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Executive Summary

Outcome of Waiting Lists (OWL) Study Waiting for Drug Treatment: Effects on Uptake and Immediate Outcome

Report prepared by:
Michael Donmall, Ali Watson, Tim Millar and Graham Dunn

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Disclaimer

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Dr Mike Donmall was the project leader on this study. He is Senior Research Fellow at the University of Manchester School of Epidemiology & Health Sciences and Director of the Drug Misuse Research Unit.

Alison Watson was the lead researcher on this project. Ali now works as Research Manager with the Big Life Company in Manchester but retains her links with the DMRU as an Honorary Research Associate.

Tim Millar was the lead advisor to this project. He is Research Fellow at the DMRU and is currently working on multi-level analyses of prevalence data and research focusing on treatment and criminal justice interventions.
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Advisors

Andrew Jones was an advisor to this project. He is Research Associate at the DMRU with special responsibility for Arrest Referral monitoring and research.

Petra Meier was an advisor to this project. She is currently an NHS Training Fellow investigating client counsellor relationship processes in drug treatment.

A reduction in waiting times is one of the key aims of the NHS Plan and reduction in the numbers of drug misusers being denied immediate access to appropriate treatment is one of the objectives spelt out in the Government's Drugs Strategy (Tackling Drugs to Build a Better Britain, 1998). Furthermore, contemporary guidance on acceptable lengths of wait issued in March 2002 by the National Treatment Agency (NTA) sets waiting time targets (from 2 to 3 weeks by 2003/04) for each treatment modality outlined in Models of Care and has identified waiting times as one of four Key Performance Indicators for drug misuse services (National Treatment Agency, 2002).

A review of the literature suggests a scarcity of studies on the independent effects of waiting for drug treatment on an individual's admission to and engagement with treatment regimes, and that the results are inconclusive.

This project, part of the Department of Health's Drug Misuse Research Initiative, has focused on treatment for opiate use, specifically substitute prescribing with methadone. We have investigated:

- *the current status of waiting lists and times for drug treatment (methadone*
- *prescribing and in-patient treatment for opiate users) across England*
- *the impact of waiting on treatment uptake and retention, and*
- *the effects of waiting on those seeking treatment.*

The investigation has acute relevance for policy makers, for providers of drug treatment services and for those seeking and waiting for treatment. There have been four component studies:

Study 1: National Survey of Drug Services - a national questionnaire survey of drug services to identify, quantify and describe factors which influence waiting lists and their management.
Study 2: The Effect of Waiting Times on Treatment Uptake - a prospective study of new referrals.
Study 3: The Effect of Waiting Times on Retention in Treatment - a retrospective study of client records.
Study 4: Client Perspectives of Waiting for Treatment - an interview survey of drug users' perspectives of the effect of waiting for treatment.

Study 1: National Survey of Drug Services

Following preliminary interviews with agency managers and service commissioners from around the country to explore factors relevant to the determination and management of waiting lists for drug treatment, a national agency survey was undertaken.

Questionnaires were sent to all 643 identified drug treatment services in England and 322 (50%) were completed and returned between December 2000 and January 2001. In total, 296 were valid individual agency responses (37% from target prescribing services and 27% from target in patient services). An examination of basic information about non-respondent agencies from existing lists suggested a similar spread of types of agencies providing similar treatment options to the respondent group.

Waiting lists were apparent in all areas of service provision. Of those offering the target treatment options, 66% indicated that they had a current waiting list for substitute prescribing and 77% had a waiting list for in-patient treatment.

Target agencies reported a mean client caseload of around 200 (range 6 – 1,200). Although 25% had client caseloads of only 50 or fewer, many indicated that they were operating close to capacity: 45% reported a staff shortfall (ranging from 0.5 to 6.0 WTE1), 49% of these services were at least 1.5 WTE clinical workers down at the time the survey was carried out. Nearly half (45%) reported that their prescribing budget was usually overspent and a further 46% that it was spent up to the limit.

The number of clients waiting at a service ranged from 0-275. A quarter (25%) of services had 52 people or more waiting for treatment, 7% had 100 or more. Services reported average waiting times from referral to assessment of eight weeks (range 0-52 weeks), although 50% of services reported waits of four weeks or less. Following assessment, services reported a mean wait of four weeks to start of treatment (range 0-30 weeks), although 50% reported waits of two weeks or less. The total wait from referral to starting treatment, for non-priority clients, ranged from 0 to 54 weeks, with a mean of 12 weeks, with half waiting up to eight weeks but a quarter waiting 16 weeks or more.

Note: these are agencies' own estimates: waiting times reported by agencies in the survey were not always consistent with those actually observed in the subsequent study period. Such 'waiting perceptions' may not always be accurate.

Considerable volatility was found in waiting times. Possible reasons for increases in waiting times suggested by agency managers during the recruitment stage include: resource problems (staff, lack of medical cover, accommodation); caseload issues (increasing referrals, increasing numbers of priority clients, more complex clients); procedural changes (difficulties

with shared care arrangements, introduction of dose testing).

