The 2014 Adams – de Crespigny – Harvey Oration

'Speak Up' by Jennifer Holmes

I pay my respects to the traditional owners of this land that we are meeting on today and pay my respect to elders past and present. I would also like to acknowledge some people who have been significant influences on my career and publicly thank them for their mentoring, support and inspiration. Dr Edith Collins of the Drugs in Pregnancy Service at RPAH, Dr Lynette Cusack from South Australia, Dr Daryle Deering from New Zealand, Dr James Bell from Langton, Jude Byrne and Fiona Poeder from AVIL and NUAA and finally all you wonderful DANA colleagues and friends. It is a great honour for me to be delivering this oration as the three wonderful women Meredith Adams, Charlotte De Crespigny and Tonia Harvey have been wonderful colleagues and friends.

"Speak up" What a delicious topic for someone like me. Vocal!
There are so many topics I would love to speak up about:

- Alcohol taxation
- Our drinking culture
- Drug law reform
- Child protection
- Homelessness
- Inequality
- Leadership
- Service user/consumer participation
- Electronic medical records
- Medicare co payment

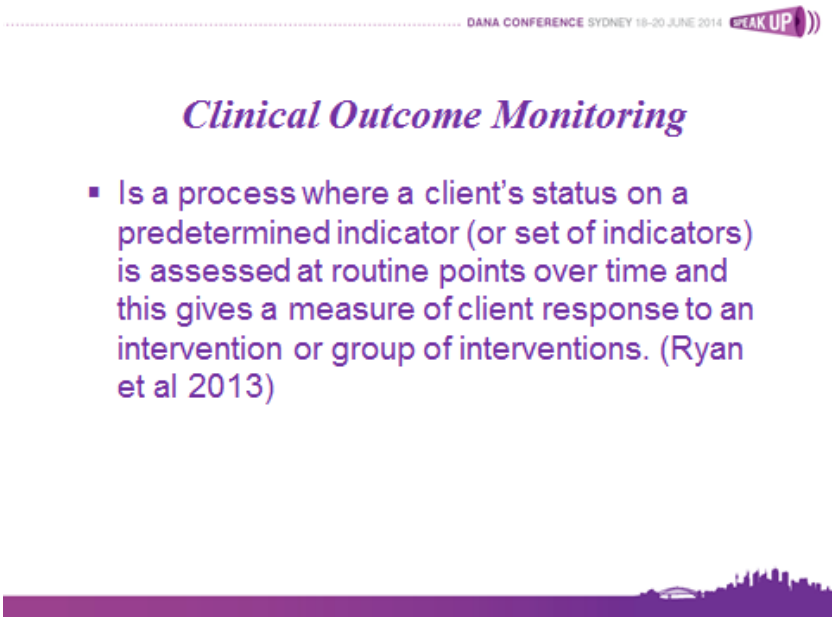
The list could go on for quite a while. There are so many things to be spoken about however today I have decided to refine my topic to what have been the enduring themes of my drug and alcohol nursing career.

There are three themes:

- Clinical outcome monitoring
- Structural and culture issues in opioid pharmacotherapy treatment
- Stigma and discrimination towards people who inject drugs

This may surprise you but I believe that these themes interrelate and by addressing one it can ameliorate the other. At this point I wish we could have a conversation rather than an oration. However that could take up the rest of the conference. When I first started preparing this speech it was based only my lived experience, observations and reflections on my career in the sector that I have great affection for but despair about our slow rate of change. However I also had a quick look at the literature to see if I could further develop my personal analysis. Let's begin.

Outcome monitoring in Drug and Alcohol treatment why is so hard? I went to a workshop in 1993. I came away inspired by Maree Teesson. It didn't seem to be rocket science.



You just need an instrument that measures drug use, health and social wellbeing and repeat it at regular intervals. I reckon I could get something useful implemented in the Opioid Treatment Program before the end of the year, two at the most. My aim was to get a drug and alcohol indicator added to the Australian Council on Healthcare Standards (ACHS) clinical indicator program. First we tried the Opioid Treatment Index. A great Australian research tool but those quantity/frequency fractions for drug use are not user friendly or meaningful to clients or clinicians. It was a bit long too.

Wow a new millennium! I was sure that this would be the dawn of a new era for outcome monitoring. Let's try the Brief Treatment Outcome Measure or BTOM as it was known. Unfortunately it was not very brief and there was minimal sustained uptake. Learning's from this project were that a top down approach with minimal clinical leadership and structural support was not the way to achieve clinical outcome monitoring for Drug and Alcohol treatment.

