Planning for drug treatment services: estimating population need and demand for treatment

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Abstract

There is a growing body of literature concerned with alcohol and other drug treatment modelling. In the main these models have been developed as simulations, for the purposes of evaluating policy options. Despite this burgeoning literature, there has been very limited work on developing planning models that assist with identifying the extent of both need and demand for drug treatment services. This is surprising given the focus of health planners on ensuring efficient allocation of health resources to areas of need. "Unmet need" is defined as the proportion of people who meet diagnostic criteria for dependence but who are not in receipt of treatment. This is therefore inclusive of people who may be suitable for treatment but do not seek it or request it, those who simply do not want treatment and those who want help via means other than formal treatment. "Unmet demand", on the other hand, is defined as the proportion of people who seek treatment but are unable to access it – that is they want treatment and seek it but for any number of reasons do not receive treatment. Both unmet need and unmet demand are important estimates in planning for services – while the former likely overestimates the true proportion of people who would access treatment, the latter underestimates the true proportion because it does not accommodate those who do not attempt to seek treatment but who would if the treatment service system was appropriate for them. Furthermore, both concepts are dynamic – and influenced by individual characteristics as well as treatment system characteristics. This paper addresses the literature on unmet need and unmet demand, provides new data on estimates for Australia, and exposes the substantial methodological and conceptual difficulties when exploring need and demand for drug treatment.

Introduction

This paper outlines the challenges associated with population planning models for alcohol and other drug (AOD) treatment services. Models can enhance the ability of health planners to determine and plan for an adequate array of AOD services based on treatment need and treatment demand. Treatment works and providing accessible, available and evidence-based treatments is a fundamental component of effective responses to alcohol and drug use and harm. Despite the most obvious importance of providing treatment, health planners have surprisingly few tools to plan for the AOD treatment needs of their population.

This is despite the ubiquity of health planning modelling. A model is "a mathematical framework representing some aspects of reality at a sufficient level of detail to inform a clinical or policy decision" (Caro et al., 2012, p. 798). The area of Decision Support Systems is burgeoning, as health planners and policy analysts look for better and more sophisticated ways of ensuring that decisions are grounded in data and information. A decision support tool is defined as 'an interactive, computer-based system that provides decision makers with easy access to data and models to support semi-structured or unstructured tasks' (Bosworth, 2003, p. 635). Any decision support tool is merely an artificial representation of a system, and has inherent limitations. The most commonly referred to in the literature is the problem of the accuracy of the data entered into the model; and the extent to which the model represents the system components adequately. Balancing simplicity and complexity is a key challenge.

There is a growing body of literature concerned with alcohol and other drug modelling. These models have been developed as simulations, for the purposes of evaluating policy options. These include the agent-based model developed by Agar (Agar, 2005; Agar and Wilson, 2002); the stocks and flows model of controlling cocaine (Rydell and Everingham, 1994), agent-based policing models (Perez and Dray, 2005; Perez et al., 2006); (Dray et al., 2008); SimSmoke (Levy et al., 2005), Weatherburn and colleagues work on a simulation of the NSW criminal justice system (Clark and Lind, 2003; Lind et al., 2001), 'The Persistent Poppy' (Levin et al., 1975), the Drug Policy Research Center (DPRC) at RAND simulation for community drug policy (Kahan et al., 1993), and our work on pharmacotherapy maintenance (Chalmers et al., 2009; Ritter and Chalmers, 2009)and Hepatitis C treatment (Zeiler et al., 2010). Despite this burgeoning literature, the number of papers outlining planning models for AOD treatment services is limited. Indeed, only the work of Brian Rush stands out in the treatment planning area (Rush, 1990, 2010).

Despite general health planning modelling, and alcohol and drug modelling work, there is almost no literature of modelling treatment need and treatment demand. This paper sets out to explore the central concepts behind treatment planning: need for treatment and demand for treatment. We outline the various approaches to assessing the extent of unmet need and unmet demand, and the substantial challenges associated with creating estimates to insert into models or to assist health planners. The paper focuses initially on unmet need and provides examples of estimates and the difficulties associated with the accuracy of such estimates. This is followed by analysis of the methods of estimating unmet demand, and examples are given. We then, lastly, turn to other considerations in planning treatment services around need and demand – including the dynamic interplay between demand for treatment and service system characteristics. We remain surprised at the paucity of good science in this area.

Unmet need

Need for treatment is usually defined by the presence of a disorder that is known to respond to effective interventions. Unmet need for treatment, therefore, can be represented by the numbers of people at a population level, who meet diagnostic criteria for dependence or abuse and who would benefit from treatment but do not access it. Unmet need, therefore, is quantified as the number of people who meet diagnostic criteria but who are not in treatment.

There have been simple attempts to measure the gap between the number of people who meet diagnostic criteria for substance use disorders and the number receiving treatment (unmet need). For example, USA data (United States Department of Health and Human Services. SAMHSA, 2010) revealed a treatment rate of 19.1% for those with an identified illicit drug problem (and for specialist AOD treatment). This suggests an unmet treatment need of 80.9%. In an analysis of national household survey data (2002 to 2004), Becker (2008) found that unmet need for opioid treatment was 84.8% (that is, 15.2% of those who met diagnostic criteria for opioid use disorder had received some form of treatment in the past year).

Research on the unmet need for mental health treatment internationally confirms the picture of large unmet need. For example, for depression, the treatment gap (unmet need) was 56.3%; and for generalised anxiety disorder 57.5% (Kohn, 2004). Interestingly in this global picture of the treatment gap, alcohol abuse and dependence had the highest gap in treatment (highest unmet need) – with a median across countries of 78% (that is, 78% of people who meet diagnostic criteria for alcohol

abuse or dependence have not been in receipt of treatment). The Australian figure cited in this WHO work for alcohol abuse/dependence was 72% (treatment gap; unmet need) (Kohn, 2004).

