Staying True

A plan to measure fidelity in the delivery of early psychosis services in Australia

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Introduction

Psychosis is a vicious illness. It most commonly strikes at a time in life when many of the skills necessary for establishing oneself as an independent adult are being developed. Its onset at this time can limit these developments leading to significant disability. In combination with symptoms which are often experienced as confusing and frightening, psychosis has long been an illness that has required a strong, early and consistent response. Through the policy of the Commonwealth Government to fund early psychosis services for young people with first episode psychosis, Australia is meeting this challenge.

Australia has been a pioneer in the development of a model of care focused on early psychosis (Killackey, Nelson et al. 2008). The work conducted over nearly three decades at the Aubrey Lewis unit of Royal Park Hospital and subsequently the Early Psychosis Prevention and Intervention Centre (EPPIC) in Melbourne has formed the basis for an internationally recognised model of care for this population. The key philosophy underpinning this model has been that through early and intensive intervention, the progression of illness could be slowed and the development of disability minimised. To achieve this requires a multi-disciplinary approach, with a focus on a broad range of outcomes. These outcomes extend far beyond the traditional stabilisation of acute symptomatology to consider social and functional recovery too. A focus has also developed on identifying those at ultra-high risk of developing psychosis and intervening early to prevent the onset of illness.

Based on the EPPIC model, the EPPIC National Support Program has described sixteen core elements of care that need to be present in an early psychosis service (Stavely, Hughes et al. 2014). These 16 elements are based on a mixture of research evidence, consensus of Australian and international experts, and the experience of the EPPIC service over 30 years.

As the national scaling up of early psychosis services commences (hYEPP), it is important that there is a means to measure the degree to which new services are faithfully implementing these core elements into their own service. This is important because research and experience has shown that the presence of these elements leads to better outcomes for young people with early psychosis and their families. Further, measurement of progress towards fidelity with the EPPIC model will allow new services to identify areas in which they may need to improve. Finally, such a measure will allow the Commonwealth to be certain that the services are providing what it is paying them to provide.

This document begins the process of developing a measure of fidelity to the EPPIC model. It will contain a brief overview of the concept of measurement of fidelity, a discussion of the importance of fidelity, an examination of previous uses of fidelity measures in mental health programs and a consideration of the ways in which fidelity can be measured. In the following section a rationale will be described for the measurement of fidelity in the hYEPP services and the question of what a good fidelity measure should do in this context will be addressed. In the penultimate section discussion will focus on each core element and describe possible approaches to the measurement of fidelity. Finally, the document will conclude with a plan for the further development, trialling and refining of a tool to measure the fidelity of early psychosis services developed under the present program.

Fidelity

What is fidelity?

Most simply put, fidelity is a measure of the accuracy of implementation of a model or an intervention. Measuring fidelity to models of care and to individual interventions is important, because evidence suggests that the best results are achieved with the highest levels of fidelity to models (Drake, Goldman et al. 2001).

Definitions of fidelity have varied little over time. Mowbray et al. (2003) in one of the more widely cited reviews of the fidelity construct defined it as "the extent to which delivery of an intervention adheres to the protocol or program model originally developed" (p.315). However, the review then goes on to explore the complexities behind that simple statement. These include whether or not fidelity is being measured at a program or intervention level, whether the purpose is for research or practice implementation and to what degree adaptation needs to be allowed for, if at all. More recently fidelity has been defined as "the extent to which a program adheres to the intended model, both including features that are critical to achieving the intended outcomes and excluding those that would interfere" (Monroe-DeVita, Teague et al. 2011) (p.17).

How is fidelity measured?

There are two principal approaches to measuring fidelity (Mowbray, Holter et al. 2003). Firstly it can be assessed through the rating of external experts. In this situation, documentation relating to the program would be provided to the experts, or they may visit the program and observe it in action. Documentation can include paperwork, but may also include video of sessions or other more broadly defined documentation. During visits, as well as observing, interviews may be carried out with staff and clients of the program. The second method of assessing fidelity is through the use of surveys or questionnaires that are completed either by those delivering an intervention, their clients, or both. So for example in the measurement of fidelity to a particular psychological intervention, a psychologist may have to fill in a questionnaire after the session identifying which techniques were used and importantly, which were not. The psychologist's client may also be required to fill in a questionnaire identifying any techniques that they noticed being used during the session. These might then be combined to assess the level of fidelity to the particular intervention.

