
Using a Community Engagement approach to ensure equality of access, experience and outcome from the IAPT programme in the North West of England

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Introduction

This report summarises the findings of seven equality impact assessments carried out by seven community organisations across the North West of England examining the equality issues for specific communities in connection with the roll out of the Improving Access to Psychological Therapies Programme. In summarising, this report attempts to draw out the common themes that emerged across the individual reports produced by each group and presented to its own local PCT in a way that transferable learning can be usefully shared.

The Improving Access to Psychological Therapies Programme

The Improving Access to Psychological Therapies Programme is intended to deliver on the Government's 2005 General Election manifesto commitment to provide improved access to psychological therapies for people who require the help of mental health services. It also responds to service users' requests for more personalised services based around their individual needs.

Traditionally there have been long waiting times for psychological therapies in the treatment of common mental health problems. The programme has been established to improve services and ensure better outcomes for people accessing support.

Depression and anxiety can affect everyone. People from all communities may be affected, although the way that they may be affected may be different. It is important that everyone in the population has equal access to, experience of and outcomes from psychological therapies. When planning services, steps must be taken to eliminate discrimination and promote equality of opportunity and good relations between

different groups of people. Equality legislation obliges PCTs to carry out Equality Impact Assessments on their local plans.

The North West

In 2008 5 PCTs were selected to begin the roll-out of the IAPT programme within the North West region:

- East Lancashire
- West Cheshire
- Central and Eastern Cheshire
- Salford
- Knowsley.

Since 2009 the programme has been extended further to include number of new PCTs.

NHS North West is supporting frontline practitioners, managers and commissioners in the delivery of psychological therapies by running a *collaborative*, bringing commissioners and planners from across the region together on a regular basis to share best practice.

Equality and Diversity within the IAPT Programme

In August 2008 the NHS published the results of its Equality Impact Assessment of the IAPT programme. This stressed the importance of commissioning a balanced portfolio of clinically effective services to promote equality. This may involve creating dedicated and specific services targeting particular groups or working in partnership with particular voluntary sector or community groups. It suggested that micro-analysis of need may be necessary to identify groups in the community with specific needs, such as Black and minority ethnic communities and older people. It highlighted the following concerns:

Older people and young people – People at different stages in their life have different psychological needs. Although there has been a lot of work demonstrating

clinical outcomes for adults of working age, the tools used are often not validated, or appropriate, for other age groups. Access for children and young people is a particular area of concern. Over 1,300,000 older people have depression and mental illness and this number is expected to rise over the next few years as the population ages.

Disability – Large numbers of people develop psychological problems as a result of illness or disability. There is a substantial literature base concerning the co-morbidity of long-term conditions such as diabetes, ischaemic heart disease and chronic obstructive pulmonary disease and common mental health problems. 40% of people with Parkinson's disease have depression. There is a need to address the broader access requirements of individuals with a range of other disabilities, including the needs of people with learning disabilities, sensory impairment and physical disabilities.

Race, religion and belief – It has been suggested that some people, including those from Black and minority ethnic communities, may find that traditional psychological therapies do not always meet their needs. The evidence base for and appropriateness of the NICE¹ recommended psychological interventions needs assessing against the needs of a range of different cultural groups, taking account of issues related to race and to religion and belief.

Gender – There is a need to determine whether services are equally meeting the needs of both men and women. One in ten new mothers suffer from post-natal depression, of whom less than one in five receive psychological treatment. Of the 7 million carers in Britain, one in five females and one in ten males report mental illness.

Sexual orientation – It is widely acknowledged that the needs of gay, lesbian and bi-sexual groups have hitherto not been fully met.

In November 2008 guidance was produced for Commissioning for the Whole Community. This was

followed up by a series of Positive Practice Guides, produced by experts working together as Special Interest Groups, giving 'top-tips' on commissioning IAPT services for specific communities². Guides were produced for the following groups and conditions:

- Black and minority ethnic communities
- Older people
- Perinatal care
- Offenders
- Long term conditions
- Medically unexplained symptoms
- Veterans
- Learning disability.

Using a Community Engagement approach to ensure equality of access, experience and outcome from the IAPT programme for all in the North West of England

NHS North West commissioned the International School for Communities, Rights and Inclusion (ISCRI) to undertake a series of equality impact assessments, across a range of equality strands, in partnership with a number of local community groups utilising a community engagement approach. This work was designed to augment the equalities work that PCTs across the North West were already doing and was consistent with the guidance from the NHS in 2008 suggesting that micro-analysis of the specific needs of specific groups might be necessary.

The community engagement model, which has been embedded in a series of both national and local community engagement initiatives, including the Department of Health's *Delivering race equality in mental health care programme* is described in detail elsewhere^{3,4}. In summary, the process involves the recruitment of host community organisations, who in

¹ (NICE) National Institute for Health and Clinical Excellence

² <http://www.iapt.nhs.uk/special-interests/>

³ Fountain, J. Patel, K. Buffin, J. (2007) Community Engagement: The Centre for Ethnicity and Health Model. In Domineg, D. Fountain, J. Schatz, E. Bröring, G (eds) Overcoming Barriers: Migration, marginalisation and access to health services. Amsterdam, Amsterdam Oecumenisch Centrum (AOMC)/Correlation network for social inclusion and health

⁴ Bashford, J. Buffin, J. Patel, K. (2003) Community Engagement, Report 2: The Findings The Centre for Ethnicity and Health

turn recruit a number of lay community people who are trained and supported to raise awareness of a particular issue within their own community and gather information back from the community which can be used to help shape and improve the delivery and commissioning of services. Community groups are supported financially with the award of a small grant to cover their costs (including the cost of paying lay people from the community to become involved in the project), as well as methodologically via a package of training and support (in this case provided by ISCRI and a steering group made up of local commissioners). The process is represented diagrammatically in diagram 1 below.