Unmet need for treatment, given that its definition relies on the presence of diagnosable disorder, is estimated for different drug classes. (We return later to the problem of polydrug use, and the limitations of existing estimates of unmet need in this context). Thus, in the case of opioid dependence, unmet need for opioid pharmacotherapy maintenance treatment has been estimated for a number of different countries, as shown in the Table below.

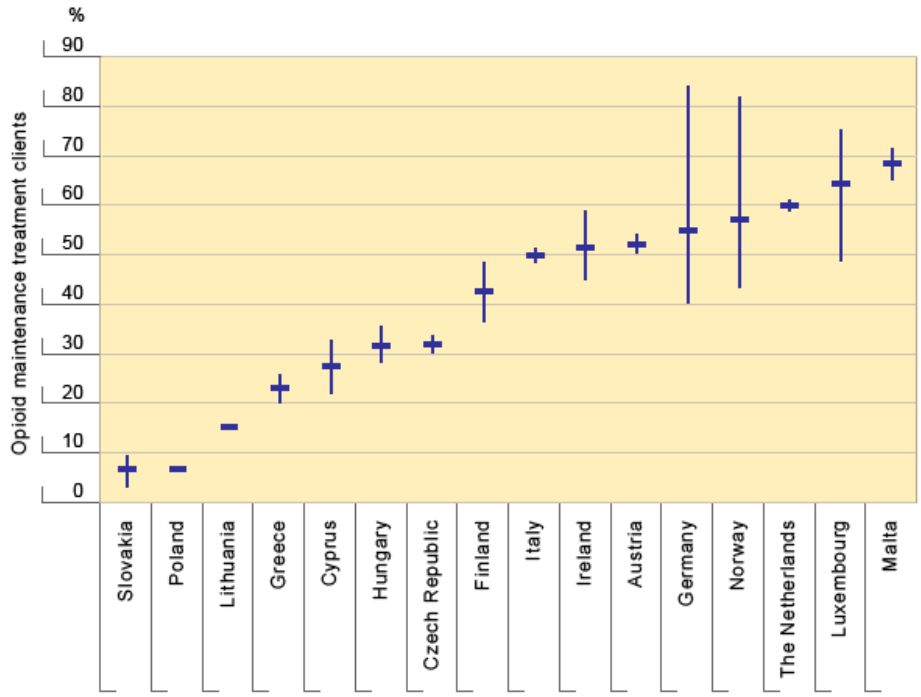
Table 1: Comparative rates of pharmacotherapy maintenance treatment relative to estimated size of problem opioid population around the world

	Problem opioid users	Clients in pharmacotherapy maintenance	% in treatment
European Union and Norway	1,300,000	695,000	53.5%
Canada	80,000	22,000	27.5%
China	2,500,000	242,000	9.7%
USA	1,200,000	660,000	55.0%

Notes: These numbers are indicative only and variation between countries may be attributed to different methods and sources of data to estimate the total number of problem opioid users and total number of clients in OTP. Source: Taken from (European Monitoring Centre for Drugs and Drug Addiction, 2011a) EMCDDA annual report, 2011, table 11, p.78 http://www.emcdda.europa.eu/attachements.cfm/att_143743_EN_EMCDDA_AR2011_EN.pdf. We have not been able to verify these numbers. Estimates of problem opioid users taken from household surveys and other direct estimation techniques may under-estimate the true number of problem opioid users due to issues discussed further in section 5.1 of this report. As a result, the % of problem opioid users in treatment may be over-estimated. We checked the USA prevalence against the recently published World Drug Report(2012) ; and the Canadian figure against (Popova et al., 2006), however we could not readily validate the numbers as the sources are circular.

This table shows that unmet need for opioid maintenance treatment varies greatly between countries – with the lowest apparent unmet need in the USA (45% unmet need) and the highest in China (91%). Similarly, Figure 1 shows the variability with EU countries.

Figure 1: Opioid maintenance treatment clients as a percentage of the estimated number of problem opioid users, 2009 or most recent year available



Notes: Only 16 countries had reliable estimates of the number of problem opioid users.
Source: Taken from EMCDDA Statistical Bulletin (2011b) (http://www.emcdda.europa.eu/stats11/hsrfig1)
The total number of patients also varies markedly between countries – some programs are quite small (eg Cyprus with n=286 patients) whereas other programs are large (eg France n=137,541 people in OTP).

There are substantial uncertainties with these pharmacotherapy maintenance treatment figures, including knowing both the underlying population rate – a problem we turn to next, and knowing how many people are in treatment (which we deal with second).

Underlying population rate – the problem of unmet need derived from population prevalence

In Australia, we are familiar with the problem of inaccurate population prevalence, as we demonstrate here. In order to derive unmet need for opioid pharmacotherapy maintenance in Australia, we compare the number in treatment with the prevalence rate of opioid dependency. There are two sources for the prevalence estimation: the general population household survey, and the general population mental health survey. The latter includes diagnostic criteria whereas the former measures consumption rate (without diagnosis). The population prevalence estimates derived from these two sources are shown in the table below.

Table 2: Estimated number of regular heroin users/opioid dependent people in Australia using direct estimation

Data Source	Survey year	Prevalence (%)	Estimated number of users
2007 National Survey of Mental Health and	2007	0.09	12,767[1]

Wellbeing: DSM-IV Opioid Dependence			
2010 National Drug Strategy Household Survey: recent heroin users	2010	0.28	41,722[2]

1. ERP 15 to 64 year olds: 14185752, at 2007 ABS data
2. ERP 15 to 64 year olds: 14901041, at 2010 ABS data

The population prevalence (final column) can be compared with the numbers currently in treatment to assess the gap (unmet need). The annual NOPSAD report provides the Australian data for the numbers of clients in opioid pharmacotherapy maintenance on census day in Australia (Australian Institute of Health and Welfare, 2012b). On census day in 2011, the total number of clients in Australia was 46,446 (Sixty nine percent of clients were in receipt of methadone and 14% buprenorphine). This is likely to be a reasonable accurate figure of current client numbers given that there are substantial administrative burdens associated with providing Schedule 8 drugs of dependence, and administrative records are therefore largely accurate (or at least more accurate than, for example estimating the number of clients receiving 'counselling' on any one day).

