



What Are We Called? User? Consumer? Survivor?

August 2009

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Registered Office: MacLeod and MacCallum, 28 Queensgate, Inverness. IV1 1YN



CONTENTS PAGE No

WHAT IS HUG? Page 3

INTRODUCTION Page 4

WHICH WORDS DO WE PREFER THE MOST? Page 4

WHICH WORDS DID PEOPLE LIKE LEAST? Page 5

ARE THERE ANY BETTER WORDS THAT WE COULD USE? Page 5

OUR THOUGHTS ON EACH WORD. Page 6

ACKNOWLEDGEMENTS Page 11

WHAT IS HUG?

HUG stands for the Highland Users Group, which is a network of people who use, or have used, mental health services in the Highlands.

At present, HUG has approximately 360 members and 14 branches across the Highlands. HUG has been in existence now for 12 years. Between them, members of HUG have experience of nearly all the mental health services in the Highlands.

HUG wants people with mental health problems to live without discrimination and to be equal partners in their communities. They should be respected for their diversity and who they are.

We should:

- Be proud of who we are
- Be valued
- Not be feared
- Live lives free from harassment
- Live the lives we choose
- Be accepted by friends and loved ones
- Not be ashamed of what we have experienced

We hope to achieve this by:

- Speaking out about the services we need and the lives we want to lead.
- Challenging stigma and raising awareness and understanding of mental health issues.

HUG's aims are as follows:

- To be the voice of people in Highland who have experienced mental health problems.
- To promote the interests of people in Highland who use or have used mental health services.
- To eliminate stigma and discrimination against people with mental health problems.
- To promote equality of opportunity for people with mental health problems irrespective of creed, sexuality, gender, race or disability.
- To improve understanding about the lives of people with mental health problems.
- To participate in the planning, development and management of services for users at a local, Highland and national level.
- To identify gaps in services and to campaign to have them filled.
- To find ways of improving the lives, services and treatments of people with mental health problems.
- To share information and news on mental health issues among mental health service user groups and interested parties.
- To increase knowledge about resources, treatments and rights for users.
- To promote cooperation between agencies concerned with mental health.

INTRODUCTION

HUG stands for the Highland Users Group. Nearly everyone loves our acronym HUG but lots of people struggle with the word 'user' in our title. In fact, some people who like the things that HUG stands for have refused to join because of their dislike of the word 'user'.

There are all sorts of words that are used to describe people with mental health problems: user; service user; client; customer; consumer; survivor; patient and sufferer.

However, we have not found a word that everyone likes and agrees with and yet we get tired of the constant debate about what to call people with mental health problems.

As a result we decided to look at all the words that we were aware of that are used to describe us and see what we thought of them in an attempt to settle the debate, at least for the moment.

In the autumn and winter of 2008 we incorporated this discussion into the usual round of HUG branch meetings involving 13 of our branches and including a total of 107 people.

WHICH WORDS DO WE PREFER THE MOST?

We asked each branch of HUG what word they liked the most and recorded the results. Sometimes branches liked more than one word and therefore the total votes is more than the number of branches.

Name	Number of Branches
User	4
Patient	5
Client	4
Consumer	0
Service user	4
Customer	0
Survivor	3
Sufferer	1

As can be seen we did not solve this issue in one question, 'patient' was the most popular choice closely followed by 'user', 'service user' and 'client'.

WHICH WORDS DID PEOPLE LIKE LEAST?

We asked each branch of HUG which word they liked least and recorded the results. Again, groups sometimes disliked more than one word.

Name	Number of Branches
User	5
Patient	0
Client	4
Consumer	4
Service user	1
Customer	2
Survivor	0
Sufferer	3

It is interesting to see that, although no one disliked the word 'patient', 'user' (which was also a popular word) was the most unpopular as was 'client' and 'consumer' which was not a popular word at all.

ARE THERE ANY BETTER WORDS THAT WE COULD USE?

We asked each branch of HUG if they could think of better words or phrases to use than those that are currently used and came up with the following answers:

- People who have mental health problems
- People

These were the two most popular words/phrases with agreement that we need to concentrate on keeping us, the person, at the centre of any description that defines us

- People with lived experience of mental health problems
- Group member or member

The above phrases were the next most popular and again it can be seen that the emphasis is on the person.

- Ill
- Mentally ill

These, more medically orientated and descriptive words, were the next most popular with a feeling that we should be blunt and realistic about the condition we experience.

There was also a strong feeling by some of us that no one word would ever be suitable and that different words could be appropriate in certain situations and not in others. Some people thought that there should be no words to describe us and that any word that describes an impairment will inevitably label us negatively.

Other words that were suggested were:

- Victim
- Team
- Mentally challenged
- Socially challenged
- Supported person
- Mental health patient
- Participant
- Mad, crazy, nutter or any other word that can demonstrate that we are reclaiming the vocabulary and refuse to feel shame but instead feel pride in our condition.

OUR THOUGHTS ON EACH WORD

We discussed each of the words that are presently used about us and tried to work out what each one meant to us or what it made us think about.

USER

This made us think of drug users. Almost every group said that the popular image associated with this word was of addiction.

It sounded very official almost as if we had signed a contract. We felt that it was unfriendly with a stigma associated with it and a suggestion that we cannot cope and need help to manage. We felt that it meant that we needed to see a doctor and that it was a word used in the towns and cities of the east coast compared to the west where people were just referred to by their names or as people. 'User' took away the focus from us as people and individuals.

We also felt that it implied that we were abusing or taking advantage and 'sponging off' the system or other people and that it diminished us ("*you're just a user.*") We felt that it implied vulnerability and that we were separate and different from the rest of society.

