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# Service user, patient, client, user or survivor: describing recipients of mental health services

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**Aims and method** To determine which terms receivers of mental health services wish to be known by (service user, patient, client, user, survivor) according to the professional consulted (psychiatrist, nurse, psychologist, social worker, occupational therapist). We conducted a questionnaire study to assess terms by like or dislike and by rank order. There were 336 participants from local catchment area secondary care community and in-patient settings in east Hertfordshire.

**Results** Patient is the preferred term when consulted by psychiatrists and nurses, but it is equally preferable to client for social workers and occupational therapists. Service user is disliked more than liked overall, particularly by those who consulted a health professional, but not by those who consulted a social worker. A significant minority wish to be regarded as a survivor or user.

**Clinical implications** National and local mental health services should adopt evidence-based terminology in referring to 'patient' or, in some groups, 'patient or client' in preference to 'service user'.

**Declaration of interest** None.

Various terms are used to describe receivers of health services. The General Medical Council refers to people treated by a doctor as patients;<sup>1</sup> the Nursing and Midwifery Council refers to people, patients/clients and clients/patients;<sup>2</sup> the British Association of Social Workers refers to service users;<sup>3</sup> the British Psychological Society (in *Code of Ethics and Conduct*) and the College of Occupational Therapists both refer to clients.<sup>4,5</sup> A former chairman of the Patients' Association suggested alternatives to patient, considering the terms client, consumer and user, with an overall preference for the term user.<sup>6</sup>

The National Service Framework for Mental Health refers to service user 48 times, patient 12 times and client twice. The Royal College of Psychiatrists, in its report Mental Illness: Stigmatisation and Discrimination within the Medical Profession, refers to patient 77 times, service user 7 times and user (independently of service user)

twice. Of national mental health charities, SANE refers to 'people affected by mental illness' (www.sane.org.uk/AboutSANE), whereas MIND variously refers to user, service user or user/survivor.

In a study of adult psychiatric out-patient clinic attendees in London, Ritchie *et al* reported that of those expressing a preference for patient or client (96%) rather than 'other', 77% favoured patient and 23% client, whereas 47% disliked client and 14% disliked patient.<sup>10</sup>

In another London study, 133 people who received care from care coordinators from community mental health centres were asked about their preference of the terms patient, client or service user when being addressed by different mental health professionals. The survey indicated that between 7 and 10% wished to be addressed as a service user, 41 to 75% as a patient, and 17 to 47% as a client, the percentage varying according to the different professional

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discipline: 67% preferred to be called patients by psychiatrists, but there was no significant difference in preference for the term patient or client when used by community psychiatric nurses, occupational therapists, psychologists or social workers. This study did not, however, relate the question of preference to the discipline actually consulted; thus, the survey included an unstated proportion of questions relating to professionals in disciplines not consulted.

It was not known how receivers of mental health services within the UK National Health Service (NHS) wish (and do not wish) to be referred to as by professionals in different disciplines who they consult, despite widespread use of the term service user by the Department of Health.

# Method

# **Objectives**

We wished to identify preference rates for the terms 'service user', 'patient', 'client', 'user', and 'survivor', according to the professional discipline consulted (psychiatrist, nurse, psychologist, social worker, occupational therapist). Preferences were determined by indicating like/dislike, and also by ranking the different terms.

# Study design

The questionnaire comprised two questions.

- 1 Would you like a [name of discipline specified] to regard you as a service user, patient, client, survivor or user? (Responses were indicated by ticking one of the three boxes for each term: yes/no/unsure.)
- 2 Please rank your order of preference for the term by which you would prefer a [name of discipline specified] to regard you as. (The five terms were listed with guidance on how to rank them. Additional space was included for optional comments.)

An information leaflet about the study was provided. The question order and the order in which the terms appeared were counterbalanced across different versions of the questionnaire.

Ethical approval for the study was granted by the local research ethics committee.

### Setting

The study was carried out in a single-site secondary care mental health community setting (out-patient, day hospital) and mental health in-patient wards.

# **Participants**

The participants were receivers of mental health services (general adult, post-natal and old age psychiatry), most of whom live within the catchment area of Queen Elizabeth II Hospital in east Hertfordshire. Data were collected over two periods of time totalling 15 months.

# Inclusion criteria

We included those who consulted a trained mental health professional in at least one of these disciplines: mental health nurse, occupational therapist, psychiatrist, clinical psychologist or social worker, under community or in-patient mental healthcare, in the Queen Elizabeth II Hospital catchment area.

Participants were allowed to contribute data more than once, provided that each of their questionnaires related to a different professional group.

#### Exclusion criteria

We excluded those who either declined to participate or who were known not to understand that they were receiving mental health services. Professionals were asked not to hand the questionnaire to such individuals. (Most catchment area patients are fluent in English: those who were known not to understand that they were receiving mental health services would be some patients with dementia.)

Questionnaires (together with an information leaflet) were distributed by, or on behalf of, mental health professionals. Participants were given a questionnaire specific to the mental health professional they were consulting.

#### Results

# Main outcome measures

A total of 368 completed questionnaires were returned. Eighteen were excluded because the participants had returned more than one questionnaire for the same professional group; in such cases, the most recently completed questionnaire was retained and earlier returns were excluded. The remaining 350 questionnaires were spread across the five professional groups as follows: clinical psychologist (n=8), nurse (n=139), occupational therapist (n=49), psychiatrist (n=130), and social worker (n=24). The returns from those who consulted a clinical psychologist were not analysed due to their small number.