When the diagnostic criteria are applied (2007 NSMHWB), it is clear that the numbers in treatment far exceed the estimated size of the dependent population (12,767 versus 46,446). Even when the more 'generous' population estimate of recent heroin use taken from the household survey is used, the population prevalence still exceeds the numbers in treatment. This points out the significant problem associated with accurate population prevalence estimation.

Even when we turn to more sophisticated epidemiological methods, such as back-projection, capture-recapture, multiplier methods, or a combination of two or three methods (Frischer et al., 2001; Smit et al., 2006), we find substantial uncertainties around the population prevalence estimation. For example: indicator data used in Degenhardt et al (2004) to estimate the numbers of opioid users in one state in Australia, NSW, were collected from multiple sources. 1) The number of opioid-related deaths. 2) The number of opioid-related arrests. 3) The number of non-fatal overdoses attended by ambulances. And 4) The number of maintenance pharmacotherapy clients. The median number of opioid users in 2002 based on all four multiplier methods resulted in 19,850 users with a lower range of 17,800 and an upper range of 41,900. Back-calculating these numbers to the estimated resident population in 2002 (n=3,771,035)[1] resulted in prevalence estimates of 0.53%

[1] The total population estimates of NSW in 2010 were provided by the Australian Bureau of Statistics (ABS). The population estimate is based on the 2006 Australian Census and adjusted for the natural increase in the population over time (i.e. adjusting for births and deaths) as well as net overseas migration. State level estimates are also adjusted to take into account residential movement between states. The population estimates are based on the 'estimated resident population', which counts the population that live in private and non-private households (i.e. hotels, boarding houses, gaols, and hospitals) for more than 6 months of the year (Pink, 2008).

and a range of 0.47% to 1.1%. Assuming the prevalence has not changed since 2002, the total number of opioid users in 2010 in NSW is estimated to be approximately 25,786 with a lower range of 22,867 and upper range of 53,519.

Applying these population prevalence estimates to the current NSW pharmacotherapy maintenance treatment population (19,114 OTP clients: NOPSAD), results in an unmet need calculation as given in the below table. Unmet need for opioid pharmacotherapy maintenance ranged between 16.4% and 64.3%, depending on the underlying population prevalence estimate. At least with the application of better epidemiological methods, there are not more people in treatment than exist in the population! However, despite the much more sophisticated epidemiological measures than were applied in simply taking diagnostic rates (Table 2), the range of plausible figures for unmet need is very large.

Table 3: Summary of unmet need estimates for NSW

Estimates of NSW heavy opioid user population	Using # in OTP on 2010 census day; 19,114 from NOPSAD 2010 annual report
25,786 (median estimate)	25.9%
22,867 (lower estimate)	16.4%
53,519 (upper estimate)	64.3%

The huge variation in the estimates makes the health planners problem acute – should they be planning for a 16% gap or a 64% gap?

There are many potential sources of error. Diagnostic criteria to determine the presence of disorder (abuse or dependence) can vary from survey to survey (and some, such as the Household Survey do not include diagnostic criteria). The multiplier methods work on the assumption that the indicator data are an accurate representation of a subpopulation of opioid users in the total heroin using population. This assumption rests on the notion that all opioid related deaths, non-fatal overdoses, and arrests are accurately and comprehensively collected as well as the assumption that no change has occurred over time in the way the indicator data is measured. An inherent limitation of using multipliers to estimate prevalence includes the need to have access to accurate estimates of opioid users in a sub-population and prior knowledge of the probability that a regular opioid user will be in the targeted sub-population. This information is generally based on the assumption that health or arrest statistics are accurately reported as well as using data from smaller cohort studies of opioid or injecting drug users to derive the multipliers (Degenhardt et al., 2004). A secondary limitation,

similar to the indicator data, is that the multipliers may change over time depending on external factors, for example changes in drug purity and the use of heroin in combination with other drugs and/or alcohol can rapidly influence the number of overdoses. The NSW population estimates used to generate the total number of opioid users in 2010 were taken from the ABS, which reports estimates on the total resident population from the 2006 Australian Census. The ABS adjusts for natural population growth since 2006, net overseas migration, and state to state migration. However, the census under-samples from individuals who do not have a permanent residence (homeless). Since a significant proportion of the homeless are also regular opioid users, it is likely that the use of NSW resident population may result in some inaccuracy regarding prevalence of heavy opioid users.

Underlying treatment rate – the problem of estimating unmet need

In the above analyses of opioid pharmacotherapy maintenance treatment, we have assumed that the numbers in treatment at any one point in time are reasonable accurate (for the reasons detailed above). This is not the case, however, for other forms of alcohol or drug treatment. Examination of the population prevalence for alcohol, cannabis, amphetamine and benzodiazepine dependence and abuse (see Table 4, taken from AusBod: (Begg et al., 2007)) provides an estimate of the numbers of adults in Australia with the disorders.

Table 4: Population prevalence for alcohol, cannabis, heroin, amphetamine and benzodiazepine use disorders

Substance Use Disorder	Population prevalence rate 18-64 years	Australian population, 18-64 years[1] with substance used disorder	Numbers in treatment[2]
Alcohol	6.36	912,081	68,167
Cannabis	1.77	253,833	31,762
Amphetamines	0.51	73,138	12,563
Benzodiazepines	0.38	54,495	2,488

Note 1: the Estimated Resident Population of 18 to 64 year olds for Australia in 2012 was 14340898 (ABS data)
Note 2: Australian Institute of Health and Welfare (2012a)

The final column provides the numbers receiving treatment in Australia for each of these drug classes. The data in the above table show the large discrepancy between the number of people who meet diagnostic criteria for each disorder, and the numbers who receive treatment (demonstrating large unmet need). However, the treatment numbers represent a significant underestimation. This is because the only available treatment data is that which is collected from specialist AOD services. Many people receive treatment from services within primary care and general practice settings (eg

through GP's) and others receive care through social and welfare services that are not specially designed as AOD treatment agencies. Additionally, the numbers in the final column are not actually 'people'; they are 'episodes of care'. So it is possible that one person receives multiple episodes of care during the course of a year. Currently in Australia there is no unique identifier in the treatment data to enable a researcher or health planner to distinguish between episodes and individual people.