Some of us associated it with I.T. and I.T. systems.

We also felt that it implied we had a choice which we sometimes don't have; by 'using' a service, we have decided and want to use it, instead of having to or sometimes being forced to use services.

Some of us liked it or didn't mind it. We felt that it was a widely accepted word and that by beginning with the letter 'U' it put us at the centre.

PATIENT

Many of us liked this word. We felt that it was descriptive and neutral and that it was used about everyone and sums up what is happening to us.

However, we felt that it was a word that should be used in a particular context which is usually if we are seeing a medical professional or are in hospital, even that we are confined to a bed, which is something most of us are not engaged in all the time.

Some of us felt that it signified inequality "*you are the little patient*" and also that it concentrates on sickness which is not everything that we are. It is a very medical word with some stigma, as it is all about illness. The concentration on illness was offensive to some of us. Even when it is ok with us we felt that it only applied when we were actively or seriously ill which is not always the case.

We also worried that it was old fashioned and that it makes no reference to mental illness and that it does not give any suggestion of recovery. This made us feel that it could be a permanent and possibly demeaning word to use about us. We felt that in other situations we would not use it to describe us because we are not a patient of a drop in centre or an employment project or a community centre.

CLIENT

Many of us didn't like this word as we felt that it implied inequality and that issues of power were a part of the word. We feel "*like a thing or being at school*" some of us felt that it was very negative and that it was all about things we pay for.

Some of us viewed it as a very business and commerce orientated word with legal associations. It felt very clinical and it made a few of us think of prostitution. To some of us it implied difference and class division as well as being strongly associated with social work services. It implies that someone is making a living off of us and feels like a very impersonal word.

Some of us liked it, thinking that it gave an expectation of professionalism and high standards of behaviour. It feels professional which is good but may create its own barriers because it is all about professionals. A few of us felt that it had little stigma and that it implied partnership and relationship. Some of us liked it because it was very neutral.

CONSUMER

This was not a word that many of us liked. It was too official, too American and too much about excess and materialism. It was about eating and shopping.

It was a management word; (provider and consumer) which we didn't identify with.

"It applies to supermarkets not to people made to have services."

We associated it with opinion polls and surveys and the idea that we are there to buy things and enjoy them.

"You don't eat mental health services"

To many of us it was a meaningless word with more associations about being a gas or electricity consumer than about us as people.

SERVICE USER

Some of us liked this because it was associated with services and therefore moved away from the idea that we were taking advantage of other people or taking drugs. It also linked us to providers and made links between us and professionals. It was a very factual word which makes it OK. It implies we are benefiting from something. It was also good because it gets away from words that concentrate on just health or a particular service.

However, some of us disliked it as we don't 'use' we 'suffer.' Some of us also associated the word with the language of banks and the army and all the bad aspects of the word 'user' used on its own. A few of us said that they would never introduce themselves with this word. Some of us felt that it was too long winded.

SURVIVOR

This word produced a varied reaction. Some of us were repelled by it and said that it implied we had just got through by the 'skin of our teeth' and that recovery was a much better concept. The idea that we may have 'survived the system' was alien to most of us.

A few of us disliked it because some of us don't survive mental illness and this needs to be respected. We also felt that it could be glib and patronising, that it implied a plane crash rather than our reality, and that it implied that, instead of getting on with life and living, we were just surviving. It was also a word that we felt that was more commonly applied to people who had been subject to rape or abuse.

We worried that it carried its own pressure; what if we cannot survive despite our best efforts and some of us thought that it forced us into the role of victim.

In contrast, the idea that we had survived the worst and come out the other end was very appealing to some of us; the idea that we manage, despite the system is very appealing. It implies fighting back and getting better, and it can be something that applies to any struggle with adversity and that we have managed despite all the odds being against us.

SUFFERER

Most of us disliked this word. It was very negative with no end in sight or any prospect of recovery. It felt like a very demeaning word.

However, a few of us said that it was accurate in that we do suffer and this needs to be described. A few of us said that it gave us a quiet feeling.

CARER

In one group, we also had carers present so we looked at this word too and found that although most people were OK with the word that there were negative sides to it. It can give rise to inaccurate assumptions and make people forget that we are also parents and partners, children and friends. That if we are seen as a carer then we are expected to do certain things whether we want to or not, that it implies the care is one way and is often confused with people who act as paid carers.

CONCLUSION

As can be seen from the account above we haven't yet solved the debate about the words that should be used to describe people with mental health problems. There are pros and cons to most words.

However, there are some words that most of us don't like and these are 'consumer,' 'customer' and 'sufferer'. We would recommend that we try to avoid using these words to describe us in the future.

The context in which the words are used is important. So, although most people have little problem with the word 'patient', it should probably be used when connected to medical treatment.

'User' has both advantages and disadvantages and strong views on both sides but people tend to like 'service user' as much and dislike 'service user' less than they dislike 'user' .so it would probably be best to use the phrase 'service user' in preference to the word 'user'.

Other words should be used according to personal preference and context.

Ideally we would refer to people like us as just that, as people, or if we need defining, as 'people who have mental health problems/schizophrenia/depression/anxiety' etc. This phrase, although a long one, is the preferred way that we would like to be referred to.

Within HUG we are left with the problem of how to use our own name. We had divided views on this. Many people said that in the context of the title there was no problem in using the word user. Others said that we should replace the name Highland Users Group with the single word 'HUG' but many had enthusiasm for the name '**H**ighlands **U**nited for **G**ood mental health. We will consult further with our Round Table for further guidance on this issue.

ACKNOWLEDGEMENTS

With thanks to all the members of HUG, and other mental health service users, who contributed to this report.

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