# **Endorsement of terms**

The first section of the questionnaire gave participants the opportunity to endorse each of the following terms: client, patient, service user, survivor, and user. Participants were allowed to endorse all, some or none of these terms. A breakdown of responses from all 350 questionnaires is shown in Table 1. Permitted responses were 'yes', 'no' and 'unsure'; non-responses are denoted as 'blank' in all the tables. The term patient emerges as a clear favourite, eliciting the highest percentage of positive endorsements, the lowest percentage of negative endorsements and the lowest percentage of uncertain or non-responses.

The same data broken down within each of the four professional groups analysed are presented in the online supplement to this article (and in online Table DS1). Patient was the most frequently endorsed term in relation to the four professional groups, emerging as the clear favourite in relation to psychiatrists and nurses; and being slightly preferred to client in relation to social workers and occupational therapists. The terms user and survivor received the fewest number of endorsements within all professional contexts.

Table 1         Participants' preferences by term (all questionnaires, n = 350)					
	User	Survivor	Client	Patient	Service user
Response			n (%)		
Yes	47 (13.4)	51 (14.6)	151 (43.1)	254 (72.6)	79 (22.6)
No	158 (45.1)	158 (45.1)	89 (25.4)	39 (11.1)	116 (33.1)
Unsure	36 (10.3)	36 (10.3)	29 (8.3)	11 (3.1)	46 (13.1)
Blank	109 (31.1)	105 (30)	81 (23.1)	46 (13.1)	109 (31.1)

Table 2 Measures of central tendency for rankings across all professional groups (n = 249), where 1 = most preferred and 5 = least preferred User Survivor Client Patient Service user 2.22 (1.09) 1.76 (1.15) 3.06 (0.99) Mean (s.d.) 3.96 (0.97) 4 (1.23) Median 4 4 2 1 3 5 2 Mode 4 3

### Ranking of terms

In the second part of the questionnaire, participants were asked to rank each of the five terms in order of preference, where 1 indicated the most preferable term and 5 indicated the least preferable term.

After excluding the questionnaires above (online supplement: Results), 249/350 were eligible for analysis. Table 2 displays the measures of central tendency for each of the five terms across all 249 included questionnaires (irrespective of professional group). Again, patient was the most popular choice and was ranked significantly higher than the next most popular choice, client (P<0.0001), whereas survivor and user were the least preferred terms. This profile was consistent across all three measures of central tendency.

The data were split according to professional groupings: online Table DS2 shows the preference for the five terms in relation to each professional group. Data were also analysed separately for each of the professional groups to establish whether the most preferred term was ranked significantly higher than its nearest competitor (online Table DS2). For all professions, this comparison (using a related measures *t*-test) was between patient and client since these were always the first and second preferred choices. Significant preferences were found for patient when used by both nurses and psychiatrists. However, there were no reliable differences between the rankings for patient and client when used by social workers and occupational therapists.

These two approaches to analysis (i.e. analysis by term and professional group) converge to show that patient emerges as the clearly preferred term to be used by psychiatrists and nurses, but is equally preferable to client when used by the other professions.

# Participants contributing ratings for more than one profession

A total of 14 participants contributed valid ratings for two different professions; the data are summarised in online Table DS3. Of those, only one changed their preference when considering a different mental health professional. Although this is clearly a very small subset of participants, the data suggest that individual preferences tend to be fixed rather than variable.

#### Qualitative data

Participants were invited to make additional comments or suggest alternative terms. The relevant comments are presented in Box 1.

# Box 1 Additional comments

- 'Patient is the only title that seems relevant'
- 'I would like [to be] referred to as patient, but I feel I am trying hard to be a survivor'
- 'I am NOT a user of any kind. I didn't like any of the labels, patient is too formal but the nearest'
- 'I am a patient!'
- 'Friend would be a better term'
- 'I believe addiction is an illness. If I was in with cancer I would expect to be called a cancer patient so what is the difference?'
- 'I don't care what term is used'
- 'I believe the word "user" is inappropriate and would make people feel bad about being here'
- 'Mental health issues should be treated in a similar way to other health issues, therefore a medical model is most appropriate in a medical context'
- 'I see mental health problems in the same way as physical problems, and therefore being called a patient is appropriate for both. I see a counsellor, for which I pay – for this I think either patient or client is appropriate'
- 'I regard the other terms as totally inappropriate' [the participant preferred the term patient]
- 'I do not like client it's reminiscent of prostitutes'

### **Discussion**

This study demonstrates that the known preference of the terms patient and client above service user in London as shown in previous studies<sup>10,11</sup> also applies to Hertfordshire. In Hertfordshire, this preference applies to different mental health disciplines consulted on the day. The term service user is more disliked than liked among those who consult mental health professionals except for social workers. Despite that, the term service user is incorporated into national and local mental health policy documents. The 5year review of the National Service Framework for mental health states: 'there is a need to ensure involvement of mental health service users and carers at all stages of the research process, including the identification of priorities for research', and further, 'service users are now widely involved in research - setting priorities, commenting on research proposals, and undertaking research themselves.'12

Mental health service managers and clinicians need to ensure that those who receive mental health services, and who are invited to help improve upon them, are not potentially excluded from doing so by the widespread use of terms which are less preferred and more strongly disliked. Before asking what 'user involvement' or 'service user involvement' can contribute to service development, the terminology used to describe and involve such service receivers needs to be as inclusive and representative as possible.

A small but significant proportion of individuals wish to be regarded by less popular terms such as survivor or user. Their needs and wishes should also be considered as part of evidence-based service development.

Further research may establish whether 'service users' who are invited to plan and participate in evidence-based research and service development are representative of those who regard themselves as patients or clients, and not necessarily as service users.

Mental health policy makers should recognise the evidence base for the use of the term 'patient' or, in some groups, 'patient or client' above that of 'service user'.

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