An important assumption behind estimates of unmet need derived as above is that diagnostic criteria are an accurate reflection of those who need treatment in the population. Given that the criteria are subjective, there could be a large proportion of the population that are sub-threshold cases, who are still in need of treatment given the burden of drug use. The changing definitions of DSM and ICD diagnostic criteria, with each revision, i.e. DSM-IV versus DSM-5, has a substantial impact on the population prevalence (Slade). Moreover, a proportion of people currently in treatment that make up the current treatment numbers might have failed to receive a diagnosis prior to seeking treatment.

A final consideration with estimates of need is the potential for rapidly changing population prevalence. This is perhaps best typified in the case of pharmaceutical opioid misuse. Most treatment planning for pharmacotherapy maintenance is completed on the basis of numbers of heroin dependent people. Yet pharmaceutical opioid misuse is a burgeoning problem (Bruneau et al., 2012; Havens et al., 2007). There is the potential for substantial need and demand for pharmacotherapy maintenance from this emerging group of opioid dependent people. However, estimating the extent to which it will impact on the current pharmacotherapy maintenance services is difficult. People dependent on pharmaceutical opioids may represent a different population to the current injecting opiate users. They may not find the current treatment services appropriate or attractive. Many may have chronic non-malignant pain which would require coordinated care with pain management services. They are more likely to receive pharmacotherapy maintenance from general medical practitioners (and hence demand may grow for this particular service type). Additionally, little is known about the most efficacious and cost-effective medications – whether methadone, buprenorphine or other forms of opioid maintenance are most effective for this population has yet to be established by the scientific community. While a dramatic example, it does serve to highlight that population prevalence is not straightforward and there are other considerations, such as the nature of the potential client group, that must be considered by health planners.

As can be seen from the above analyses, estimating unmet need is problematic – for any number of reasons. The estimates vary hugely. As we have demonstrated here, Mulvaney-Day, DeAngelo, Chen, Cook, and Alegria (2012) have also shown that varying definitions of unmet need and definitions of treatment produced different estimates. Importantly they additionally found that unmet need varied by racial and ethnic group, reminding us that client characteristics also play an important role in rates of unmet need.

And that's just the beginning, because in fact unmet need is not the only central concept – and has conceptual flaws. Large treatment need gaps cannot inform health services planning – because they do not take into account the difference between need for treatment and demand for treatment. At a superficial level, it could be argued that anyone who meets substance use disorder criteria is in need of and should receive treatment services (tailored to level of severity). However, the reality of patient demand for services is considerably different. In addition, formal treatment services are not necessarily always required for remission of AOD problems; the role of families, maturation, and spontaneous remission are important to acknowledge (Walters, 2000). Additionally, self-help needs to be taken into account. Thus, we draw a distinction between unmet need and unmet demand. "Unmet need" is defined as the proportion of people who meet diagnostic criteria for dependence but who are not in receipt of treatment. This is therefore inclusive of people who may be suitable for treatment but do not seek it or request it, those who simply do not want treatment and those who want help via means other than formal treatment. "Unmet demand", on the other hand, is defined as the proportion of people with substance use disorders who seek treatment but are unable to access it – that is they want treatment and seek it but for any number of reasons do not receive treatment. Arguably, unmet demand is a more important concept for health planners.

Estimates of unmet demand

Demand for treatment equates to the number of people who are seeking treatment. Unmet demand is quantified as those who are unsuccessful. Measurement of unmet demand is more challenging and complex than unmet need. This is because demand is a fluctuating state, and there is little systematic way of capturing demand, except for the obvious – demand represents the numbers who are currently receiving treatment.

The existing methods for measuring demand are: current treatment utilisation, intention to seek treatment (from surveys), and analysis of waiting lists.

Current utilisation: as noted in the above analysis of unmet need, it is not so straightforward to know who currently receives treatment – treatment occurs in multiple settings, with multiple practitioner types, and in Australia, as elsewhere, there is not one single database that collects treatment numbers. One way around estimating current demand (met demand) is to avoid administrative datasets and survey people. Population surveys do include questions about whether the respondent sought treatment. For example, in Australia, in the 1997 NSMHWB survey (Australian Bureau of Statistics, 1998) 14% of those with substance use disorders had used services. In the later 2007 Australian NSMHWB survey (Slade, Johnston, Teesson et al., 2009), 24% of respondents with substance use disorders used treatment services in the last 12 months[2]. More specifically, self-reported service use by people with alcohol dependence was 35.5% (last 12 months); and for drug dependence 52.4% (again, last 12 months) (Slade, Johnston, Oakley-Browne et al., 2009). These figures are noteworthy, and reasonably large especially when compared to above unmet need figures (Table 3 and 4). However, these figures do not quantify *unmet* demand, only *met* demand. Clearly this is unhelpful for health planners – they want to plan for those who are not in receipt of treatment.