Possible reasons for decreases in waiting times suggested by agency managers during the recruitment stage include: resource issues (filling vacant posts, increased doctor time, extra financial resources); procedural changes (introduction of triage system, employment of dedicated detoxification2 worker, deliberate overbooking of assessment clinics, alternatives to methadone, stricter rules, shared care). Such 'waiting time volatility' seems to be a feature of drug service provision.

Nearly 75% of services said they provided interim support for people while waiting. This ranged from telephone/ letter contact to motivational interviewing, 1 WTE – whole time equivalent 2 detoxification a.k.a. 'detox' complementary therapies, drop-in sessions and interim prescribing. Two-thirds of agencies (67%) said that they attempted to arrange interim prescribing via GPs for their waiting list clients.

Nearly half of services did not carry out anything that they described as waiting list management.

Study 2: The Effect of Waiting Times on Treatment Uptake

Fifteen agencies, representing a spectrum of waiting times, were selected for detailed investigation and analysis. Agencies were asked to track clients prospectively from the point of referral through assessment and up to the start of treatment. New referrals were tracked between July 2001 and March 2002. Data were analysed to identify predictors of uptake. Analysis was conducted at the client level because waiting times at the target agencies changed during the course of data collection. Multivariate analysis of factors that might influence uptake indicated no significant effect of waiting time.

The bulk of attrition occurred between referral and assessment: relatively few clients were lost following assessment (see Figure 4.5). Whilst waiting times did not predict assessment uptake at all, four factors were found to independently predict uptake. Uptake was best amongst: older clients, those with a previous experience of treatment, those self-referred or referred by their GP. Most important, we found a highly significant effect of agency: uptake being substantially better at some agencies than at others.

Whilst age and previous experience of treatment are client related factors that agencies cannot influence, referral source and other agency factors relate to the process of access and care that characterise an agency's style of operation. The study was not designed to elucidate why uptake was significantly higher in some agencies than in others, but it was very clear that the agency itself has a greater influence on uptake than waiting times. Such agency factors deserve further investigation.

Study 3: The Effect of Waiting Times on Retention in Treatment

Information from client records was examined retrospectively at 16 agencies between October 2001 and May 2002. Clients were tracked from the point of referral for up to six months from the start of prescribing in order to compare retention rates and determine the reasons for discharge from treatment. Retention levels were recorded at 1, 2, 3 and 6 months from the date of the first prescription. Again, data were analysed at the client level because waiting times at the target agencies changed during the course of data collection. Multivariate analysis of factors that might influence retention indicated no significant effect of waiting time.

Retention in treatment for three and/ or six months was influenced by the following factors: referral source, pick-up regimes, supervised consumption, duration of opiate use, problematic alcohol use on presentation, illicit methadone use on presentation and agency.

At both three and six months, GP and self-referred clients were more likely to be retained than those referred via other routes.

The effect of treatment regime appears complex and was different at three and six months. At three months, clients on a daily pick-up for some of the time were most likely to be retained; at six months clients who were on a daily pick-up some of the time or always were more likely to be retained than those who were not on such a regime. At three months clients on supervised consumption were much less likely to be retained than those not on this regime. It should be noted that agencies allocate clients to particular treatment regimes on the basis of their stability and we consider it likely that a complex interaction between a client's stability and choice of treatment regime underlies these effects.

Aspects of the client's drug use also appeared to predict retention: the longer the clients had been using opiates, the more likely they were to be retained at three months. Interestingly, those clients with problematic alcohol use as well as opiates on presen-

tation were also more likely to be retained at three months. Clients with declared illicit methadone use at presentation were more likely to be retained at six months.

Once again, the individual agency appeared to have the strongest effect. Clients at some agencies were much more likely to be retained at three and six months than at others. This suggests there was something about the way certain agencies worked that made their clients more likely to stay in treatment. Given current policy emphasis on increasing the number of drug misusers who successfully complete treatment we consider that this effect requires further detailed investigation.

Study 4: Client Perspectives of Waiting for Treatment

Fifteen case studies were carried out by interview during April and May 2002. All clients were currently waiting for treatment at four different agencies. All interviewees had already waited more than two months from initial referral to the start of the treatment programme, and four had been provided with an interim script by their GP. We found that perceptions about waiting were important in determining whether clients presented for treatment. A number said it would help if they were given a clearer idea of how long they would be expected to wait. A recurring criticism from clients was the lack of contact from the drug service during the waiting period, although this was offset where there was support from a partner and/ or other family member. Some said they would have appreciated a day, or drop-in service, whilst waiting. Some had undoubtedly increased their drug use during the waiting period, but interim prescribing had helped others to cut down their illicit use. There was clear resentment of the 'fast track' system by which arrest referred clients were able to access treatment more quickly.

Does Waiting for Treatment Matter?

