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# Estimating need and demand for treatment – a background briefing

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## **Working Paper**

This working paper has been prepared as part of the Commonwealth Department of Health and Ageing (DoHA) commissioned review of alcohol and other drug treatment service funding, being undertaken by the Drug Policy Modelling Program. The review aims to inform the distribution of Commonwealth government alcohol and other drug treatment funding.

**Comments and feedback on this Working Paper are welcome**, and can be made via email to Alison Ritter (<u>Alison.ritter@unsw.edu.au</u>).

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# Summary

Scope and definitions

- In order to review and inform the distribution of Commonwealth government alcohol and other drug treatment funding, an analysis of need and demand for treatment is required.
- While estimating both the need and demand for alcohol and other drug (AOD) treatment is necessary, it is also extremely challenging, as we demonstrate in this working paper. Two central concepts are unmet need and unmet demand.
- "Unmet need" is defined as the proportion of people who meet diagnostic criteria for substance use disorder but who are not in receipt of treatment.
- "Unmet demand", on the other hand, is defined as the proportion of people who seek treatment but are unable to access it.
- 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 would seek treatment if the treatment service system was appropriate for them.

Estimating unmet need

- In order to measure 'unmet need', the underlying diagnostic rate in the population is required. The accuracy of the diagnostic rate can be variable. The diagnostic rate can be replaced with rates of harmful consumption. In either case, though, it presumes that those identified in the underlying prevalence are by default in need of treatment. This can be contested.
- In addition to knowing the underlying prevalence rate, estimates of unmet need for treatment require an accurate assessment of numbers currently in treatment (to be subtracted in order to derive unmet need). Estimating the number of people in treatment in Australia at any one time is difficult. While we know a lot about the numbers of episodes of care in specialist AOD treatment, we know much less about the quantum of AOD treatment delivered in other settings, such as primary care, hospitals, and other community-based services.
- The concept of unmet need must be tempered with an appreciation of its limitations. It is likely to be an overestimate because it assumes that formal treatment services are necessarily always required for remission of AOD problems. This is clearly false.

Estimating unmet demand

• Arguable, unmet demand is a more important measure for treatment planning, because it only includes those who have unsuccessfully sought treatment. There are three possible

ways of measuring unmet demand: current treatment utilisation; intention to seek treatment; and analysis of waiting lists.

- Current treatment utilisation measures met demand only. And, as above, relies on accurate data about how many people receive AOD treatment. It is a limited proxy measure of unmet demand.
- Surveys asking people about their intention to seek treatment are useful in estimating unmet demand. In general, however, the survey results show that very few people self-identify as needing treatment.
- Waiting lists can measure unmet demand however there is not a systematic approach to the collection of data about waiting times. The very knowledge that there is a waiting period may discourage initiation of service contact; prospective clients may find treatment elsewhere but remain on a list; a proportion of people on waiting lists never enter treatment; and more fundamentally a waiting list only exists if there is an actual service there may be areas of demand where there are no services and hence no waiting lists.

## Other issues

- The simple quantum of unmet need or unmet demand is limited in its usefulness unless it is
  matched with different treatment types and their relative intensity. Not everyone with a
  substance use disorder requires the full array of treatment intervention. Thus, health
  planners need more sophisticated planning approaches that can accommodate variations in
  client severity, treatment types and client characteristics. This moves us beyond simple
  estimates of unmet need and unmet demand, and considers unmet need and demand for
  whom and for what type of treatment.
- DA-CCP was 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. DA-CCP estimates the prevalence of substance use disorders, by drug type, age group, and severity and then used expert consensus to estimate demand for the different treatment types (care packages).
- Understanding unmet need and unmet demand cannot be divorced from the features of treatment services (attractiveness, accessibility, affordability, geography and so on).

# Implications for the review

 The Review will focus on available prevalence data, and follow DA-CCP in its use of the NSMHWB as the most reliable source for diagnostic rates. Consideration of measures such as harmful consumption may contribute to better understanding the full range of possible estimates of need for treatment.