Intention to seek treatment/self-perceived need for treatment: in population surveys, the majority of respondents report that they do not need treatment. For example, the US National Survey on Drug Use and Health, 2010 data (United States Department of Health and Human Services. SAMHSA, 2010) showed that of the 6,384 people who demonstrated a need for treatment (as defined by meeting diagnostic criteria and not being in receipt of treatment in the last 12 months), only 392 felt the need for treatment (6%) and 193 "made the effort to seek treatment" (unsuccessfully) (3%). In the US National Epidemiologic Survey on Alcohol and Related Conditions (NESARC) (adults only), only 8.5% of those respondents with a substance use disorder perceived the need for treatment (Mojtabai and Crum, 2013). Amongst young people in the USA, the National Survey on Drug Use and Health (U.S. Department of Health and Human Services, 2006) of general population 12 to 17 year olds, found that 6% met diagnostic criteria for alcohol use disorder; and 5% met diagnostic criteria for drug use disorder. Of those who met the criteria 7% received treatment for alcohol; and 9% received treatment for drugs. This provides unmet need estimates of around 90% consistent with most other USA research. But, when asked whether they thought they needed treatment, "very few of the youths who had not received treatment perceived an unmet need for treatment" [3] (U.S. Department of Health and Human Services, 2006, p. 1).

[2] With universal healthcare in Australia, the treatment seeking rates are higher than for other developed nations such as the USA.

[3] The figures were 2.2% for alcohol and 3.5% for illicit drugs.

Waiting for treatment: the third way of deriving an estimate of unmet demand is from waiting lists. This intuitively appealing idea is that those who are waiting for treatment represent the true 'demand' population and one that health planners should be most concerned with (hence the focus on things like hospital waiting lists). Waiting lists are a proxy measure of unmet demand. The assumption is that those who want and actively seek treatment will be counted within any waiting list system – and it is these people, who have to wait for treatment, that demonstrate a real unmet demand for treatment. In waiting lists research for SUD, the first difficultly we encounter is the definition of 'waiting time'. There are various definitions used to describe different periods of waiting: largely one of two different measures. The first is the time between initial contact with a service and the first assessment (pre-assessment wait time); the second is the time between the first assessment and actual treatment admission (post-assessment wait time). The international literature varies in which definition is used in studies. In addition to the quantitative measurement of 'waiting' (number of people waiting, length of time waiting), there are a number of qualitative aspects to waiting: how prospective clients understand the waiting time; perceptions of the length of wait (clients and service providers), and perception of time – that is how heroin dependent people perceive time differently from members of the general population (Redko et al., 2006).

We conducted a search of the published literature to find studies which examined wait times for drug treatment generally and for pharmacotherapy maintenance treatment. The literature is relatively small (with about 25 papers located). We examined the published reports for the average length of waiting times and the proportion of those who enter a waiting period who subsequently receive drug treatment. We summarise the data by country[4].

In research from the USA, the resounding message from the papers we located is that there is insufficient treatment, and that waiting times are lengthy and many people who enter a waiting period do not end up accessing any drug treatment. Waiting times ranged between 0 days and 384 days (Hoffman et al., 2011). Carr et al. (2008) reported that the average waiting time for treatment entry (the time between assessment and treatment entry) was 65 days, in Ohio, USA. The proportion of people who enter a waiting period for MMT and then subsequently do not enter drug treatment reportedly ranges between 30% and 80% (Gryczynski et al., 2011). In one USA study, only 21% received MMT after 4 months of waiting (Gryczynski et al., 2009).

[4] There is another literature examining whether waiting periods make a difference to treatment outcomes, which we do not summarise here. See (Addenbrooke and Rathod, 1990; Albrecht et al., 2011; Best et al., 2002; Brucker, 2010; Carr et al., 2008; Chun et al., 2008; Donmall et al., 2005; Hoffman et al., 2011; Peles et al., 2012).

In UK research specific to pharmacotherapy maintenance, the average waiting time between referral and first assessment was 8 weeks (range 0-52 weeks) and the average waiting time between assessment and treatment admission was 4 weeks (range 0-30 weeks) (Donmall et al., 2005). In another study, there was an average wait time of 7.2 weeks from referral to assessment; and 10.6 weeks from referral to first dose of methadone (Luty, 2002). In this same study, 18% of clients had longer than 10 weeks wait to their initial assessment; 25% had a 7 day wait to initial assessment; however 45% of clients received methadone within 24 hours of their assessment (Luty, 2002). This shows the difficulty of statistical averages for waiting times.

In Canada, at any one time 20% of clients of the Supervised Injecting Centre reported trying but being unable to access treatment in the last 6 months (Milloy et al., 2010). In Israel between 2003 and 2009, 24% of patients did not wait for admission to OST, whereas for the 76% who were required to wait, the average length of the waiting period was 1.1 years (Peles et al., 2012).

In research from New Zealand, and specific to pharmacotherapy maintenance, Deering (2011), surveyed clients and service providers about the length of waiting time for treatment entry. Clients reported an average of 4.4 months wait to enter treatment. On the other hand, service providers reported an average of 1 month waiting times. Donmall et al. (2005) concluded that service provider's perceptions of the length of waiting times were not always accurate.

There are a number of reasons why the quantification of numbers of people waiting to enter treatment cannot be used as a simple measure of unmet demand:

- The very knowledge that there is a waiting period discourages initiation of service contact (Hadland et al., 2009; Milloy et al., 2010; Peterson et al., 2010; Redko et al., 2006), which remains that waiting lists underestimate potential demand
- a proportion of people on waiting lists never enter treatment, so that those who do ultimately enter treatment are likely to be different from the waiting list drop-out groups.
- Multitudinous factors (both individual and system) impact on waiting times and also on outcomes. For example, Carr et al. (2008) have shown that the length of waiting time is associated with individual characteristics such as problem severity (longer wait associated with greater problem severity). Downey et al. (2003) found gender differences in waiting times (women waited longer to enter treatment than men). Donmall et al. (2005) found that individual and agency factors affect both wait times and attrition from wait lists. These

studies reinforce that waiting time is not independent from individual, agency and system characteristics (discussed in greater detail below).

In summary, at a simplistic level, the existence of waiting lists and the average length of time that people have to wait for treatment provides one measure of unmet demand for OTP. However, as can be seen from the above brief review, the data on waiting lists and length of time waiting is highly variable, and dependent on multiple factors other than treatment slot vacancies. "...the queue is an arbitrary snapshot, reflecting only a truncated frame" (Rotstein and Alter, 2006, p. 3157). The notion of 'waiting' is highly individualised, dynamic and driven as much by service capacity as by extraneous factors such as the attractiveness of treatment and the perceived likelihood of treatment entry.

