Giving the silent majority a voice

How do you tap the views of your treatment clients (not just the vocal ones) and what do you do with the results? Experience at one drug clinic demonstrates the value and the limitations of user surveys.

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THERE HAS BEEN RECENT EMPHASIS on the value of feedback from clients/users of substance misuse services[1,2] and many services have users' representatives, users' groups and suggestion boxes or run self-completion satisfaction surveys. Valuable as they may be, these depend on service users being prepared to put their views forward or to get involved in user advocacy. The result is a self-selected sample which may be unrepresentative of less vocal service users and those averse to joining groups or getting involved in drug service social circles. Those who opt out may be suspicious of other service users, fear clinic reprisals (especially in prescribing services), and have no wish to draw attention to themselves.

This article outlines one effort to access the views of this silent body of service users. The setting was an NHS community drug team (not where I currently work). Most clients were opiate addicts on substitute prescribing; only findings from that group are reported. Two surveys were conducted, one in 1999, the other in 2001. In between the clinic had undergone substantial change. Using the same questions both years allowed some assessment of their impact. By including questions on issues addressed by national guidelines, we were also able to assess how far these conflict with patient choice.

DEVELOPING THE SURVEY

We used an interviewer-applied rather than a self-completion survey to ensure that participants' queries were addressed and items properly completed. Interviewers who are independent from the service and unable to influence clinical decisions are more likely to get candid responses.[3] To recruit these we drew on the large pool of free, skilled labour available through links with local psychology departments. Their undergraduates are happy to volunteer to gain clinically relevant experience for their CVs.

Questions for the surveys were developed from existing research and questionnaires and through discussions with clients and staff. A qualitative pilot study testing the reactions of a few service users helped us refine the questionnaire for the subsequent (easier to analyse) quantitative approach. All the items consisted of a direct question to the client followed by a series of possible answers. To questions like, "What are your main sources of income?" the client could choose several answers at once. To others such as, "Do you feel you are treated with respect at the service?" they were asked to pick one from a series of alternatives, in this case ranging from "never" to "always".

Participants were paid £2 cash for their time. They were told that this was dependent only on completing the questionnaire, not on how they responded. Offering vouchers or tokens instead would, we felt, have implied that they were not to be trusted with money. Using a single interviewer each year reduced the number of clients repeatedly participating. Just four tried this, two were recognised at once and the other two after they had signed for their second payment.

ETHICAL AND ADMINISTRATIVE ISSUES

The relative absence of red tape in non-statutory agencies allows them to be responsive in research and service development – not the case in the NHS, where health trust research and ethics committees need to be satisfied. Often they impose inappropriate application forms originally designed for randomised controlled drug trials or invasive experimental medical procedures. These can take over a day to fill in and weeks to get processed. It may save time to present the survey as an 'audit'

Take-home GOLDEN BULLETS *messages*

- User feedback mechanisms which rely on the user taking the initiative risk tapping the views of an unrepresentative set of vocal clients.
- Surveying all or a sample of all the clients taps a broader range of views.
- Especially in the NHS, administrative overheads may be reduced by conducting an 'audit' of client opinions rather than 'research'.
- Independent interviewers able to offer credible confidentiality assurances will elicit the frankest responses.
- Especially in prescribing services, national guidelines and professional standards limit the extent to which users' views can shape the service.
- Try to get the management signed up in advance to taking the results seriously without slavishly adopting their implications.

Background text

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rather than 'research'. There were also forms and checks required to pass the external interviewer as a volunteer worker.

To comply with ethical guidelines, a consent form to be signed by participants should specify what consent means and the limits of confidentiality. Ours told clients: "If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive. All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you that leaves the clinic will have your name removed so that you cannot be recognised from it. The only results shown to the clinic will be general statistics. Confidentiality could only be compromised if you state that you intend to seriously harm yourself or a named other person, or if you report abuse/neglect of a child in your care. However, you will not be asked about these issues."

Cases which seemed to require breach of confidentiality were discussed at first anonymously between the interviewer and the clinic psychologist. Only 1 out of 160 clients had to be identified in order to consider the need for a risk assessment.

GATHERING THE DATA

Adverts were placed around the waiting area to let clients know about the survey. One or two afternoons a week the interviewer came

OVER THREE-QUARTERS ADMITTED TO SUPPLEMENTING THEIR SCRIPT

to the clinic and approached any clients in the waiting area. If no counselling rooms were available, the interview took place in a corner of the waiting area.

The two surveys recruited 74 clients in 1999 and 86 in 2001. Though very few (around 7%) refused to participate, each survey captured only about a third of the relevant clients, raising concerns about representativeness. For example, frequently attending clients would be more likely to be seen. To counter this risk, interviewers varied the days they attended and persisted for nine months to help capture sporadic attenders or other less easily found clients. It was also reassuring that shortly after the second survey an audit of all methadone clients found that they averaged roughly the same dose (60mg a day) as the sample.

Nonetheless, some types of client (especially those in GP shared-care schemes) may have been under-represented. Despite this, the method remains more representative than the alternatives mentioned earlier. For example, half the 2001 sample said they would not get involved in a users' group.