- We do not have comprehensive data regarding current treatment numbers. This requires analysis across multiple datasets. The Review will undertake a comprehensive attempt to document met demand, that is the number of people receiving AOD treatment in Australia. This will entail the use of multiple datasets, including the specialist AOD database (AODTS-NMDS), the opioid pharmacotherapy database (NOPSAD), general practice data (BEACH data) and hospital admissions data (NHMD). However, it is likely that there will be missing data and a level of uncertainty regarding the final total numbers in receipt of AOD treatment.
- The gap analysis (unmet need and unmet demand) will rely on DA-CCP, and the expert consensus reached to date about treatment rates and treatment demand.
- The Review will consider estimates of need and demand for treatment in the context of considerations about client characteristics, the supply of treatment and features of treatment.

#### Introduction

Planning for alcohol and other drug (AOD) treatment services requires an understanding of the population in need of treatment and the numbers who do receive treatment. Despite the centrality of these concepts for treatment planning, there has been surprisingly little work on developing conceptual or practical planning methods or models. 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 assist health planners. The paper focuses initially on unmet need and provides examples of the difficulties associated with the accuracy of such estimates. This is followed by analysis of the methods of estimating unmet demand. We then turn to other considerations in planning treatment services around need and demand – including the dynamic interplay between demand for treatment and service system characteristics. The paper concludes with an examination of the implications of this work for generating Australian estimates of need and demand for AOD treatment.

#### **Unmet need**

Need for treatment is defined by the presence of a disorder (formal diagnosis) 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 and who would benefit from treatment but do not access it. The conceptualisation of unmet need for treatment comes from medicine and mental health – a diagnosis of a broken leg, or cancer, requires treatment. A diagnosis of schizophrenia requires treatment. Unmet need requires knowledge of the extent of prevalence of the disease or disorder and the existence of an effective treatment. There are two components to establishing unmet need: the number of people who meet diagnostic criteria; and the number of people who receive treatment. Unmet need is then calculated by the following formula:

Unmet need = number of people meeting diagnostic criteria – number of people receiving treatment.

We deal with the two parts to the equation in turn, starting with population prevalence (the number of people meeting diagnostic criteria).

# Estimating the underlying population prevalence

Estimates of unmet need for treatment rely on the presence of a diagnosable disorder. It is therefore specific to one disorder, and in the case of AOD this means that there are unmet need estimates for each alcohol and other drug use disorder (alcohol abuse/dependence; cannabis abuse/dependence and so on). The inclusion of both the abuse and dependence categories of the diagnostic system raises questions about the match between the formal diagnostic system and the notion of need for treatment. It is not clear that all people who meet criteria for abuse would appropriately *need* treatment. At the same time, there may be people who do not meet the formal diagnostic criteria (so-called sub threshold cases) who may be appropriate for treatment (Druss et al., 2007). Thus one assumption behind the definition and measurement of unmet need for AOD treatment is that substance use diagnosis is an accurate reflection of those who need treatment in the population. This may be the case for medical diseases and mental health disorders (although see Sareen et al., 2013) but may be less applicable for AOD. "Many experts have argued that diagnosis alone is not a good proxy for treatment need" (Sareen et al., 2013, p. 1941).

At one level, diagnostic criteria are arbitrary. This has most recently been demonstrated in the changes introduced between DSM-IV and DSM-V. As shown by (Mewton et al., 2011; Mewton et al., 2013) changing the diagnostic criteria results in changes to the prevalence estimate (for example the prevalence of cannabis use disorder decreased from DSM-IV (6.2%) to DSM-5 (5.4%) (Mewton et al., 2013). For establishing unmet need for treatment, this means that the unmet need estimate will depend on which diagnostic system is used to provide the population prevalence figure. And as noted above, diagnostic criteria themselves may not be an appropriate match to treatment need.