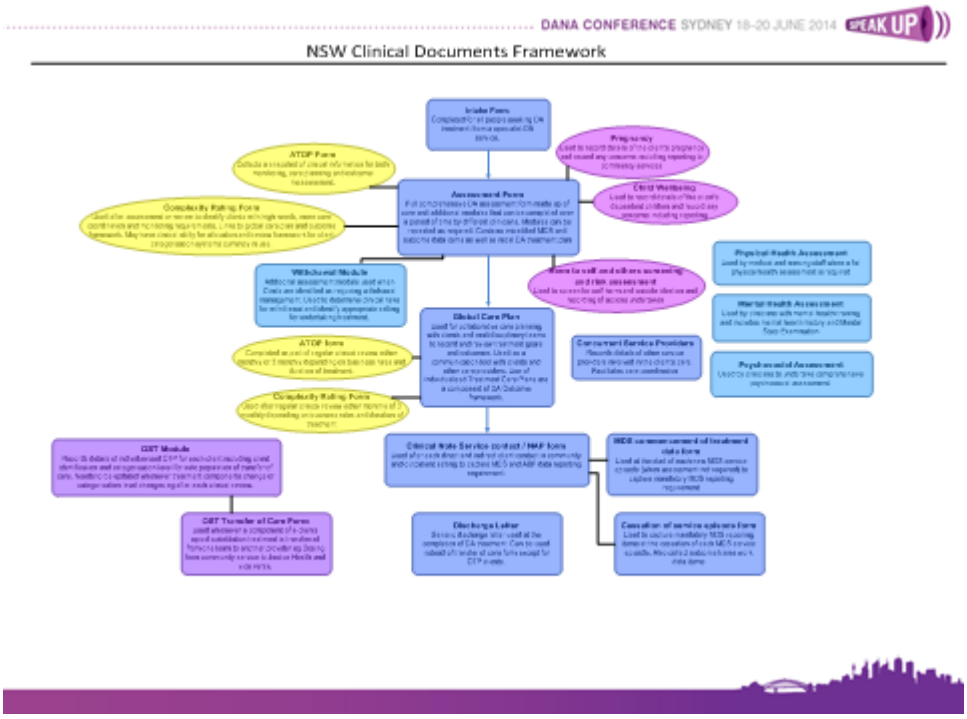
Another decade and monitoring in the drug and alcohol treatment sector continues to consist of measures of activity and throughput (e.g. number of service contacts and treatment episodes), with some 'baseline' client descriptors (e.g. NMDS demographics and principal drug of concern) and a broad categorisation of conditions of treatment cessation (e.g. service completed, transferred or referred, left without notice or died). Unfortunately this gives no indication of how effective a treatment service is in improving its clients' health.
According to the available literature and experience on the ground the implementation of outcome measures in the Drug and Alcohol sector has many challenges.
Barriers such as:

- length of the instruments;
- inadequate attention to communication and training;
- poor integration with clinical information systems;
- excessive data entry requirements;
- poor feedback for patients/clients/consumers, clinicians and administrators; and
- perception of outcome monitoring as a bureaucratic process of no value.

Thus there are few if any examples of successful application in the sector. It has been stated to me by senior public servant that it is widely perceived in NSW that it is not possible to introduce outcome monitoring in the drug and alcohol sector. It's just too hard!
I'm sorry but this is not OK it is time to speak up!

How can we work collaboratively and effectively with our clients if we cannot communicate outcomes that are easily understood by clients, their families and the community? Not to mention funders and politicians. Our inaction on the implementation of routine clinical outcome monitoring is doing our clients and the sector a significant injustice.

So what is the current state of clinical outcome monitoring in NSW? A short, one page instrument based on the UK Treatment Outcome Profile has been piloted and implemented in a range of drug and alcohol services in NSW. The instrument is called the Australian Treatment Outcome Monitoring Profile (ATOP). It is short, easy to use and score. The implementation has been a clinician led bottom up approach. The ATOP has been incorporated into the recently standardized NSW Clinical Documentation Suite.

