses of ‘illness’, ‘vulnerability’ and ‘risk’ (Rose, 1998.)

In the UK, the consumerist model has developed into a ‘stakeholder model’ that supports the view that the opinions of key parties should be taken into consideration when public services are designed and delivered (Rush, 2004.) However, this model continues to be underpinned by a belief in the commodification of welfare and constructions of individual ‘choice’, meaning that critiques relating to discourses of power and control are still necessary within this framework.

Although the term ‘consumer’ is still widely used in the US and Australasia, the most recent term to emerge in Western Europe is ‘**service user**’ (Crepaz-Keay, 2014.) Despite the term’s common usage, it has many shortcomings. For example, Stickley (2006) has discussed the ‘depersonalising’ nature of the term and points out that ‘service users’ are not a homogenous group of people. Similarly, McLaughlin (2009) has argued that the term ‘service user’ reduces an individual to just one aspect of their identity: their use of mental health services. He

asserts that the term ‘service user’ encompasses a wide range of diverse individuals who have different social identities, values, attitudes and beliefs. It has also been suggested that the term sets up a false division between the categories of ‘service provider/ health care professional’ and ‘service user’ and fails to acknowledge the fluidity between these categories (Cowden and Singh, 2007.) It also neglects those who are unable to access services or who reject mainstream clinical services.

Despite reservations, the term is in common usage and is currently used throughout NSUN documents. However, it is used with an awareness of its shortcomings and an understanding that people will identify with a variety of other terms. For example, some people who have experienced mental distress define themselves as ‘survivors’ due to the traumatic nature of the experiences they have survived (Coldham, 2012.) Many also define themselves as ‘survivors’, not only due to the effects of mental health conditions, but those of the psychiatric system itself (Stickley, 2006; Coldham, 2012). People may also self define as someone with ‘lived experience’ or they may refer to themselves as an ‘ex-user’ of mental health services. Organisations also vary in the terms they use. For example, The Royal College of Psychiatrists has recently made the decision to use the word ‘patient’ rather than ‘service user’ in its official documentation as this was felt to be non-discriminatory and less stigmatising. Look Ahead, the charitable housing association that supports people with mental health needs in London and the South East, refers to their ‘customers,’ which signals a return to a more consumerist ethos.

Another key term is that of ‘carer,’ which is widely used to refer to family members or friends who provide frequent support to someone experiencing mental distress. However, this term is also fiercely contested. Sayce, Kalathil and Watson (2012) use the more inclusive term ‘families, friends and carers’ for three related reasons:

- Many people experiencing mental distress have objected to the term ‘carer.’ This is because key relationships, such as spouse, parent, child or friend, are ignored and the reciprocity and

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complexity of these relationships are reduced to a 'one way street of care.'

- Some 'carers' see their role as part of their family responsibility and do not readily identify with the label 'carer'.
- There are diverse socio-cultural views on caring, and support within families and friendship circles which differ between communities. For example, many community languages do not have a term for 'carer.' The term 'family' also varies widely between communities and is not easily translatable.

Furthermore, the categories of 'service user' and 'carer' are not necessarily distinct as carers can also be service users themselves (Coldham, 2012.)

Having briefly outlined some of the key terms used to refer to people who use mental health services, the following section turns to address the language of involvement.

4. The Language of Involvement

The term 'involvement' is also interpreted in a variety of ways. Involvement can include a wide range of activities and is often conceived in terms of being involved in services and service improvement. However, it is crucially also about being involved in one's own care (Coldham, 2012) in peer groups, and/or in political campaigning (Kalathil, 2013a.) Although there is no standard definition, Crepez-Keay (2014) states that:

"the key principle of involvement is that an individual, who is experiencing mental distress to the extent where it is having a significant impact on their life, has some say in how they are treated, and that this is heard and responded to (p.16)"

User involvement initiatives frequently take place at the level of 'consultation', whereby policy makers and practitioners consult service users and carers, but then make their own recommendations (which may support or disregard the opinions of service users and carers). The term 'participation' has been used in order to emphasise the active nature of involvement (Coldham, 2012.) However, in recent years, the term

'co-production' has begun to be used more frequently in health and social care settings. Within this model service users and carers work in equal partnership with policy makers, commissioners and practitioners. It has been defined by the Department of Health (2010) in the following manner:

"Co-production is when you as an individual influence the support and services you receive, or when groups of people get together to influence the way that services are designed, commissioned and delivered. (cited in Coldham, 2012: 10.)"