One alternative to formal diagnosis is the use of harmful consumption measures (Fischer et al., 2012). (Indeed, there has been a recent argument put forward to replace diagnosis with 'heavy use over time – a consumption measureJ. Rehm et al., 2013). Unmet need, in this formulation, would be the difference between the proportion of people estimated to engage in harmful or 'at risk' consumption, and the numbers of people in treatment. General population surveys of alcohol and drug use could then be used to assist in estimating the proportion of the population in need of treatment. However general population surveys tend to underestimate consumption (largely because of the sampling frame for such surveys Degenhardt et al., 2011). On the other hand, there is concern that harmful consumption rates will substantially overestimate the population in need of treatment. Not everyone who consumes alcohol or drugs to predefined 'harmful' levels is likely to benefit from or requires formal treatment.

In general, greater precision in the underlying population prevalence estimation will result in more accurate measurement of unmet need for treatment. 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), can assist in establishing more accurate population prevalence. Put simply, these methods use indicators from multiple sources, such as mortality databases, arrest statistics and emergency department presentations to calculate the size of the total population. Because the methods use indicators that are likely to be associated with need for treatment, the prevalence estimation derived from these may be most fit for purpose in estimating unmet need. Nonetheless, there are a variety of technical issues associated with these epidemiological methods (see Degenhardt et al., 2004), and they are time consuming and require specialist epidemiological expertise.

In addition, there are lags in the prevalence data. For example, the latest National Survey of Mental Health and Well Being (NSMHWB) was undertaken in 2007. However, the population may have changed since 2007; especially in light of emerging trends. 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.

We now turn to the second half of unmet need estimation – the number of people in treatment.

#### Estimating the underlying treatment rate

The second component of unmet need is data about the numbers of people in receipt of treatment. Effectively this is *met need*, which needs to be subtracted from the total need population in order to determine the *unmet* need. Establishing the number of people in AOD treatment is surprisingly difficult. In the first instance, a clear conceptualisation of "treatment" is required. What is AOD treatment? The UNODC standard for drug demand measurement specifies that "Drug treatment is considered to be any structured intervention aimed specifically at addressing a person's drug use" (UNODC, 2006, p. 23). While some types of treatment readily come to mind, such withdrawal, residential rehabilitation, assessment and brief intervention and pharmacotherapy maintenance, there are other types of interventions that may meet an individual's needs. Some intervention. For example, the provision of housing or employment may be one way in which an individual ceases or reduces substance use. While this would not meet the UNODC definition of 'drug treatment', for

our purposes here (defining the proportion of people in need of treatment), the inclusion of these interventions may be important. Their exclusion may mean that unmet need is overestimated.

There are also many forms of 'treatment' which exist outside the formal treatment system. Self-help is one such example. Another is the support provided by families and friends. There is no standard for how self-help should be considered or managed within unmet need estimates. In theory, health planners do not need to plan for services for those who are in receipt of self-help. That is, recipients of self-help should not be classified in the 'unmet' need numbers. Hence the treatment utilisation numbers need to be inclusive of self-help. However, there is no record of the number of people receiving self-help (and it does not form part of the international standards for measurement of drug treatment: UNODC, 2006). In addition, many people receiving self-help are also in receipt of other forms of treatment simultaneously. It is for this latter reason, that it appears reasonable to omit numbers in self-help or other informal treatment settings from the met need estimate, although this is not ideal.

Recognised treatment for a co-occurring problem that also effectively treats a substance use disorder is another consideration. In a USA study, mental health treatment amongst those with alcohol use disorders was more common that alcohol treatment (Edlund et al., 2012). Someone with depression and alcohol dependence, for example, may receive psychotherapy and antidepressant medication for the depression, without any formal alcohol intervention. The treatment for depression alleviates the alcohol use problem. Such a person would be 'counted' in the population prevalence for alcohol use disorder but the treatment received, being outside the AOD system, would not be counted.

Measurement of formal treatment has challenges. In the first instances, identification of the settings (and potential data sources) is required. The types of formal service settings where people may receive AOD treatment include:

- The AOD specialist system, where withdrawal, counselling, residential rehabilitation and pharmacotherapy maintenance are provided;
- General hospitals, where withdrawal services and brief interventions are provided;
- General practice, where withdrawal, brief intervention, and pharmacotherapy maintenance treatment are provided;
- Community health settings where counselling is provided;
- Welfare services where counselling is provided;

- Private psychologists, where counselling is provided;
- Private hospitals, where withdrawal, residential rehabilitation and counselling are provided
- Private psychiatrists, where withdrawal and counselling are provided.