Additionally, knowing the numbers on a waiting list does not then inform the service planner about the number of treatment places required. This is because there is a dynamic interplay between the numbers of people waiting for treatment, the length of time they wait, the numbers in treatment, the average length of stay in treatment (the rotation through treatment places) and the overall treatment capacity. This is amply demonstrated in research by Kaplan & Johri (2000) who examined the number of treatment places that would be required in San Francisco to meet identified demand from waiting list data. In their modelling work, they demonstrated that with varying tolerance for delay (in wait-listed patients), the numbers of treatment places required were significantly higher when wait was one day, compared to one week[5]. The measurement of waiting times is also highly fraught – at what point does someone 'count' as being in a period of waiting? Prospective clients may find treatment elsewhere but remain on a list; some agencies may prioritise certain clients (eg pregnant women) hence influencing the demographic profile of waiting clients. The very existence of a waiting list may deter prospective clients from seeking treatment, despite a desire for treatment. Waiting lists may also influence retention – for example waiting lists may induce some people to stay in treatment longer if it is perceived to be hard to return to treatment (and conversely, the absence of perceptions of wait may induce greater rotation out of treatment). Waiting lists may also shift demand to other regions – knowing there is a waiting period in one area may encourage demand in other areas where waiting times are lower. All these factors compromise the extent to which waiting times accurately reflect unmet demand.

[5] To expand more fully on Kaplan (2000): in their model they had 6,300 opioid dependent people not in OST plus 1,400 waiting for OST, suggesting that the service capacity was 7,700 (6300 + 1400). However, when modelled taking into account the length of time people were able to wait (tolerance for delay) plus average length of treatment (ie exit rate), in actuality the numbers of treatment places require to meet demand if waiting time was 24 hours was 11,500 places; if it was one week, the number of required treatment places was 9,980. And if the tolerance for delay was one year, the number of treatment places was 6,710 – lower than the 7,700 based on a simplistic calculation.

Furthermore as treatment places increase/expand, waiting times can increase (sometimes referred to as 'induced demand' Rotstein and Alter, 2006). For example, Brands, Blake and Marsh (2002) found that expansion of MMT in Ontario increased the demand for treatment from a specialist treatment centre, whilst also expanding numbers in treatment through primary care settings. Likewise in the UK between 1995 and 1999 there was a doubling of OTP treatment places (and some additional funding), and across the same period, waiting times went from 3.6 weeks to 8.4 weeks (Stewart et al., 2004). While apparently counter-intuitive, it is a common phenomenon – increasing supply produces increasing demand. It also highlights that one shouldn't focus only on unmet demand when determining the need for extra treatment places – the extent of unmet need is important to take into consideration.

In light of the challenges for measuring unmet demand, we seek alternative ways to measure the in-need population. One possible way to improve the estimates for health planners is to build more criteria than simply meeting diagnostic criteria – as we have shown above, diagnostic criteria themselves are technically correct for estimating unmet need, but are likely to be too broad for estimating unmet demand. In some recent work we completed for a specialist youth service in Victoria, Australia we used criteria based on severity of AOD problems, coupled with vulnerability. See table below for the criteria, which were developed by youth specialists (Bruun and Mitchell, 2012).

Table 5: Problem severity and vulnerability

Moderate and severe AOD problems (defined as meeting at least one of the following dot points):

- Dependence on any substance based on SDS cut-off
- Use 4 or more substances in last month
- Any IV use
- Any current daily use of AOD (excl tobacco).

High vulnerability (defined as meeting at least one of the following dot points):

- Housing instability
- Comorbid mental health problems (K10 = 27)
- Poor physical health
- Relationship conflicts
- Crime
- No meaningful activity

The challenge here is to be able to operationalise these clinical criteria of use and vulnerability from the data sets that are available. For example, severity of dependence syndrome (SDS) is not routinely collected in the large administrative/population datasets. In lieu of SDS scores, we used diagnostic criteria. In some cases, there was no replacement variable, such as 'relationship conflicts' or 'no meaningful activity' - general population surveys do not collect these variables. Having operationalised the criteria to the best of our ability (see Attachment 1), we examined three estimates in two different datasets (both general population; household survey and NSMHWB). The three estimates were:

- Model 1= High vulnerability only
- Model 2= DSM-IV abuse/dependence only / Severe AOD problems only
- Model 3= DSM-IV abuse dependence *and* high vulnerability / Severe AOD problems *and* high vulnerability.

As this work concerned young people, we estimate the number of young people aged between 12 and 21 years, who would meet the criteria for the three models. The results are presented in table 6. The results for the NSMHWB are displayed first followed by the NDSHS results.

Table 6: Population estimates for Victorian youth: severity and vulnerability based on data from the National Survey of Mental Health and Wellbeing 2007 and the National Household Survey 2010.

	High vulnerability		**Alcohol**		**Illicit drugs**		**Substance use**			
	NSMHWB								NDSHS	
	%	Vic pop aged 12-21	%	Vic pop aged 12-21	%	Vic pop aged 12-21	%	Vic pop aged 12-21	%	Vic pop aged 12-21
Model 1	3.45	25,325	-	-	-	-	-	-	3.85	28,261
Model 2	-		1.32	9,690	0.37	2,716	1.45	10,644	0.39	3,817
Model 3	-		0.65	4,771	0.23	1,688	0.73	5,359	0.21	2,055

Notes: Model 1= Estimates of high vulnerability only, Model 2= Estimates of DSM-IV abuse/dependence only, Model 3= Estimates of DSM-IV abuse dependence *and* high vulnerability. Estimates are made using the estimated residential population as of June 2010 (Victorian population, aged 12 to 21 years = 734,057 (ABS data).
The rates of alcohol and other problems and vulnerability were taken from Australian (national) data, and applied to the Victorian youth sample. This assumes that the rate of problems and vulnerability is not substantially different between Victoria and the rest of the nation.