In their briefing paper on co-production for the Social Care Institute for Excellence (SCIE) Needham and Carr (2009) define 'co-production' as:

"active input by the people who use services, as well as – or instead of – those who have traditionally provided them. So it contrasts with approaches that treat people as passive recipient of services designed by someone else."

Some service users remain sceptical and believe there needs to be a significant culture and power shift before genuine co-production can take place (Perry et al. 2013.) Similarly, Needham and Carr (2009) note that 'co-production means involving citizens in collaborative relationships with more empowered frontline staff who are able and confident to share power and accept user expertise" (p.2) They also argue that "if co-production is to improve outcomes in social care, it will be at the 'transformative' level, avoiding versions of co-production that simply cut costs, demand compliance or reproduce existing power relations" (2009:17.)

With regard to the involvement of service users and survivors from black and minority ethnic communities, the Dancing to Our Own Tunes report (Kalathil, 2009) also states that:

"The message is clear – consultation is not involvement. If there has to be meaningful involvement of service users/survivors from black and minority ethnic communities in mainstream initiatives, there has to be structural changes in hierarchies, ways of working, assumptions, power structures within institutions, resource allocation, the location of decision making and the way people are

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treated within mental health services and outside them (p.29)"

The 'under-representation' of BME groups in involvement initiatives has frequently led to these groups being defined as 'hard to reach.' Although this term continues to be used by a variety of organisations in different contexts, it has generally been understood to mean communities or groups that are 'inaccessible to traditional and conventional methods' (Whitnell, 2004: 8.) However, Kalathil (2013a) has contested the term 'hard to reach' stating that it "assumes homogeneity within disparate groups and places the problem within the group rather than the approaches used to enable engagement' (p. 123.)" She argues that the first step towards challenging the status quo is to understand the reasons for the perceived under-representation of BME mental health service users in involvement initiatives, and to acknowledge and support the work that is already happening within local communities (for further information, see Kalathil, 2009 and 2013b.)

5. NSUN's poll of preferred terms

Due to the complex and emotive nature of this topic, NSUN was keen to find out about the language that members prefer to use in relation to their own identities and experience of mental distress. A short online questionnaire was designed via 'Survey Monkey' (a software tool to create and analyse surveys and questionnaires.) It aimed to discover which terms people identified with in the context of their own experiences, or of using mental health services. Respondents were asked to rank a list of terms (eg. 'service user', 'patient', 'person with a mental health problem') in order of preference from 1 to 13, with 1 being the most preferred term and 13 being the least preferred. Respondents were then asked to explain why they identified with their chosen terms. They were also invited to add their own preferred terms if they were not on the list and explain the reasons for these choices.

The survey was publicised in NSUN bulletins and through local networks during December 2013 and January 2014. 103 NSUN members completed

the survey; 83 completed it online and 20 people who did not have computer access completed the survey on paper.⁷ These results were subsequently entered into the Survey Monkey for the purposes of quantitative analysis. With regard to the qualitative data, recurring words and phrases were highlighted and the emerging themes have been reflected in the sections below. The findings of the survey will be used to inform NSUN's position with regard to language (see section 6).