The most readily available treatment data is that which is collected from specialist AOD services (the AODTS-NMDS). These data do not provide a count of the numbers of people, rather a count of the 'episodes of care'. It is possible that one person receives multiple episodes of care during the course of a year.<sup>1</sup> The limitations associated with the AODTS-NMDS for the purposes of estimating treatment coverage have been noted by Fischer et al (2012). The treatment numbers in the specialist system do not represent all those receiving care. The number of people receiving treatment from general hospitals and general practice settings may amount to an equivalent number of people to that in the specialist settings (effectively halving the unmet need estimate). There is no central database that collates data on numbers in treatment across all these settings. And in some instances, such as general practice, there is no record of services received (as there is no item number related to AOD aside from specialist Addiction Medicine item numbers). Double counting is also a challenge – people may attend more than one service within a year , and may receive treatment from multiple services simultaneously. Unique identifiers across all datasets would be required to eliminate double counting.

The time period for which 'unmet need' applies is also a consideration. In the prevalence estimation of the population, the usual time period is one year – that is, the number of people meeting diagnostic criteria within a 12 month period. Treatment data (met need) do not necessarily reflect a one year period: for example the pharmacotherapy data are numbers receiving medication on a single 'census' day; for the specialist AOD system, care that is received but yet to conclude is not counted.

In summary, a comprehensive approach to estimating unmet need requires accurate prevalence estimation of the size of the population in need and estimation of the numbers in receipt of treatment. This involves advanced epidemiology combined with analysis of treatment numbers across multiple treatment settings – hospital data, general practice data, welfare services, nonspecialist health services, the AOD specialist system, and self-help. Unfortunately, up-to-date epidemiological estimates and comprehensive data collections across all these treatment settings do not exist. Researchers and health planners need to turn to proxy measures and apply multipliers

<sup>&</sup>lt;sup>1</sup> AIHW has introduced a unique identifier to AODTS-NMDS which will enable future research to establish the difference between individuals and episodes of care. However this is not yet available.

based on sampled data. The ways in which both population prevalence and met need (treatment utilisation) are defined and measured will produce different estimates of unmet need (Mulvaney-Day et al., 2012). Transparency of method and clarity of definitions are essential.

International estimates of unmet need demonstrate just how large unmet need estimates can be. For example, in the USA unmet treatment need may be as high as 80 to 90% of the population in need (Becker et al., 2008; United States Department of Health and Human Services. SAMHSA, 2010). This is not unique to AOD treatment and applies equally to mental health treatment. For example, the treatment gap (unmet need) for depression was estimating globally to be 56.3%; and for generalised anxiety disorder 57.5% (Kohn, 2004). Figures around 50 to 70% would suggest a more than doubling of the existing treatment service capacity. Aside from the variety of issues raised above, unmet need may be an overestimate because it does 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 maturation and spontaneous remission are important to acknowledge (Walters, 2000). Indeed, Sareen et al (2013) have shown that people with a substance use disorder (and hence counted as 'in need') who have not received treatment are more likely to remit than those with a substance use disorder who received treatment. This demonstrates how measurement of unmet need based on diagnosis may substantially overestimate need for treatment. Thus, we draw a distinction between unmet need and unmet demand. "Unmet demand" 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 in accessing and entering treatment. Measurement of unmet demand is more challenging and complex than the measurement of 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 treatment utilisation

As noted in the above analysis of unmet need, it is not 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 respondents sought treatment. Thus, one can derive an estimate of met demand by self-reported service utilisation. For example, amongst young people (12 to 17 year olds) in the USA, the National Survey on Drug Use and Health (U.S. Department of Health and Human Services, 2006) found that 7% of those who met diagnostic criteria for alcohol use disorder received treatment; and 9% of those who met diagnostic criteria for drug use disorder received treatment. However, these figures do not quantify *unmet* demand, only *met* demand. Clearly this is less helpful 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

A second alternative method is to survey people about their intention to seek treatment, or their perceived need for treatment. This more closely approximates unmet demand than examination of met demand. This relies on self-report. 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), only 8.5% of those respondents with a substance use disorder perceived the need for treatment (Mojtabai and Crum, 2013). Perceptions about one's own need for treatment can also change over time (Munson et al., 2012). In the youth survey mentioned above, "very few of the youths who had not received treatment perceived an unmet need for treatment" <sup>2</sup> (U.S. Department of Health and Human Services, 2006, p. 1). Thus it is likely that perceived need for treatment may represent a lower estimate of unmet demand.