We have investigated the effect of waiting times amongst a group of drug users seeking treatment for opiate problems. From this study we cannot quantify the extent to which long waiting times discourage potential clients from seeking help in the first place, although we have ample indication that they do. Clients, as well as agency managers, have indicated that long waiting times may result in a degree of 'referral apathy', whereby word gets around about the wait for a particular service. "I know people who've just not bothered coming in the first place…". Thus, "waiting reputations" develop that may discourage presentation for treatment.
Insofar as clients on a waiting list are not receiving treatment, we would expect that they will continue to engage in drug misuse and associated behaviour whilst waiting. In these respects, irrespective of our findings that waiting does not affect treatment uptake or retention following referral, we judge that waiting for treatment does matter and that efforts to reduce waiting times are justified. Furthermore, a substantial minority of our small sample of interviewed clients reported that their drug use increased whilst waiting.

Although a largely unspoken observation, it is undeniable that, for many years, the field has recognised some agencies to be "better" than others. Here we have demonstrated that, irrespective of the influence of other factors, some agencies are clearly more attractive to clients, and successful, both in terms of engaging them and retaining them in treatment, than are others. Given current policy concerns that stress the importance of engaging larger numbers of drug misusers in treatment, the factors that influence agencies attractiveness to clients require much more substantial exploration than has been made to date.

Key Messages

Definitional Issues

1. Agencies define and measure their 'waiting times' in a variety of different ways (viz. referral – presentation – assessment – treatment – prescribing). It is very important that policy, national and local, is very clear over definitions.

Extent of Waiting

2. Waiting lists were apparent in all areas of service provision. Of those offering the target treatment options, two thirds had a current waiting list for substitute prescribing and over three quarters had a waiting list for in¬patient treatment.

3. Services reported a mean client caseload of just over 200 (range 6 – 1,200), although a quarter had service caseloads of 50 or less. Nearly half reported a current staff shortfall (0.5 to 6.0 WTE), and nearly half stated that their annual prescribing budget was usually overspent.

Waiting Times

4. Services reported average waiting times from referral to assessment of eight weeks (range 0-52 weeks), although 50% reported waits of four weeks or less. Following assessment, services reported a mean wait of four weeks to start of treatment (range 0-30

weeks), although 50% reported waits of two weeks or less. The average total wait from referral to treatment was 12 weeks (range 0-54 weeks), with half waiting up to eight weeks and a quarter waiting for 16 weeks or more.

5. Nearly 75% of services said they provided interim support for people while waiting.

6. This study suggests that the bulk of attrition occurs between referral and assessment, with relatively few clients 'lost' following assessment.

Waiting List Volatility

7. We observed very considerable 'volatility' in waiting times – both between agencies and within agencies over time - increases and decreases being the result of resource problems, changes in caseload profile and procedure. Relatively minor changes often have a profound effect on service delivery.

Waiting Perceptions

8. Agencies' perceptions about the length of their waiting time are not always accurate – any assessment and monitoring of waiting times should be based on objective, verifiable and clearly defined measures.

Waiting Reputations

9. Clients' perceptions of how long they will have to wait based on the reputation of particular agencies may affect whether they feel it is worth their while seeking treatment in the first place.

Waiting consequences

10.A third of clients may increase their drug use whilst waiting and there may be other negative personal and/or social consequences.

Effect of Waiting on Treatment Uptake

11. The length of time clients waited between initial referral and assessment did not have a significant effect on whether or not they took up an offer of an assessment appointment. Waiting times did not independently predict treatment uptake.

12. Our multi-variate model suggests that uptake is positively and independently predicted if the clients were older, had already experienced drug treatment, were self-referred and by the agency being attended.

Effect of Waiting on Treatment Retention

13. The length of time that clients waited between referral and the start of prescribing did not have a significant effect on retention at either three or six months. Waiting times did not independently predict retention in treatment.

14. Our multi-variate model suggests that retention at both three and six months is positively and independently predicted by the agency being attended, by clients being self or GP referred and by the use of a daily methadone pick-up regime for some of the treatment time.

15. In addition at three months, clients were independently more likely to be retained in treatment the longer they had been using opiates and if they were also problematic alcohol users, but less likely to be if they were put on supervised consumption.

16. At six months, clients were independently more likely to be retained in treatment if already using methadone on presentation, but less likely to be if they were combined users of heroin and benzodiazepines on presentation.

Other Factors and the Agency Effect

17. Waiting times should not be used on their own as a measure of the quality of service provision at least in terms of uptake and retention. Other factors have been shown to influence these outcomes.

18. Most consistent is the highly significant effect that the agency itself has on whether clients are taken on and retained in a methadone treatment regime. Some agencies are evidently much better than others at engaging clients and retaining them in treatment.

19. Given current policy concerns that stress the importance of engaging larger numbers of drug misusers in treatment, the factors that influence agencies attractiveness to clients require much more substantial exploration than has been made to date. ■