5.1 Making Sense of the Data

When designing the survey, a 'ranking question' option was selected in the Survey Monkey. As respondents completed the survey, the software tallied the responses for each question. It then automatically calculated the mean average ranking for each term (total score ÷ number of people scoring the term) so that it was possible to determine which answer choice was the highest ranked overall (i.e. the term with the lowest average ranking.) The table below lists the terms in order of preference based on the average ranking (see column three.) A manual tally was also made of the number of occasions a term was marked as a first preference and this is recorded in the fourth column. The additional rows record the results of a manual tally for: a) the number of people who scored the same number for multiple terms; b) the number of people who did not rank all the terms, and c) the number of people who scored all terms as '0.'

7. NSUN would like to thank the People in Mind and Kaleidoscope Plus group in West Bromwich for their input into this survey.

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List of Terms (in order of preference based on average ranking)	Average Ranking	No. of occasions a term was ranked 1st preference
1. Person with direct or lived experience of mental distress	4	19
2. Service user	5	18
3. Person with mental health experience	5	13
4. Expert by experience	5	16
5. Person with a mental health condition	6	8
6. Client	6	18
7. Patient	7	11
8. Person with a mental health problem	7	4
9. Survivor of mental distress	7	2
10. Person with a mental illness	8	4
11. Survivor of the psychiatric system	8	10
12. Consumer	9	0
13. Mad	1	1
No. of people who scored multiple terms equally (eg. '1' or '13' for several terms.)	9	
No. of people who did not rank all the terms	15	
No. of people who scored all terms as '0'	1	

The list initially appears to provide a relatively straightforward list of terms in order of preference. However, several issues emerged with regard to the way people indicated their preferences numerically. 25 respondents interpreted the survey instructions in different ways. Several people selected '1' and '13' for multiple terms. Some grouped terms into three broad categories of preference, scoring terms as '1', '5', or '13' rather than ranking each term from 1 to 13. 15 people selected their preferred term, or several preferred terms, but did not score the others (or ranked them as '0'.) For example, one person ranked terms from 1 – 9, but rather than rating their least preferred terms, they chose to write about why they disliked these terms instead. Some may have

repeated or missed out numbers when ranking by accident. One person rated all of the terms as '0' stating "I do not identify with any of the above terms, they are all either unacceptable or meaningless." Although the numerical task was interpreted in a number of different ways, it has not affected the calculation of the averages. The responses do suggest however, that a number of people struggled to quantify and rank the list of identity labels. This highlights the problematic nature of such a task due to the complex, varied and shifting nature of identities.

There are also some possible inconsistencies between the quantitative and qualitative data. For example, one respondent indicated that their

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preferred term was 'patient', but in the response section stated that they were 'expert by experience'. One person ranked six terms and stated "no one term describes all aspects of living with a mental illness." It is interesting to note that although the term 'mental illness' was used in the qualitative response section, it was not one of the terms that had been given a quantitative ranking. Another respondent stated that "it's discrimination to use service user as a name, these people are human beings and because they use the service they are called this. Just because they have mental health issues they should not be labeled." Given the strength of feeling it is perhaps surprising that this person ranked the term 'service user' as '7' rather than '12' or '13'. It is possible that some of these terms had been ranked, or missed out, in error. However, they could be further indications of the fluidity of identities and the difficulties inherent in attempting to quantify them.

The differences between the average ranking column and the first preference column in the table also draw attention to some of the problems of arranging a list of identity markers into a definite order of preference. For example, the table shows that the term 'client' was ranked as a first preference on 18 occasions, indicating that it was one of the most popular terms. However, its average ranking was '6', raising the possibility that the term was considerably less popular and more divisive than it might first appear. The term 'survivor of mental distress' appeared to be unpopular (and was rated '9' out of the 13 terms in the order of preference), but it was most frequently rated as a second preference (on 23 occasions). These examples help to demonstrate that the quantitative results alone do not necessarily allow for clear or straightforward answers.

With regard to the qualitative responses it is important to move beyond a surface analysis of people's reasons for selecting certain terms in order to identify the values and discourses underpinning these decisions. This has the potential to move the debate away from simplistic (and potentially divisive) discussions of 'which term is better' and towards a more subtle and nuanced analysis that questions the apparently fixed and stable nature of identity.