#### Waiting for treatment

<sup>&</sup>lt;sup>2</sup> The figures were 2.2% for alcohol and 3.5% for illicit drugs.

The third way of deriving an estimate of unmet demand is examination of waiting to enter treatment. 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 is therefore seen to be a proxy measure of unmet demand. In most instances, waiting focusses on 'waiting lists' (rather than self-reported experiences of waiting). 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 substance use disorders, the first difficulty we encounter is the definition of 'waiting time'. There are two predominant definitions used to define periods of waiting. 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 – for example how heroin dependent people perceive time differently from members of the general population (Redko et al., 2006).<sup>3</sup>

Waiting time has been reported in a number of different ways. One way is as a range of days, for example, waiting times for AOD treatment in the USA ranged between 0 days and 384 days (Hoffman, Ford, et al., 2011). Alternately, the average numbers of days waiting is reported, for example 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 percentage of people unable to access treatment is another measure that has been reported. For example, 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). Sometimes multiple measures are given, for example in Israel (between 2003 and 2009), 76% of patients were required to wait for methadone maintenance, and the average length of the waiting period was 1.1 years (Peles et al., 2012). Or, the percentage of people who did not receive treatment after waiting, for example in a USA study, only 21% of clients received MMT after 4 months of waiting (Gryczynski et al., 2009). There are no recognised standards for how waiting time should be measured or reported.

<sup>&</sup>lt;sup>3</sup> 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, Quanbeck, et al., 2011; Peles et al., 2012).

In the absence of formal waiting list data, surveys of perceptions of waiting times can be undertaken. One challenge with this, though, is the differing perceptions depending on who is asked. It appears that client perception of wait times and clinician perspectives of wait times can vary. In research from New Zealand, and specific to pharmacotherapy maintenance, Deering (2011), found that 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. In other work, 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 means that waiting lists underestimate potential demand
- A proportion of people on waiting lists never enter treatment
- 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 resulting in misinterpretation of unmet demand
- A waiting list only exists if there is an actual service there may be areas of demand where there are no services and hence no waiting lists
- Waiting lists may 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
- The measurement of waiting times is somewhat arbitrary at what point does someone 'count' as being in a period of waiting?
- 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. (See also Andrews et al., 2013). These studies reinforce that waiting time is not independent from individual, agency and system characteristics (discussed in greater detail below).

All these factors compromise the extent to which waiting times accurately reflect unmet demand.

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 AOD treatment. 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.<sup>4</sup>

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 should not focus only on unmet demand when determining the need for extra treatment places – the extent of unmet need is important to take into consideration. A final consideration, applicable to both unmet need and unmet demand, is that these are measures at a single point in time - both unmet need and unmet demand estimates are subject to uncertainties and in reality can change on a daily basis.

<sup>&</sup>lt;sup>4</sup> 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.

In summary, measurement of unmet demand can be undertaken in three different ways. Each of these has significant limitations, and full consideration of limitations of each method is required. In light of the review of both unmet need and unmet demand estimation, it appears that there are both strengths and challenges associated with many aspects of these measures. What becomes apparent is that simple ways of estimating unmet need or unmet demand are 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. We turn to these considerations next.