As can be seen in the last example, while it is possible to have the person delivering an intervention rating their fidelity to the intervention, it raises problems of, at the very least, the perception of bias. For this reason it is often more desirable, where possible, to have interventions and programs independently rated. Returning to the above example, this might be done by audio or video taping the session and having an independent expert rater assess the session for fidelity. However, more complex programs with many elements may require a combination of self and independent-expert rated methods. Ideally, the self-rated scales would also be subject to review and validation by the independent-experts.

The best fidelity rating methods provide good feedback to programs in order for them to be able to identify those elements of their practice that are not at the required standard. In these methods, the criteria for achieving different levels of fidelity on each element of the program are clear. A good example of such a fidelity tool is the Individual Placement and Support (IPS) Fidelity Scale (<u>http://sites.dartmouth.edu/ips/fidelity/fidelity-scales/</u>). IPS is an employment intervention for people with mental illness in which an employment specialist is embedded in a mental health team (Chinnery and Killackey 2013). IPS is based on 8 principles, which in this scale have been broken down into 25 assessable items. Each item is scored from 1-5 points with a clear description of the criteria for each score. In the scale, the data sources for scoring each item are detailed. Figure 1 shows two sample items from the IPS Fidelity Scale

Figure 1: Two sample items from the IPS Fidelity Scale

Criterion	Data Source	Anchor
1. <u>Caseload size:</u> Employment specialists have individual employment caseloads. The maximum caseload for any full-time employment specialist is 20 or fewer clients	Management information system, Documents, Interview	Anchol $1 = Ratio of 41 or more clients per employmentspecialist2 = Ratio of 31- 40 clients per employmentspecialist3 = Ratio of 26 - 30 clients per employmentspecialist4 = Ratio of 21 - 25 clients per employmentspecialist5 = Ratio of 20 or fewer clients per employmentspecialist$
2. <u>Employment services</u> <u>staff:</u> Employment specialists provide only employment services	Management information system, Documents, Interview	 1 = Employment specialists provide employment services less than 60% of the time 2 = Employment specialists provide employment services 60-74% of the time 3 = Employment specialists provide employment services 75-89% of the time 4 = Employment specialists provide employment services 90-95% of the time 5 = Employment specialists provide employment services 96% or more of the time

The IPS fidelity scale is completed by an independent trained rater who visits the sites where IPS is being conducted. They have interviews that may be with mental health staff, clients, employment specialists, employers and families, access to the management information system, access to relevant documents such as clinical records, policies and procedure manuals, and they may observe the employment specialist at work.

What should a good fidelity measure do?

A good fidelity measure should achieve a number of simple goals. Firstly it should be able to discriminate between the intervention and program of interest, and something that is similar but not the program or intervention. For example a fidelity scale for cognitive behaviour therapy (CBT) of depression should be able to tell when CBT is being delivered and when supportive counselling is being delivered.

A good fidelity scale should also be able to suggest areas that need to be addressed to improve. For example in the IPS fidelity scale mentioned above, the 5 point scoring scales, each with a clear anchor point, illustrate exactly why a particular score was achieved. This then allows managers and program staff to address the areas in which a less than maximal score was given in order to improve fidelity and hence outcome for clients. Finally, a good fidelity scale should be able to accommodate some flexibility to allow for local adaptation, but should also be able to say when an intervention or program has been adapted so much that it can no longer be said to be the intervention or program that it purports to be. This is important as in many situations local adaptations need to be made. However, for nearly all stakeholders, clients, staff, managers and funders, it is important to know the point at which the intervention around which there is evidence and for which there is funding, ceases to be that intervention. Again, the IPS scale is illustrative in that in consideration of its overall scores it uses the following categories (bear in mind possible scores on the scale range from 25 to a maximum of 125): 115-125 = exemplary fidelity; 100-114 = good fidelity; 74-99 = fair fidelity; 73 and below = not individual placement and support. (Dartmouth IPS Supported Employment Center 2008). Therefore there is flexibility in the scoring system, but only to a point.

Why is measuring fidelity important?

Increasingly it is seen that measuring the fidelity of the implementation of a program or intervention is an important component of evidence-based practice (Mowbray, Holter et al. 2003). As will be discussed in the brief history of fidelity measurement in mental healthcare below, basing practices on rigorously developed evidence is a relatively recent phenomenon. In essence the implementation of an evidence-based practice or model, is the attempt to replicate that practice or model in a different context. Therefore, in order to ensure that the practice has the best chance to work as designed, it is important to measure that it is being implemented faithfully. This ensures that the program or intervention that is being applied to client groups is the same as the one on which the evidence was developed.