As such, the following key themes were identified through analysis of the qualitative responses:

- the rigid and restrictive nature of identity markers
- the importance of context and setting
- the need for identity markers that do not perpetuate stigma and discrimination
- being respected and valued as a person
- focus on lived experience
- value of expertise and emphasis on empowerment.

The rigid and restrictive nature of identity markers

One of the main themes to be identified from the qualitative data was the rigid and restrictive nature of identity markers. A number of respondents questioned or rejected particular terms because they did not help to describe their own, or other people's experiences. This was particularly the case with regard to terms that suggested 'use of services' or 'diagnosis of a 'condition':

"I'm not using services, so I'm not a service user. Services, when I did use them, were helpful, so could not have 'survived' them."

"As an ex-patient I find some of these totally unsuitable."

"Patient' or 'mental health condition' are too restrictive – not every single one of us is or has been a patient or has been diagnosed."

These terms were seen as being unhelpful or inappropriate because they were not able to accurately or completely capture the complexity of people's lived experiences. Several respondents rejected all of the terms and drew attention to the impossibility of identifying with a single 'one size fits all' label:

"None are particularly helpful or descriptive; the most useful are possibly the more anodyne."

"None of the terms are really appropriate."

"No one term describes all aspects of living with a mental illness."

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Others selected particular terms because they were seen to be less restrictive and did not impose a single identity:

"Person with mental health experience is least related to the medical model. It is also inclusive of many different experiences and does not impose a singular identity."

"For me service user has strong historical context distinct from just using services. It is something as such that I feel more ownership over than other terms. Many of the others feel like aims to be PC [politically correct] – they do not reflect the underlying issue of identity and are rather imposed, or what people think are more acceptable. I think the use of language is over-hyped and detracts from the real issues at stake of power. Forming a single language of mental health puts us all into one box and defines us as a ubiquitous group."

For the second respondent, fruitless attempts to search for the "right" term are restrictive and detract from 'the real issues at stake'. Homogenising identity categories are framed within a power dynamic, whereby identity categories are created by the powerful and imposed on, or internalised by, the powerless. Thus, the 'underlying issue of identity' is located by this person within the context of a wider emancipatory project to acknowledge a multiplicity of different identities that are created and owned by people with lived experiences.

The importance of context and setting

A number of respondents challenged the fixed nature of identity markers by highlighting the importance of context. This was particularly evident in relation to the term 'mad'. The quantitative tables indicate that 'mad' was the least popular term. However, the qualitative data revealed that some people responded positively to the term, but its usage was dependent on the context and setting:

"I do like 'mad' but it is only appropriate in certain contexts."

"'Mad' is OK if we use it ourselves."

"I use the word mad among friends but would not like it in a derogatory sense."

"Mad is fine in certain contexts, when it is not used as a pejorative term."

"I like 'mad' personally but this is too often used pejoratively."

Once again, this highlights the inadequacy of quantitative data to fully reflect nuance, ambivalence and complexity with regard to issues of identity.

Several respondents raised the issue of having to adopt identity labels in certain settings in order to engage with services:

"I am a person who has experienced both mental health and mental ill health. I'm not happy to be defined by an illness label. However when I am involved with mental health services I feel they are required by me as I am unwell and therefore a client of the service who has experience of their own mental health problems and recovery."

"Of course, it also depends on the context. I find the client or service user terms acceptable when used in connection with my contact with the MH services. I would not like to be labeled as a service-user outside of this context."

Another respondent noted that they identified with the term 'survivor' but this was not how they wished to be identified all the time in every context:

"Whilst the word survivor is how you feel some days you don't want to be reminded of it every time you sign a piece of paper!"

The first respondent explains that although they do not feel comfortable with "an illness label... I feel they are required by me." This requirement to adopt an essentialised identity in order to connect with services again highlights underlying issues of power whereby identity is constructed through 'dominant discourses' (such as the language of medicine or health and social care policy.) These responses also highlight the way in which many respondents constructed their own identities as inherently flexible and shifting, dependent upon emotional experience, setting or 'requirement'.