### More sophisticated planning models

The simple quantum of unmet need or unmet demand is limited in its usefulness unless it is matched with 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. In addition, unmet need or demand will vary by population characteristics such as age and gender) (as shown by Fischer et al., 2012). Thus estimates of unmet need or demand need to accommodate the specific drug type, plus the specific treatment type, plus population characteristics<sup>5</sup>. Thus, health planners need more sophisticated approaches to developing suitable predictions for resource allocations that can accommodate variations in client severity, treatment types and client characteristics. This moves us beyond simple estimates of unmet need and unmet demand, and considers unmet need and demand for whom and for what type of treatment.

There are two existing models that have been developed to address the relationship between need and demand estimation and client characteristics and treatment type. One of them is the Australian DA-CCP (Drug and Alcohol Clinical Care & Prevention) planning model (NSW Ministry of Health, 2013), which will be described in more detail below. The other is a model from Canada. This work, led by Brian Rush (Rush et al., 2012) 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 helpseeking varied by the tiers and the model developers made extensive use of Delphi procedures to

<sup>&</sup>lt;sup>5</sup> There are other considerations in unmet need and unmet demand – that is, who defines the need or demand? Implicit in this paper is the idea that the person him or herself and/or a clinician defines the need/demand for treatment. However, as pointed out by Robin Room, there are at least two other parties who define the need for treatment: the State (through programs such as diversion) and the family/significant other. (See Room et al., 1996; Storbjork and Room, 2008).

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.

### The Drug and Alcohol Clinical Care & Prevention (DA-CCP) planning model

DA-CCP (NSW Ministry of Health, 2013) was 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). 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.

Of most interest for this paper is the epidemiology, treatment need and treatment demand. The epidemiology for the model was based on the Australian Burden of Disease work (AusBod Begg et al., 2007) which in turn relied largely on the 1997 National Survey of Mental Health and Wellbeing (NSMHWB) (Australian Bureau of Statistics, 1998; Hall et al., 1999). The Composite International Diagnostic Interview (CIDI) was used as the interview tool to establish the rates of ICD-10 diagnoses of dependence and harmful use of alcohol, cannabis, sedatives, opioids, and stimulants. The last two classes (opioids and stimulants) are very low prevalence disorders in the general population, and as noted earlier in this paper, general population surveys underestimate the prevalence of these drug classes (Degenhardt et al., 2011; Hall et al., 2000). DA-CCP therefore sought alternate epidemiology for heroin and stimulants (amphetamine). DA-CCP does not account for poly-drug diagnoses, and therefore may require adjustment for potential double-counting of demand for treatment by a proportion who are poly-drug dependent.

DA-CCP distinguishes between mild, moderate and severe disability, because different care packages are required depending on severity. The division into mild, moderate and severe was facilitated by the available Australian data on disability weights from AusBod (Begg et al., 2007). The proportion of those meeting diagnostic criteria who would fall within the severe disability category, using the AusBod disability weights, was calculated first and combined with knowledge and expert judgement to divide the remaining numbers between mild and moderate disability.

Treatment need and treatment demand were established for DA-CCP based on existing research and expert judgement. 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 et al., 2009), 24% of respondents with substance use disorders used treatment services in the last 12 months. Expert consensus was then used to ascertain a realistic but optimal treatment demand rate for the model. The Tolkien work (Tolkien II Team, 2006) noted an ideal treatment coverage of 51% for alcohol use disorders (70% for harmful use and 30% for dependence. See also Andrews et al., 2004). Optimal treatment coverage, that includes consideration of the proportion of people who do not want nor seek treatment needed to be considered in light of these figures plus by drug type.

DA-CCP, as a research tool, will provide the possibility for analysis of the extent of demand for treatment by drug type and by treatment type for the review. When compared against current treatment utilisation (met demand), an analysis of the gap between met and unmet demand can be undertaken.

Despite the sophistication associated with DA-CCP, and the attention to important aspects such as treatment types and levels of care, DA-CCP still relies on prevalence estimation for the underlying population disorder rates. And the model relies 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. This leads into the final section of this working paper, where we discuss how the estimates of unmet need and demand cannot be divorced from consideration of the treatment service features.

#### **Other considerations**

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 likely to be one driver of whether people seek treatment or not. Other drivers are the attractiveness, affordability and accessibility of services. Thus demand for treatment is not divorced from the characteristics of the treatment service system.