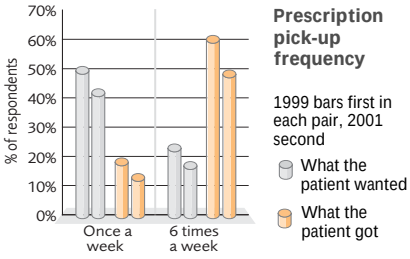
WHAT THE PATIENTS SAID

This analysis of the findings highlights those of greatest clinical relevance and also any major changes between 1999 and 2001.

DOSES OK, PICK-UPS TOO FREQUENT

Asked about their current dose of methadone and how much they felt they needed, on average clients in 1999 said they received 69mg daily but needed 78mg, while in 2001 the figures were 60mg and 63mg. In both cases detailed examination of the figures showed that for most individuals, provision came close to matching felt need.

We also asked how often they collected their medication and how often they would like to. Both years, patients clearly wanted to collect less frequently than they had to. About 60% wanted to come at most once a week, but only about 20% did so. Once a week was the most preferred frequency, but around half or more of clients were made to come six times a week.



MOST USING 'ON TOP'

Next there were some questions about continuing illegal drug use. First we asked how often they had used drugs (excluding cannabis, alcohol or their script) in the last four weeks. Over three-quarters admitted to supplementing their script. Of these, about half did so at least three times a week.

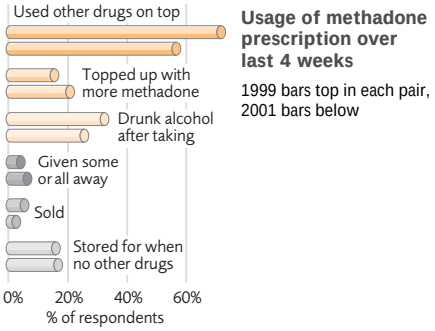
We also asked how often clients had injected in the past four weeks. Since only about 5% were prescribed injectables, the answers overwhelmingly reflect illicit use. Though ending injecting is a major goal for oral maintenance, in both years about half of the samples had recently injected and 16-17% had done so daily. Beyond these daily injectors, the figures may reflect a widespread desire for a periodic 'treat' in the form of the rush from injecting. If so, for these users it is unlikely that prescribing more oral methadone will have much impact.

When they did inject, few (4% of the full sample in one year, 7% in the other) had shared needles, but almost a fifth had shared spoons in the past month and most of these had done so at least weekly.

FEW 'MODEL' PATIENTS BUT DIVERSION RARE

Since clients commonly took other drugs, the question arises, what were they doing with their methadone? For any methadone service, this is a key issue. Diversion of prescribed drugs on to the illicit market attracts criticism and is associated with overdose among the recipients.

To probe this we asked: "Over the last 4 weeks, have you done any of the following with your methadone script?" There followed six options, several of which could be endorsed by the same client. Few had used their methadone as might have ideally been intended, with perhaps some improvement from 1999 to 2001. A minority took more methadone, and most used other drugs 'on top' (72% in 1999; 57% in 2001). A quarter elevated their risk of overdose by drinking after taking methadone and around 1 in 6



saved it 'for a rainy day' when nothing better was to hand. However, diversion was rare.

In line with this finding, asked about their main sources of income, just a handful endorsed drug dealing. Other crimes were also rare. Among the remaining options, over 80% said their main sources included benefits but no more than 17-18% stipulated casual or waged work. The impression of little crime remained when clients were asked about crimes in the past four weeks, but the proportion who admitted to theft increased from 8% in 1999 to 14% in 2001. Before treatment, most dependent opiate users commit revenue-raising crimes,[4] so the service can take comfort from these findings.

SATISFIED BUT NOT *very* SATISFIED

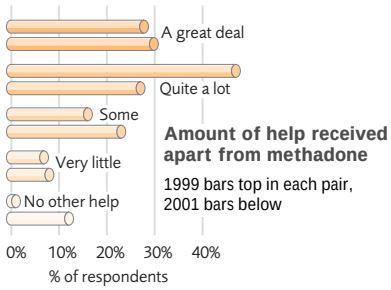
We decided to ask how clients felt about the main individual they related to at the clinic and about the service in general – important not just as direct quality indicators, but also because a good therapeutic relationship is a marker of effective treatment.[5]

Around 80% said their relationship with their key worker was good or very good and just 1 in a 100 saw it as poor or worse. These figures suggest that dramatically bad key working was rare, but the fact that under half the patients saw the relationship as 'very good' also suggests room for improvement.[6]

Social, welfare and counselling services can improve outcomes from methadone treatment.[7,8] To assess how far the service helped in these regards, we asked: "Apart from getting methadone, how much help would you say you've had from this service (eg, report-writing, DSS, housing)?" The service had been helpful, but there was scope for more. Only 1 in 3 clients said they had received "a great deal" of help, and by 2001, 43% said that at best they had received "some". While on most other measures little

had changed between 1999 and 2001, this measure appeared to detect a reduction in the amount of practical help offered to clients.