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The need for identity markers that do not perpetuate stigma and discrimination

Related to the idea of having an identity imposed upon you was the fear of receiving a stigmatising label:

"Labels' are used by the media and more often than not a social stigma is created. Avoiding this is most beneficial to all."

"Any label can be detrimental to me."

"The term mental health has too much stigma attached to it and people fear it as it is not specific."

"I don't like labeling at all. However I realise there needs to be a generic term."

As such, there was a rejection of identity markers and labels that were seen to perpetuate discrimination. For some, the least stigmatising terms were the ones that focused on a variety of lived experiences and challenged the medical model of mental health:

"'Person with mental health experience' is least related to the medical model. It is also inclusive of many different experiences and does not impose a singular identity."

"Prefer service user as it is both short and snappy, and is less open to labeling. Patient really gives a medical model feel I don't like."

"I don't like terms such as patient, consumer or client because they can be used to define people."

"I prefer not to be thought of as mentally ill due to others perceptions."

However, people who made sense of their own experiences within the context of the medical model tended to select terms like 'patient' or 'client' on the basis that it removed and challenged discrimination.

"Everyone is a patient at some stage. It does not label me as different."

"Why do we not use this term [patient] for mental as well as physical illness? If you make a distinction you will increase stigma whether you mean it or not."

"People who use physical health services are referred to as 'patients.' so why not those who use

mental health services? Why differentiate between the two?"

Similarly, the respondents who objected to the term 'service user' tended to do so because it was seen to be creating an unhelpful distinction between the use of physical and mental health services:

"At the moment the term service user is used but I don't like it, it makes me feel different than those who are considered as clients or patients with physical health issues, whether they have an illness, disease, condition or physical ailment eg. broken limb, wounds etc. I would rather be called mad if I have to be distinguished from other patients."

"As NHS refers to people as 'patients' it is going to be difficult to change such an ingrained label. I see no difference why an individual with a mental health condition should be seen as 'different', it is still an illness therefore preferred term 'patient' to show no difference from others using any health related service. I detest the term service user as it only relates to those seen as less worthy of the term patient."

Although people related to terms very differently on the basis of how they made sense of their own experiences and positioned themselves in relation to the medical model of mental illness, respondents were united in their desire to challenge stigma and discrimination and to be treated equally.

Being respected and valued as a person

A further key theme to be identified in the qualitative comments related to the need to move away from restrictive labels or identity markers and towards a recognition and valuing of each individual person:

"My preferred options relate to a 'person' and not a label and therefore sound more personal."

"Sadly the one term that is not there is my name. Coping with my condition is bad enough without being seen as a set of symptoms rather than as a person."

"My preferred term would usually be "person" ie no label attached unless it is VITAL for it to be otherwise

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and then it should be person or people first eg. 'people who use our services'."

A number of the terms listed in the survey began with the words 'person with.' For example:

- person with direct or lived experience of mental distress
- person with mental health experience
- person with a mental health condition
- person with a mental health problem
- person with a mental illness

People responded positively to this emphasis and many comments were made along the following lines:

I rate highest those terms which remind the listener (esp. professionals) that I am a person just like them.

I am first a person and an individual – other descriptors follow later.

I am a person first, it is not just my experiences of mental health that give me expertise but all my other skills and experiences.

Although this is not necessarily a surprising finding, it is an important one, particularly in a context where people have traditionally been categorised and labeled by others, often according to a medical diagnosis, and this dominant label has threatened to subsume all other identities, skills and experiences.

The focus on lived experience

When people responded to the terms beginning with the phrase 'person with...' they tended to do so based on whether the term connected with their own experience and how they made sense of it. Although the most popular term in the survey was 'person with direct or lived experience of mental distress', what emerged from the data more broadly was an emphasis on the different ways in which people referred to their lived experiences, for example, as mental health, mental distress, mental illness, mental health condition, mental health problem, rather than

as an identity marker in and of itself.