A number of observations can be drawn from the above data. If the need estimate is derived solely on the basis of substance use, there may be 25,000 or so young people in need of treatment. However if health planners are concerned with ensuring services to the highly vulnerable group of young people, the numbers in need are substantially smaller (between 3,800 and 9,000). Furthermore, if health planners are only concerned with ensuring sufficient services for those young

people who are both alcohol or other drug users and who are highly vulnerable, the in-need population educes to between 2,000 and 4,000 young people[6].

These figures do not provide sufficient reassurance to health planners – and demonstrate how the choice of datasets (two are compared here) along with the choice of operationalisation of criteria plus the criteria themselves can have a substantial influence on estimates of the in-need population.

More sophisticated planning models

What becomes apparent given all the above is that simple way of estimating unmet need or unmet demand is confounding. But perhaps more compelling is the argument that any endeavour to estimate unmet need or unmet demand as per the above approaches does not take into consideration a number of other features which are essential for health planners. Most people who consume substances are polydrug users – hence an estimate of the need or demand for alcohol treatment cannot be divorced from other forms of treatment. (There are multiple double-counting problems in need and demand estimates). In addition, health planners need to consider which treatments are more cost-effective for which population group. Thus planning needs to account for different treatment types and their relative intensity. Not everyone with a substance use disorder requires the full array of treatment interventions – withdrawal, counselling and residential rehabilitation. Some people respond to brief interventions. Thus, health planners need more sophistication in developing suitable predictions for resource allocations that can accommodate variations in both client severity and in treatment types. There are two such models in development at present, and these are briefly summarised below.

DA-CCP – one example of a model to predict unmet demand

The Drug and Alcohol Clinical Care & Prevention (DA-CCP) national planning model has been developed in order to facilitate planning for alcohol and other drug services in Australia, and provide a basis for national consistency in approaches to planning across all the Australian health jurisdictions. The specific objectives of the project were: to build the first national population based model for drug and alcohol service planning; to estimate the need and demand for treatment; to use clinical evidence and expert consensus to specify optimal care packages; and to calculate the resources needed to provide these care packages. The model followed the principles of population-based planning that were used in the Mental Health Clinical Care and Prevention (MH-CCP) model of 2000 (New South Wales Department of Health, 2001; Pirkis et al., 2007) and is known as DA-CCP

[6] The YSAS service sees about 2,300 young people per annum.

(Drug and Alcohol Clinical Care & Prevention). In summary, the model estimated the prevalence of substance use disorders, by drug type, age group, and severity and then used expert consensus to estimates demand for treatment. This epidemiology was then distributed between service types, referred to as care packages that represented evidence-based and/or expert judgement regarding care for one year. The model calculates the resources required to deliver that level of care. There are thus four essential components: the epidemiology, treatment need and treatment demand, care packages and resource estimation. The model also covers harm reduction services, and contains the functionality to include prevention activities across the whole population.

Canada model – needs-based planning model

This work, led by Brian Rush (Rush, 2013) has entailed the development of a needs-based planning model for Canadian provinces. The model is predicated on different categories of problem severity, reflecting tiers of a population health pyramid, such that the need for more intensive treatment and support increased for people in the higher compared to lower tiers. The estimates of rates of help-seeking varied by the tiers and the model developers made extensive use of Delphi procedures to derive estimates for the model. In a similar way to DA-CCP the model includes a variety of treatment types, including withdrawal management, community and residential services as well as screening, brief intervention and referral to treatment from generalist services.

Despite the sophistication associated with both these models, and their attention to important aspects such as treatment types and levels of acre, both models still rely on prevalence estimation for the underlying population disorder rates. And both models rely on expert judgement to ascertain demand for treatment – what appropriate rate to use from the total potential number in need of treatment who will seek treatment if the treatment services were appropriate, available and attractive.

Summary and issues

Both unmet need and unmet demand are important estimates in planning for services – while the former likely overestimates the true proportion of people who would access treatment, the latter underestimates the true proportion because it does not accommodate those who do not attempt to seek treatment but who would if the treatment service system was appropriate for them.

In essence, the challenges in estimating unmet need and unmet demand are the inaccuracy of population prevalence data; the inaccuracy of current treatment numbers; and the lack of suitable

data on demand for treatment. Even if we were to have accurate data for these aspects, the health planners are still faced with the challenge of interpreting what the numbers mean for treatment places.

Understanding unmet need and unmet demand cannot be divorced from the treatment service system. Unmet demand can be driven by lack of availability of services, but also be driven by service and agency characteristics. For example, the distribution of treatment places between specialist service providers and general medical practitioners is important; the attractiveness and accessibility of services drives demand for services.

Geographical variation is another important consideration. Health planning analyses frequently focus on unmet need and unmet demand at a state level. This masks substantial regional or local area variation. Geographical variation in unmet need for illicit drug treatment has been shown in USA data. The USA 2009 National Survey on Drug Use and Health survey (United States Department of Health and Human Services. SAMHSA, 2010) showed variation in unmet treatment need between a high of 88.2% for the west south central region; and a 'low' of 71.4% in the middle Atlantic region. In 2010 the USA figures revealed additional variation between counties that were categorised as large metropolitan, small metropolitan and non-metropolitan (urbanised, less urbanised and completely rural) which revealed the lowest rates of unmet treatment need were found in the three non-metropolitan counties (although still amounting to about 70% unmet need) (United States Department of Health and Human Services. SAMHSA, 2010). Canadian provinces also show significant variation in methadone maintenance treatment rates from a sample of injecting drug users ranging from 18% in Quebec City to 46% in Edmonton (Fischer et al., 2005).

Luty (2002) describes the geographical variation in waiting times for drug treatment across England and Wales. While the statistical average length of wait was 7 weeks (across the country), this varied between 7 days and 10 weeks depending on the location (local health authority). Gryczynski et al. (2011) make the important point that local treatment systems have unique patterns with respect to treatment access, and management of prospective clients.