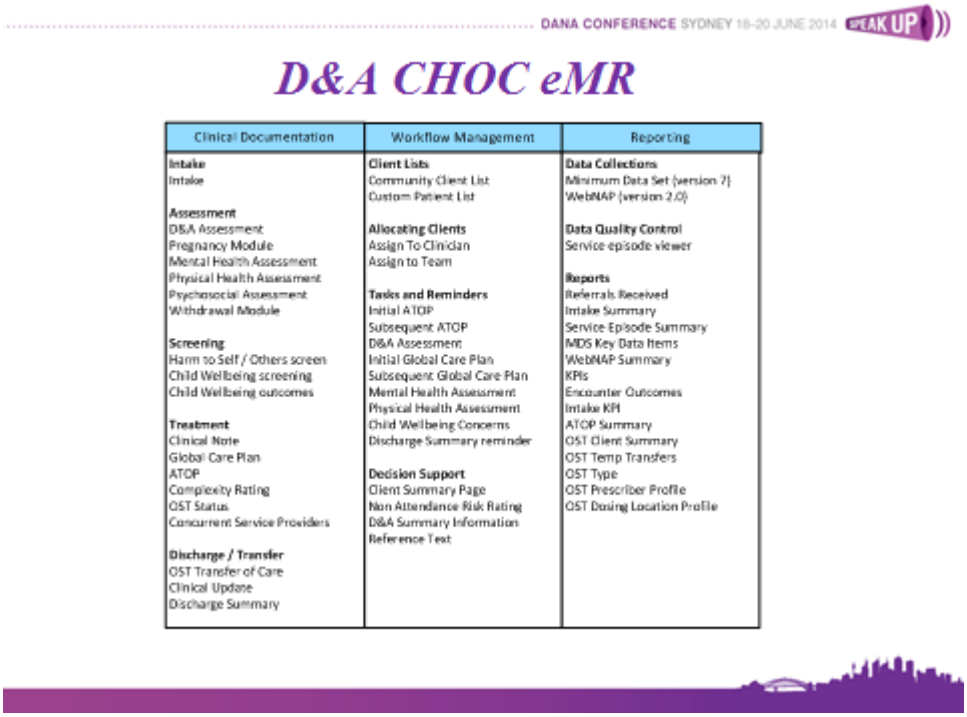


While a lot of the clinical documents are used by most services there are a number of new additions. These include:

- Acquired Brain Injury Risk Factor Screening from ARBIAS
- A complexity rating tool
- A global care plan to promote collaborative care planning and shared care
- Risk identification
- Discharge/Transfer of care.

A Clinical Documentation Guide is being produced and a clinical change management project is planned to support the implementation of this documentation suite and clinical processes for collaborative care planning, assertive follow-up of non-attendance and discharge/transfer of care.

The clinical documentation suite and clinical processes have been built into the Community and Outpatient Care (CHOC) Electronic Medical Record (eMR) for Drug and Alcohol. This electronic medical record is an additional component to the current inpatient and emergency department eMR and is about to be implemented into two Local Health Districts in NSW with several others to follow in 2015/16.



Incorporation of the ATOP and the complexity rating tool into the clinical documentation suite and the eMR will integrated completion of the outcome monitoring instruments into routine clinical practice. The eMR also provides decision support such as reminders, quality reports and graphical time series results for real time feedback to clients and clinicians.
June 2014 - Audit time - What progress has been made on clinical outcome monitoring in NSW?

- ✓ Short, acceptable, clinically useful instrument - ATOP
- ✓ Training and support materials
- ✓ Integrated into NSW Drug and Alcohol Clinical Documentation suite
- ✓ Integrated into CHOC electronic medical record.
- ✓ Individual client results available in graphical format
- ⅓ Clinical change management project planned
- × Single composite outcome measure with high communication power

While significant progress has been made a single composite measure that is readily understood i.e. high communication power and easily incorporated into dashboard indicators, annual reports or website league tables and the ACHS clinical indicator programs is not yet available. So we still can't definitively communicate if clients improve in treatment.
Now it time to explore the next theme structural and culture issues in opioid pharmacotherapy treatment.

My first drug and alcohol job was as a nurse counselor in the Opioid Treatment Program for pregnant women at RPAH. I struggled to understand some of the slightly bizarre components of the program and I am still uncomfortable that these remain today so it is time to speak out. The medication administration facility at RPAH was a converted bathroom with bullet proof