"Terms such as person with mental health problems/mental illness are preferable to me as it describes part of a person's life experience as opposed to necessarily being something that defines them... Ideally, I would use the term 'person who has experiences of mental ill-health/mental distress/mental health problems' or 'person who has been affected by mental ill-health/mental distress/mental health problems'. This then describes something they have experienced rather than using the experience to define who they are."

"I identify as having lived experience of mental distress as it is not medical model focused and speaks to the expertise I have in self management."

"Some activists feel they have moved on, are managing their mental health and are no longer in touch with services but still carry the identity. That's why I prefer 'lived experience.' I think we should talk about mental health as a positive thing (like wellbeing) and not confuse it with illness or distress. I prefer 'distress' because 'illness' is too closely allied to the medical model of treatment."

Although these respondents position themselves in different ways with regard to understandings of 'illness,' all emphasise the lived experiential aspects of identity. The focus on experience was also highlighted within the comments relating to the term 'person with mental health experience'. As a 'label' or identity marker it was criticised for being 'meaningless' and far too general:

"Person with mental health experience is just plain ridiculous as everyone in the world has that."

"Mental health experience is something that is common to everyone whether it is excellent, good, average, poor or b-awful."

However, people appeared to respond positively to the phrase, not necessarily as a specific identity marker, but because it foregrounded and referred to lived experiences.

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The value of expertise and emphasis on empowerment

The term 'expert by experience' was seen as empowering and positive by many, because it

"...values and honours the reality that we know best what has worked for us and we should have an equal say in what happens to us as well as professionals who are also experts."

"Expert by experience shows that you have become expert in the knowledge of your condition and you have the experience to give information and help others."

Acknowledgement of the importance and value of expertise and experience appeared to be significant for many when identifying with particular terms. However, when using the term 'expert by experience' as an identity marker some criticised the term stating that experience in and of itself should not automatically make someone an 'expert':

"Each individual's experience of mental health is unique to them, but I do not feel that it makes him/her an expert."

"I find expressions such as expert by experience a tad patronising and offering spurious non-educational knowledge."

In addition to the emphasis on understanding, empathy and 'expertise' gained through lived experiences whether as an identity label or in broader terms there was also a focus on active empowerment. Consequently, people tended to identify with terms that were seen to promote positive choices:

"Client' feels like you have more say in the service you are being offered. Sounds like you have a choice over decisions rather than something that is being done to you."

By contrast, the term 'consumer' was unpopular due to its association with the consumerist ideology and the promotion of spurious notions of 'choice'.

"Consumer' indicates choice that is not always there."

"I am not a consumer because often I don't have a choice."

5.2 Discussion

As we have seen, there are inconsistencies within the quantitative data generated by this survey. The extended qualitative comments provided by participants point to further complexities in how people make sense of their experience and identity. The key themes and values emerging from the qualitative data, as discussed above, highlight that identities are fluid and contextual. The terms that people identified with were frequently based on how they helped to make sense of their own lived experiences. The data also indicated that respondents were not keen to attach themselves to a singular identity that defined their experience of mental distress. People construct and negotiate their identities in unique, complex and varied ways in different settings. Identity, and the language used to express it, is a matter of process rather than definition.

It is important to bear in mind that language preference is also predicated on membership (or non-membership) of preferred groups and communities. For example, the preferred term used by the membership of ENUSP (European Network of (ex)Users and Survivors of Psychiatry) is 'survivor,' indicating alliance with the group's primary purpose as one that is predicated on a political interrogation of psychiatry and the systems and laws that support it. Similarly, people who find the 'an illness/health problem like any other' model of understanding mental health problems useful in making sense of their experience (a model that informs many anti-discrimination programmes and diagnosis-based groups) prefer the term 'patient' or 'client' (or 'consumer' in the US context). It is therefore interesting to consider the way in which the language preferred by NSUN members reflects NSUN as a group, considering its emergence from the political base of the 'user'/'survivor' movement.