Programs or interventions that have been implemented with high fidelity tend to show better outcomes for the clients to whom the program or intervention is delivered (Becker, Smith et al. 2001, Drake, Goldman et al. 2001, Monroe-DeVita, Teague et al. 2011). It has also been noted that because many programs in the psychosocial and social services arenas take a long time to demonstrate outcomes, that measurement of fidelity may, in the short term, serve as a proxy variable for program success (Monroe-DeVita, Teague et al. 2011).

There is often an economic rationale behind the implementation of a new program as well. That is, a new program is launched because it is believed that not only will it deliver better outcomes or address a previously neglected problem, but that in doing so it will save more than it costs. For example, widespread breast cancer screening leads to lower treatment costs through early intervention. Most often these economic assessments have been worked out on the basis of the evidence that was used to mount the case for the scaling up of an intervention that may have only previously been a research or demonstration project. In this case again, measuring fidelity is crucially important. It ensures that the funder is getting the program that they paid for and are more likely to get the outcomes that have been suggested by the evidence base. In some jurisdictions, funding is provided on the basis of fidelity ratings to the model (Drake, Bond et al. 2012).

A brief history of the application of fidelity to mental health

In 1879, writing in the American Journal of Psychiatry, Bodington (1879), stated that in relation to selecting appropriate treatments:

practitioners of the art of medicine are now-a-days reputed to be persons of discreet and sober judgment, of well-balanced minds imbued with the true scientific spirit, which takes in all facts, and impartially considers all sides of a question. All remedies whatever, are at the disposal of practitioners to reject or employ them under the sole guidance of their own judgment

As can be imagined, this approach meant that there was often little evidence base to the treatments that could be applied (e.g. ice baths, prolonged baths, warm wraps, fever treatment and insulin comas to name but a few applied to psychotic illness). It was only in the second half of the last century that there was increased recognition of the need for a firm evidence base. A person whose name is now synonomous with evidence-based medicine is Archie Cochrane. His experiences of being a prisoner of war medical officer for his fellow POWs, many with tuberculosis, led him to recognise the importance of the evidence underlying treatment decisions -

I remember at that time reading one of those propaganda pamphlets, considered suitable for POW medical officers about 'clinical freedom and democracy'. I found it impossible to understand. I had considerable freedom of clinical choice of therapy: my trouble was that I did not know which to use and when. I would gladly have sacrificed my freedom for a little knowledge. I had never heard then of 'randomised controlled trials', but I knew there was no real evidence that anything we had to offer had any effect on tuberculosis, and I was afraid that I shortened the lives of some of my friends by unnecessary intervention

This desire for knowing what worked and what did not would in time lead to the development of evidence based medicine and the Cochrane Collaboration, named in honour of Archie Cochrane.

Despite development towards evidence based medicine as we now conceptualise it since the publication of Cochrane's book in 1972 (Cochrane 1972), it was only in 1992 that it was used for the first time (Guyatt, Cairns et al. 1992). The article in which it was used described a new approach that would be based on clinicians being able to access and appraise the literature in order to determine the treatments with the most evidence and then to use this to guide their practice. As more information became available, the volume of it soon overwhelmed the ability of an individual to synthesize. Shortly afterwards the Cochrane Collaboration was established to systematically gather and publish evidence related to health, and in the mid-1990s clinical practice guidelines began to be developed. These guidelines described pharmacological, behavioural and psychological interventions for the various disorders that were supported by evidence.

Through the 1990s and into the early years of the current century there was a great effort to collate data and issue statements about which treatments worked. For example Gaebel and colleagues, in reviewing guidelines for schizophrenia, found 27 sets of guidelines from 23 countries (Gaebel, Weinmann et al. 2005). Despite the massive effort involved in the collection of data and construction of systematic reviews, meta-analyses and practice guidelines over the last 15 years there is evidence that recommendations of guidelines for both psychosocial and pharmacological treatments are not faithfully translated into practice (Rosenman, Christensen et al. 2008). For example, in a national survey in the United States, West and colleagues found that:

rates of conformance with the [PORT] guideline recommendations were significantly lower for psychosocial recommendations than for psychopharmacologic recommendations: for psychosocial recommendations rates ranged from 0 percent to 43 percent, whereas for psychopharmacologic recommendations rates ranged from 30 to 100 percent." (West, Wilk et al. 2005)

Similarly surveys of people with mental illness reveal that very few of them are gaining access to evidence based treatments (Hall 2004), while other studies have found that the level of prescription practices that adhere to guideline recommendations is poor (Leslie and Rosenheck 2004, Weinmann, Janssen et al. 2005).