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. 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). Aside from the importance of geographical variation in unmet need and demand, there are also dynamic interactions between locations, making it difficult to plan locally in isolation from other areas. For example, given that people move to get into AOD treatment when there is local excess demand, an increase in treatment places in one area may free up treatment places in another.

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 the availability of mental health services accounted for service use (Diaz-Granados et al., 2010). That is supply of treatment can drive the demand for treatment. As such any consideration of assessing unmet need or demand for treatment must take into consideration how treatment is supplied and configured. One useful model for this is from Australian researchers in primary health care. Seven dimensions of service system accessibility have been documented: availability; geography; affordability; accommodation; timeliness; acceptability and awareness (Russell et al., 2013). Availability (defined as the fit between the volume and type of services and the volume and type of population need) is regarded as one of the "basic structural elements" (Russell et al., 2013, p. 69) to health care planning. This working paper has focussed on availability (through unmet need and

unmet demand analysis) but it cannot be divorced from other components of effective treatment service system planning, as per the other dimensions listed above. For example, Munson et al. (2012) found that the experiences of young people seeking mental health treatment represent 'dynamic' characterisations of treatment seeking – being both cross-sectional and time variant. The notion of dynamic interplays between need for treatment and demand for treatment and the features of the systems of care and individual characteristics cannot be overstated.

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 pharmacotherapy maintenance 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 and may shift demand away from (or to) other AOD treatment types. 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.

#### **Summary and Conclusions**

1. 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. Both unmet need and unmet demand will be concepts used in the DoHA commissioned review of Commonwealth treatment funding.

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2. We do not have accurate population prevalence data. This means we cannot truly assess the numbers of people potentially in need of treatment. An important research task, beyond the scope of the DoHA review, is to improve population prevalence estimation. The Review will focus on available prevalence data, and follow DA-CCP in its use of the NSMHWB as the most reliable source for diagnostic rates. Importantly, however, ranges around the prevalence estimates will be used. This is because, as we have seen, diagnostic rates represent only one way of identifying the population in need. Consideration of measures such as harmful consumption may contribute to better understanding the full range of possible estimates of need for treatment.

3. We do not have comprehensive data regarding current treatment numbers. This requires analysis across multiple datasets. The DoHA review of AOD services funding will be a comprehensive attempt to document met demand, that is the number of people receiving AOD treatment in Australia. This will entail the use of multiple datasets, including the specialist AOD database (AODTS-NMDS), the opioid pharmacotherapy database (NOPSAD), general practice data (BEACH data) and hospital admissions data (NHMD). However, it is likely that there will be missing data and a level of uncertainty regarding the final total numbers in receipt of AOD treatment.

4. The gap analysis (unmet need and unmet demand) will rely on DA-CCP (NSW Ministry of Health, 2013), and the expert consensus reached to date about treatment rates and treatment demand. The review team will conduct further sensitivity analyses on the DA-CCP model to establish plausible ranges of resource requirements for Australia.

5. DA-CCP does not accommodate geography in the model. As the DoHA commissioned review is a national project, we will not generate geographically confined estimates of unmet need, demand or treatment utilisation. However, given our awareness of the importance of geography in health planning, a separate sub-project will examine how funders can incorporate geography (or spatial dimensions) into their assessment of needs and their approaches to treatment funding.

6. There are no systematic administrative datasets in Australia on waiting, although it is quite clear that people wait to enter AOD treatment in Australia. Given the complexity of analysing 'waiting' and the substantial limitations in interpretation of the data, as discussed in the above section, it is beyond the scope of the review to include analysis of waiting lists or waiting time. However, we encourage other research teams to undertake analysis of waiting for treatment in Australia, including both quantitative and qualitative data on waiting.

7. Understanding unmet need and unmet demand cannot be divorced from the features of treatment services (attractiveness, accessibility, affordability and so on). The review will consider estimates of demand for treatment in the context of considerations about client characteristics, the supply of treatment and treatment features.

We would be pleased to receive any comments on this Working paper. Please direct comments to: <u>Alison.ritter@unsw.edu.au</u>

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