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Moreover, the language we use to talk about identities and experiences, as we have seen, is influenced by the context we live in. Despite recent policy and practice innovations in recovery orientation and user involvement in mental health services, the broader context of 'mental health' can be seen as one where there is an increased re-medicalisation. This is evidenced by the DSM-5 debates,^{9 10} the recent findings of Mental Health Minimum Datasets,¹¹ CQC findings on involuntary admissions¹² and Community Treatment Orders.¹³ Research has highlighted that service users are often not satisfied with the way in which mental health professionals place an emphasis on medical models in recovery approaches (Gould, 2012: 38.) There is also emerging anecdotal evidence that more and more people are forced to accept, or seen to be accepting (reluctantly in many cases,) a medical understanding and articulation of their issues given the increasingly difficult situations with benefits cuts and Work Capability Assessments.^{14 15}

The Royal College of Psychiatrists has recently taken the decision to abandon the term 'service user' in order to replace it with the term 'patient'.¹⁶ In an article for the Scottish Recovery Network (2013) David Christmas argues that there is evidence to suggest that 'service user' is an increasingly unpopular term and is problematic because

"...it is unique to mental healthcare, it automatically defines members of the group as having a mental illness. No other medical speciality has 'service users.' A 'patient' could have any kind of illness, but a 'service user' is almost always someone with a

psychiatric illness. Parity of esteem between mental and physical health becomes impossible unless we are all patients."

This decision to prioritise 'patient' as their preferred term points to the fact that the fundamental way in which they choose to understand and engage with people needing mental health care is using a bio-medical model that sees all distress as a 'psychiatric illness'. This decision makes sense within this specific context, but also points to the restrictive nature of understanding mental health in a medicalised way. When considering NSUN's position regarding language and identity, we will also need to consider our specific contexts and the roles we hope to fulfill as an organisation that primarily works to achieve human rights and self-determination for people in relation to their mental health needs.

In that sense, NSUN, by definition, brings together people and organisations with a diversity of views about experience, identity and the language we use to talk about these. Here, it might be useful to look at the concept of 'strategic essentialism' as a way of understanding how we work in a unified way even as we grapple with our differences and diversities. Strategic essentialism is a concept introduced by Gayatri Chakravorty Spivak (1987) in the context of postcolonial theory and has then been developed and used within many minority movements questioning power hierarchies in our societies, including feminism, queer theory and racialisation debates. Strategic essentialism is used by groups or political formations in order to bring forward group identities in order to question and challenge power structures and oppression while also paying attention to the inherent differences existing amongst members of groups.

Writing about this form of 'anti-identity identity politics', Will Hall states that "we have strength when we create a 'we' out of the isolation and divide-and-conquer of oppression. So I can speak for shared experience, to some degree, as long as I also create that welcome space for diversity that negates identity for a moment."¹⁷ This is a temporary essentialisation,

9. <https://www.madinamerica.com/2013/02/rejuvenating-abolitionism-of-psychiatric-labels-even-some-establishment-psychiatrists-embarrassed-by-new-dsm-5/>

10. <https://www.madinamerica.com/2013/06/why-the-fuss-over-the-dsm-5-when-did-it-start-to-matter-and-how-much-longer-will-it/>

11. <http://www.hscic.gov.uk/catalogue/PUB12745/mhb-1213-ann-rep.pdf>

12. http://www.cqc.org.uk/sites/default/files/media/documents/cqc_mentalhealth_2012_13_07_update.pdf

13. http://www.mentalhealthalliance.org.uk/resources/SCT_briefing_paper.pdf

14. <http://www.newstatesman.com/business/2013/08/secret-cuts-6-how-are-those-mental-health-problems-treated-atos>

15. <https://www.facebook.com/pages/Mental-Health-Resistance-Network/479666938752033>

16. <http://www.scottishrecovery.net/Latest-News/should-patients-be-patients.html>

17. <http://malingeringnormal.wordpress.com/2013/12/09/will-hall-on-the-anti-identity-identity-politics-of-madness/>

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which is mindful of context and the shifting nature of contexts, while members continue to engage in internal discussions and debates about differences.