So now there is a clearer picture than ever before about what treatments currently available produce the best outcomes, but little idea about implementing it faithfully.

At the same time as calls for an evidence base in medicine were growing, there was a simultaneous rise in the interest in the development of fidelity. In relation to mental health, this arose through the realisation a rigorous evidence base was never going to be developed

for psychotherapy if there was little definition of what each therapy consisted of, and in which ways it was different from other therapies (Bond, Williams et al. 2000). This led to the development of treatment manuals, particularly for studies of psychotherapy. A logical consequence of the use of a treatment manual in a study was the need to ensure that the therapy was administered according to the manual. This led to measures of fidelity being developed. As studies began to show that treatments work, the treatments were disseminated. A key aspect of the dissemination was the fidelity scale, which was used in this context to determine that the treatment being applied in the new clinical environment was the same as the one developed and found to be effective in the research environment (Bond, Williams et al. 2000).

Early Psychosis and Fidelity

Core Elements and Standards

There are a number of ways in which fidelity scales are developed. One way is to conduct a Delphi like exercise in order to establish the core elements of a program or intervention and then develop a scale to measure whether or not those elements are present. This works well in situations where there is a program or practice but the elements have not previously been well articulated. In the case of the EPPIC model on which hYEPP services are based, the 16 core elements have already been developed and well articulated (Hughes, Stavely et al. 2014). The issue here then is to determine what is the best way to measure fidelity to each of these measures.

The EPPIC Model and Service Implementation guide (Stavely, Hughes et al. 2013) sets standards at three different levels for the 16 core elements. The first level is described as the minimum non-negotiable standards that must be in place to provide a service. There are 57 of these across the 16 core elements. The second level outlines a further 68 standards across the 16 core elements that are required in order to achieve full fidelity to the model. The third level describes 92 further standards that are drawn from important guidelines including the Australian Clinical Guidelines for Early Psychosis 2nd Edition (ORYGEN Youth Health 2010). These are standards to which all service providers are expected to adhere to in the model. As such they may not be specifically relevant to fidelity of the overall model, but may be relevant to fidelity to practices that inform specific elements.

The 16 core elements and the standards derived from them will form the basis of the fidelity scale to be developed.

A Plan

To date there have been no published fidelity scales in first episode psychosis (Addington, McKenzie et al. 2013). However, both in Australia in response to the new national early psychosis program (based on the EPPIC Model), and internationally, there is increased interest in the topic of fidelity in first episode psychosis intervention.

In this section a plan for the development of a fidelity measure for the national early psychosis program will be elucidated. In planning for this development there are six key aims.

- 1. Develop a fidelity measure that covers:
 - a. Program fidelity;
 - b. Intervention fidelity
- 2. Where feasible incorporate existing validated measures of fidelity
- 3. Conduct feasibility and usability evaluation of scales
- 4. That the developed measure be useful to headspace in the administration and management of the program
- 5. That the developed measure be useful to the Commonwealth in managing the overall budget measure and informing the funding of the program
- 6. That the developed measure be useful to the individual centres in allowing them to identify areas in need of improvement in their service delivery

It is envisaged that development of the program fidelity scale will commence by reviewing each of the descriptions of the 16 core components, and in conjunction with the standards described in the EPPIC model and Service Implementation guide (Stavely, Hughes et al. 2013), develop a number of items that measure the degree to which that standard and the whole element is present.

As stated, in order for this scale to be useful, wherever possible the scale will not use a dichotomous present/absent paradigm. Instead, effort will be made to make a continuous scale with clear anchor points. Whereas a present/absent scoring system would make for ease of administration and potentially be useful to funders, it would not achieve the other aims of being useful to services or to headspace.