The geographical variation in unmet need and demand is consistent with a conceptual model of service utilisation that takes into consideration individual characteristics (predisposing factors, enabling factors and need factors) along with those of the environment (resources and organisation) and social norms (societal determinants: technology, norms) (Andersen and Newman, 2005). In

Canadian research on unmet need for mental health services, the geographical variation in availability of mental health services between health regions accounted for service use (that is supply drove variation in MH service utilisation) (Diaz-Granados et al., 2010). At the same time, individual characteristics (such as gender, age, household income, and education) were also associated with MH health service utilisation, but the between-region variability was largely accounted for by supply of services (Diaz-Granados et al., 2010).

Whilst focussed on mental health service utilisation, the work from Munson et al. (2012) provides a framework for understanding unmet need and unmet demand in young people. In qualitative work interviewing sixty young people (18 to 25 years of age), Munson et al. (2012) found that the experiences of young people represent 'dynamic' characterisations of treatment seeking – being both cross-sectional and time variant. Service use changed over time; for some young people continuous treatment, for others single or multiple gaps in treatment, which were largely driven by changes in the young person's perceptions of his/her own needs as changing, or perceptions about the effectiveness of treatment. A variety of factors were derived that were associated with service use. These included social and normative factors, perceived obstacles, competing demands, and knowledge. The authors note that all these factors can change within an individual over time, accounting for the dynamics of treatment seeking.

There is not a clear relationship between generating new treatment places and meeting demand. Studies have demonstrated that when new treatment places are established (and/or existing services are improved) demand for treatment increases. A number of papers have described what occurs in the context of increased number of OTP places (Bammer et al., 2000; Brands et al., 2002). In the only published Australian research, Bammer and colleagues (2000) reported that the expansion of the Canberra OTP program was associated with a temporary reduction in length of retention in the OTP program. It was also associated with reduced demand for other treatment (in this case methadone reduction programs), as well as continued waiting lists (Bammer et al., 2000) despite the expansion. Therefore simply providing more places based on unmet need or unmet demand estimates will not necessarily meet demand. Additionally, the actual number of new treatment places that should be established to address the service gap cannot directly be estimated from the unmet need and demand figures. As described earlier, the work of Kaplan & Johri (2000) shows that the number of treatment places required is not simply a function of the number of people out of treatment, but also a function of the retention time in treatment, the cycling behaviour of patients and individual's tolerance for delay. The extent to which treatment services

are accessible, attractive and perceived to meet the needs of patients is also essential information in managing unmet demand. Lastly, we want to reinforce that unmet need and unmet demand estimates are subject to uncertainties and in reality rates can change on a daily basis.

Acknowledgements

This paper was developed out of a number of pieces of commissioned research including from the NSW Mental Health and Drug and Alcohol Office, the Youth Substance Abuse Service, Victoria and work completed as part of the DA-CCP model, funded by the Commonwealth Department of Health and Ageing and the NSW Ministry of Health (Mental Health and Drug and Alcohol Office). Prof Alison Ritter is funded by an NHMRC Senior Research Fellowship. Dr Matthew Sunderland is funded by an NHMRC Postdoctoral Fellowship. Dr Jenny Chalmers is funded out of Drug Policy Modelling Program core funds (Colonial Foundation Trust).

Attachment 1: Operationalisation of the severity and vulnerability criteria

NSMHWB 2007

Moderate and severe AOD problems:

- Met DSM-IV criteria for substance dependence in the past 12 months
- Met DSM-IV criteria for substance abuse in the past 12 months

High vulnerability – at least one of the following:

- High psychological distress measured by meeting the cut off of 22 or more on the Kessler 10 Psychological distress scale. We chose 22 rather than the 27 used in the YoCo because the ABS cut-off for high and very high psychological distress is >22.
- The presence of one or more physical condition. Operationalised through the NSMHWB question: "In the past 12 months have you had or received treatment for... asthma, cancer, stroke, heart conditions, rheumatism or arthritis, diabetes/high blood sugar levels, and other conditions (hay fever, sinusitis, emphysema, bronchitis, anaemia, epilepsy, oedema, hernias, kidney problems, migraine, psoriasis, stomach ulcer, thyroid problem, tuberculosis, and back or neck pain)".
- Once homeless. Operationalised through the NSMHWB question: "Have you ever in your life been homeless?"
- Once in corrective services. Operationalised through the NSMHWB question: "Have you ever in your life been in corrective services?"

We derived 3 estimates (Models) from the NSMHWB data:

Model 1= High vulnerability only

Model 2= DSM-IV abuse/dependence only

Model 3= DSM-IV abuse dependence *and* high vulnerability.

NDSHS 2010

Severe AOD problems:

- Operationalised by determining if at least three separate substances were used in the past month (substances included: alcohol, cannabis, ecstasy, amphetamine, cocaine, hallucinogens, inhalants, heroin, ketamine, GHB, pain killers, tranquillisers, and methadone) *OR* any injecting drug use *OR* any daily use of at least one substance (substances included: alcohol, cannabis, ecstasy, amphetamine, cocaine, hallucinogens, inhalants, heroin, ketamine, GHB, pain killers, tranquillisers, and methadone).

High vulnerability – at least one of the following:

- High psychological distress measured by meeting the cut off of 22 or more on the Kessler 10 Psychological distress scale. As above, we chose 22 rather than the 27 used in the YoCo because the ABS cut-off for high and very high psychological distress is >22.
- The presence of one or more physical condition. This was operationalised through the NDSHS question: “In the past 12 months have you been diagnosed or treated for... diabetes, heart disease, hypertension, low iron/anaemia, asthma, cancer, and other illness (sexually transmitted infections, hepatitis B or C, other)”.

We derived 3 estimates (Models) from the NDSHS data:

Model 1= High vulnerability only

Model 2= Severe AOD problems only

Model 3= Severe AOD problems *and* high vulnerability.

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