Another important quality indicator is captured by the term 'respect'.[5] Here too there was a high level of satisfaction but also a hint of deterioration. In 1999, 74% of patients felt they were "always" treated with respect at the service but in 2001, 66%. Most of the rest felt they were "usually" treated with respect. Similarly, at least 9 in 10 ex-



pressed satisfaction with the "general level of confidentiality" but those who were dissatisfied increased slightly from 5% to 10%.

In both years just 4% felt their appointment times were "not at all convenient" and about half that they were "very convenient". In between were around 40% for whom convenience at 'fair' might be improved.

The final substantive question was, "Would you like to join a 'users' group to help us and other bodies, like social services, improve and plan drug services in the future?" In 1999, 78% said they would but by 2001 just half were willing to participate.

FINDINGS CONFLICTED WITH THE CLINIC's WISH TO KEEP METHADONE SCRIPTS AS CONTROLLED AS POSSIBLE

The surveys ended with a question intended to test the validity of the client's previous answers but which perhaps also probed the degree to which they trusted the service. Asked, "Did you feel the need to lie about any of your answers?" in 1999 just 4% said "Yes" and in 2001, 11%.

CLIENT REACTIONS REFLECT CLINIC CHANGES

Between the two surveys the clinic's client capacity had increased, it had become consultant-led as opposed to led by a multidisciplinary team, and it had started to actively seek user representation. Prescribing practices had been tightened up, with supervised administration, more frequent reviews, swifter sanctions for non-attendance or poor compliance, compulsory tapering of concurrent benzodiazepine prescriptions, and a narrowing of opioid prescription options down to oral methadone. Trends seen in the surveys may not be due these changes. Alternative explanations include random sampling variation, caseload changes, or broader social trends. However, there is a pattern to the findings which fits with how one might expect the changes to impact on clients.

Over the three years the surveys recorded a slight decrease in average methadone doses, a decrease in the use of illicit drugs 'on top', but increases in the use of illicit methadone and in the proportion of clients engaging in theft. Satisfaction with key-worker relationships remained stable but there were slight reductions in perceived respect, satisfaction with confidentiality, practical support, and perhaps also trust. Some disaffiliation from the service may be apparent in the sharp fall in the numbers prepared to get join a users' group, though this could also be a reaction to the fact that by the second survey the potential for involvement had became a reality

A MIXED BAG

The surveys had given some useful insights into clients' needs and views. Though not dissatisfied with the amount of drugs prescribed, they were often dissatisfied with how often they had to collect them. Periodic (but not daily) supplementing of prescriptions with other drugs was the norm, suggesting that it may be unrealistic to wait for consecutive 'clean' urine tests before moving clients on to less intensively supported prescribing options such as GP shared care.

The clinic was not (some might say, should not) satisfying clients' desires for periodic 'treats' in the form of injectable drugs, leaving the door open to continued sharing of injecting equipment. Acceptance that continued injecting is common could be the basis for providing more information on the risks of sharing equipment such as spoons. Low levels of self-reported crime appeared to confirm the efficacy of dispensing free opioids, but the service was not helping clients to gain income from employment. Daily attendance at a chemist might be hampering efforts to find work, or perhaps much more help was required.[9] It was pleasing to note that clients were generally happy with key-worker relationships, respect, confidentiality, appointment times, and (to a lesser degree) the amount of practical help provided by the clinic.

WE HEAR YOU *but* … LIMITS TO USER INFLUENCE

When it came to the use made of the findings, arguably the service got more out of it than the clients. It was able to show health trust managers that, as required, some attempt had been made at 'user involvement'. Little change was made as a result to the clinic's administrative or clinical procedures. This may have been partly because the findings reassured management that little change was needed. Key workers and the clinic as a whole were generally seen as providing a good service. But satisfaction was neither complete nor universal, especially in relation to the core prescribing elements. Here how far the clinic could/would move to satisfy clients' desires was constrained by national guidelines and professional standards on issues such as supervised consumption, daily pick-up of prescriptions, and the prescribing of injectables. Agencies and doctors are not prepared to risk being pilloried for transgressing these 'guidelines' if something goes wrong.

The centre knows best

As a result, the client's influence is effectively relegated to the elements of the service that, for most, probably matter least. On the key issues, a central authority has already decided (perhaps rightly) what is best for them. User involvement in these circumstances risks being tokenistic. Perhaps before such exercises these is a need for preparatory work to get the management signed up to taking the results seriously, without slavishly adopting their implications.

The findings were useful for educating less experienced doctors who may have assumed their prescriptions were being used as directed. But generally reaction to the findings was muted, because in some respects they conflicted with the wish to tightly control methadone scripts for fear of overdose, diversion and aggravating tolerance and withdrawal. The widespread 'topping up' with illicitly obtained drugs revealed by the surveys may undermine the grounds for these fears.

There are also hints in the findings that government pressure via the NTA to take on more clients could be eroding the extent to which workers can mount labour-intensive supportive interventions. At the far end of this process, clinical services become little more than dispensaries. Nobody wants this to happen, but with client numbers the most visible and high profile indicator of performance, the risk is that numbers will be achieved at the cost of quality.

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