As the presence of each core element is important in its own right, a scoring system that reflects this will be developed. The EPPIC Model and Service Implementation guide clearly states that each of the 16 components needs to be present in order to implement the model with fidelity. Therefore a score of sub-components of each core component will be determined in order to be able to state whether or not that component is achieving minimal fidelity. In order to be said to be achieving fidelity, a service will have to achieve at least minimal fidelity in all 16 components. Within each component other scores will be described indicating differing levels of fidelity above minimum. The total score possible for each core element will be determined by the number of sub-component items, and the scale used in each item. For example if an element consisted of 4 sub-components and each was scored on a 5-point scale (1-5), the possible scores would range from 4-20.

The second area of work will be to examine the literature to find examples of already existing fidelity scales for the interventions that underpin the elements. For example the functional recovery program indicates that the Individual Placement and Support (IPS) intervention should be used to support young people with psychosis to return to school or work. IPS has an existing fidelity scale (Dartmouth IPS Supported Employment Center 2008) which would be utilised in order to examine the degree of fidelity with which IPS was administered in the EPPIC program. Where no fidelity scale exists for an intervention we would first consult with international colleagues in order to unearth any unpublished scales, and failing this would consider devising our own measure. In this way the aim of being able to have a more detailed level of fidelity measures at the intervention level would be achieved. If some scales need to be developed separately these would be the subject of separate projects. This would not interfere with or delay the program fidelity measure.

The third area of work (which may happen concurrently with some elements of the second area) will be trialling and evaluating the fidelity measure. Trialling will be conducted at headspace Youth Early Psychosis Program (hYEPP) sites. This will allow for an assessment of the usability and validity of the measure. Initially only the program level measure will be

trialled. Individual intervention fidelity measures will be trialled if and as they are developed. In the case of already existing intervention measures they will not need to be trialled if they have already achieved validation. This stage will also examine who is best to administer the measure and what sort of access to the program, staff, young people, families and documentation will be required. Increasingly fidelity measures are seen to be more valid if administered by experts independent from the program being evaluated (Bond, Drake et al. 2012).

Timeline for development

January – April 2015

- Operationalise each element using standards in the EPPIC Model and Service Implementation guide.
- Develop sub-element items and scoring scheme.
- Establish fidelity category scores (no fidelity, marginal fidelity, good fidelity, excellent fidelity) for each element and the whole program
- Produce draft program level fidelity scale

May - June 2015

- Consult with sites on items and anchors
- Revise scale in conjunction with outcomes of consultations
- Produce draft scale for piloting

June – August 2015

- Pilot fidelity scale with sites
- Prepare reporting format post application of fidelity scale for programs, headspace and Commonwealth

Conclusion

There is likely to be some kickback from traditionalists around the measurement of fidelity, as indeed there has been with implementing guidelines and other aspects of evidencebased medicine. The spirit of Bodington has not completely died out. One of the critiques of evidence-based medicine is that it takes the art of health care away and leaves only the science. This proposition should be rejected. Evidence based medicine and its associated guidelines and fidelity measures only ensures that the interventions provided are the best possible in light of the currently available resources and the currently available knowledge. There is still much in all of health care and particularly in mental healthcare for us to learn. Beyond the light of empirical fact is an area where the data does not yet exist to guide practice. It is in this area that the art of medicine is still very much needed as this quote from the autobiography of Archie Cochrane – the father of evidence-based medicine – demonstrates.

Another event at Elsterhorst had a marked effect on me. The Germans dumped a young Soviet prisoner in my ward late one night. The ward was full, so I put him in my room as he was moribund and screaming and I did not want to wake the ward. I examined him. He had obvious gross bilateral cavitation and a severe pleural rub. I thought the latter was the cause of the pain and the screaming. I had no morphia, just aspirin, which had no effect.

I felt desperate. I knew very little Russian then and there was no one in the ward who did. I finally instinctively sat down on the bed and took him in my arms, and the screaming stopped almost at once. He died peacefully in my arms a few hours later. It was not the pleurisy that caused the screaming but loneliness. It was a wonderful education about the care of the dying. I was ashamed of my misdiagnosis and kept the story secret.(Cochrane 1989)

Measuring fidelity is an increasingly recognised aspect of evidence-based medicine. As Australia embarks on the establishment of a national program of early psychosis intervention, it is important that each service setting is providing treatment of the same high standards. This will ensure that a young person with psychosis in Perth gets the same quality of care and chance of recovery as a young person in Sydney or Melbourne, or in any of the other places that early psychosis services are established.

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