Another way in which we could make sense of the complexities of how we use language is by using the insights from the Russian linguist and cultural theorist Mikhail Bakhtin (1981.) According to Bakhtin, dominant forms of language, 'monoglossia', take the appearance of being natural, fixed, stable and unifying. But language which operates at a more individualised, personal level – 'heteroglossia' - is more fluid, shifting and dynamic. For example, dominant medicalised psychiatric discourses are 'monoglossic' in nature; they pretend to be natural, stable and unitary. However at the 'heteroglossic' level, individuals are constantly rejecting, resisting and challenging dominant language and discourses. It is possible to engage with monoglossic discourses through continued acknowledgement and understanding of the more complex, subtle and heteroglossic ways in which identities are constructed.

It is also important to bear in mind that identities are multiple and intersect with each other. Lived experience of mental distress should not be considered in isolation as though it were a distinct and autonomous variable. The separation of mental distress from other frameworks of social domination (eg. ethnicity, gender and class) can have the effect of suppressing the experiences of marginalised groups, thus rendering them invisible. Patricia Hill Collins (1990) in her work *Black Feminist Thought* asserts that ethnicity, class and gender should be seen as 'interlocking systems of oppression' within an overarching 'matrix of domination' (p.222.) This model of social inequality expands the focus of analysis from merely describing one system of oppression to a more subtle and detailed investigation of the ways in which different systems of oppression interconnect. This approach also acknowledges that "depending on the context, an individual may be an oppressor, a member of an oppressed group, or simultaneously oppressor and oppressed" (1990: 225.) This 'intersectionality' can be helpful when thinking more broadly about identities and lived experiences of mental distress.

The type of strategic essentialism that NSUN employs will necessarily need to take into consideration the diversity of its membership and the intersecting contexts of experience that inform people's use of language and identity, and connect these to the organisation's values, role and purpose. Rather than supplying a set of popular terms to be used in the future by NSUN, the analysis of the survey data enables a reflection on the values underpinning the selection and ranking of terms. Many of the key themes highlighted within the qualitative responses (eg. challenging stigma and discrimination, respecting people, foregrounding lived experience, valuing expertise and empowering people) directly support NSUN's value base, particularly with regard to the foregrounding of lived experience and the validation of this as expertise in order to change and improve mental health services. A certain amount of 'strategic essentialism' will be necessary in order to engage with the dominant (medicalised) discourses, but this need not be divisive or restrictive. Focusing on our shared values allows for difference, whether we refer to ourselves as 'survivors', 'service users', 'patients' or 'people with lived experience'.

6. Conclusion

This document has aimed to provide an overview of terms used in relation to mental wellbeing. It has also reported on the findings of a small survey of NSUN members in relation to their preferred terms. This discussion of language and individual preference could be viewed as a distraction or an irrelevance, bearing in mind that the dominant discourses of policy and psychiatry have their own preferred terminology and continue to be rooted within the medical model of mental illness. However, it is only by having an awareness of the historical context of terms and an ongoing awareness of the preferences of our members that we will be able to effectively challenge dominant discourses and continue to influence service development.

Whilst seeking to provide alternatives to the medical model, this document does not aim to be prescriptive. Language is contextual and collective terms need to

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be used with an awareness of diversity rather than a desire for uniformity or neat homogeneity. There is no single language of mental wellbeing and the 'perfect' term does not exist. A consensus on this issue is not possible or desirable. However, when considering collective terms, the findings of our survey will inform our approach to language use in the future, particularly with regard to referring to our members first and foremost as 'people.' ●

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without us'**

NSUN
Riverside House
27-29 Vauxhall Grove
Vauxhall, London
SW8 1SY

Telephone
020 7820 8982

Email
info@nsun.org.uk

Website
www.nsun.org.uk

Registered Charity
number: 1135980

Company number
7166851

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