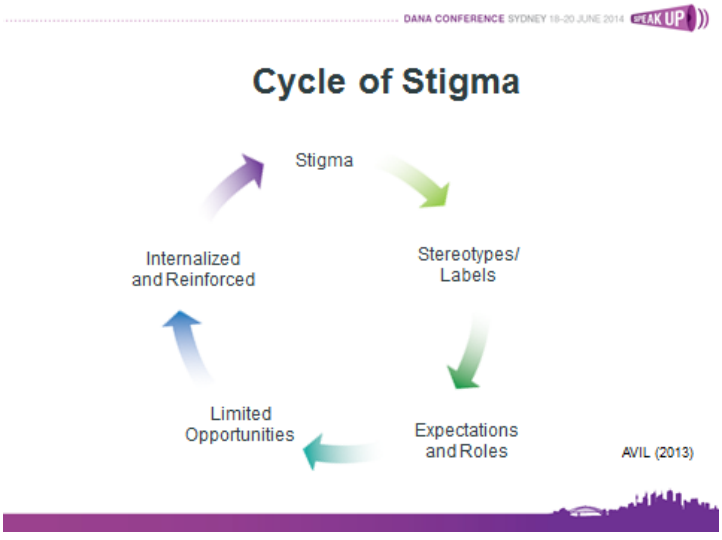
glass and a tiny hatch to pass the medication through. It was impossible to communicate through this glass so we opened the door and clients sat next to us while we prepared and checked their medication dose. When the service was renovated we had to fight the regulatory authority not to have bullet proof glass installed. We had a pleasant waiting room with tea and coffee making facilities and no security guard. What a good service. However I remember being challenged by the Drug and Alcohol Director who stated that it was not OK for our clients to be passive recipients of treatment. I confess that at the time I did not really understand what he meant by this but it stuck with me. I think I do now so thanks Danny.

Sione Crawford in his 2013 commentary in the International Journal of Drug Policy makes some telling observations about the structural and cultural issues in opioid pharmacotherapy treatment. The title 'Shouting through bullet-proof glass' is an evocative metaphor for issues in Opioid Substitution Treatment (OST). The structural issues explored by Crawford and other authors from overseas such as Harris and McElrath (2012) have been uncomfortable constants throughout my career. "The history of the Opioid Substitution Treatment program in Australia has been complex and convoluted. A number of strands of reasoning and needs have become entangled to turn the system into something of a stuck knot." (Crawford, 2013) Crawford highlights the ambivalence about OST felt by consumers, funders and the general community. He also explores the lack of meaningful consumer participation in services. The presentations at last year's DANA conference of consumers working together with service providers in New Zealand were wonderful case studies of effective collaboration. If we are going to shift the power dynamics in OST we need to invite or clients to be active participants in treatment. We have a lot to learn from our New Zealand colleagues.

Harris and McElrath (2012) discuss social control and institutional stigma in OST in Ireland. These structural and cultural issues reinforce 'spoiled' identities and hampers reintegration into main stream society. They further argue that social control and institutional stigma create the conditions for poor outcomes with OST.

This would never happen in Australia would it? How do we know? We don't routinely collect outcomes. Have you made the connection between my themes yet?

People who inject drugs particularly those who are dependent on opiates can't be trusted, carry guns and they don't know what is best for them.



I know we don't think this but why do we set up our treatment system to reinforce this prejudicial belief held by many in the health system and the community. People on opioid substitution treatment must be observed and monitored until they are stable. What's stable? Clean urines! I still remember Jude Byrne telling me one day many years ago in Canberra that people who continue to inject drugs are not dirty. Lesson learnt, language is powerful.

Our system particularly in NSW is so tied up with supervision that it is almost impossible for our clients to get on with their lives. Perhaps if we had something else besides urine drug screens to measure stability we could free up the system. How about a brief simple outcome monitoring tool to monitor stability and allow clients to move out of our overly regulated and supervised institutionalized system? This would allow treatment to be more accessible, flexible, respectful and able to be individualised in true collaboration with our clients. Perhaps clients should be able to determine their own treatment goals and plans as well, instead of leaving treatment and replacing it with a self-managed injectable opioid regime albeit an illicit one.

I have an asthma management plan that I negotiate with my doctor. We discuss what treatment regime I am willing and able to comply with and if they don't collaborate I change doctors. If only it were so easy for clients in OST.

Now for my summation. Stigma leads to stereotyping and labeling, this feeds expectations and roles that perpetuate structural and cultural barriers to effective treatment delivery. This leads to limited opportunities, poor treatment retention and negative beliefs are reinforced and internalized. How can we start to interrupt this despairing cycle? Let’s take an axe to the stuck knot.

If we routinely monitor outcomes and collaborate with our clients we can start to individualize treatment to meet their needs. This will dismantle some of the structural barriers inherent in the current system. It will also provide data for outcome indicators with high communication power that can demonstrate to our clients, health colleagues, the community and funders that Drug and Alcohol treatment works and it is worth ongoing investment.

Surely this is a better approach that what was proposed at the NSW Parliamentary Inquiry into Drug and Treatment last year. Involuntary treatment with Naltrexone implants.

It is time to speak up
Thank you

Putting together the puzzle Stigma, discrimination and injecting drug use

AVIL Training Module for Health Professionals and students

Contact Fiona Poeder at NUAA