Seven community organisations were recruited to undertake local Equality Impact Assessments. These groups completed application forms in response to information fliers about the project that were circulated in each participating PCT area. Some PCTs chose to focus the EIA in their area around a particular equality strand, reflecting the make-up of their local population and the specific concerns that they had with respect to the effective role out and commissioning of IAPT services for specific communities. This was the case in East Lancashire for example, where particular attempts were made to recruit groups who could target the South Asian and Gypsy, Roma and Traveller Community.

Diagram 1: the Community Engagement Process

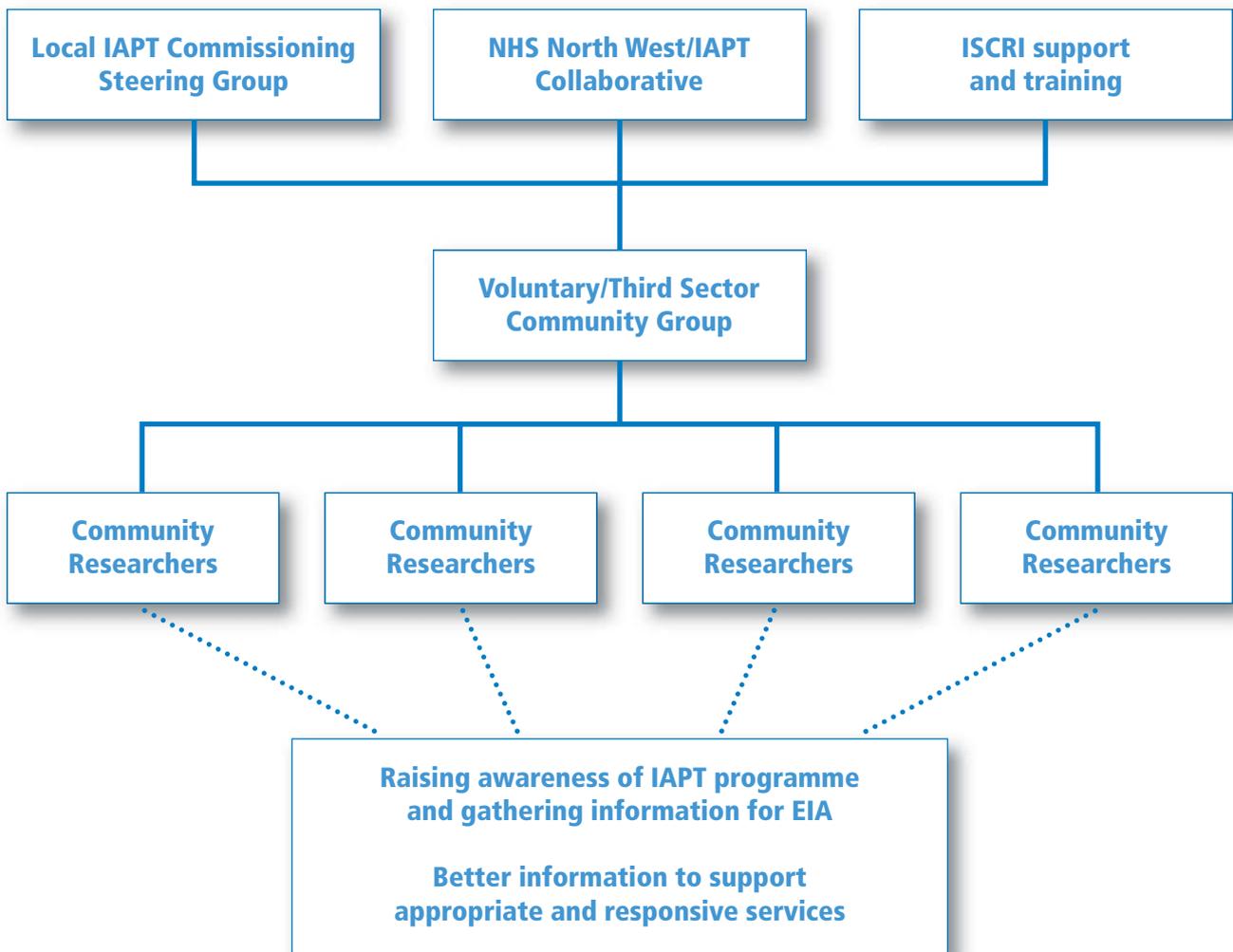


Table 1: Summary of selected groups.

Name of Group	Area	Equality Strand	Methods
Polish Association of Crewe	Central and Eastern Cheshire	Race – Polish and Eastern European	A Polish community development worker supported three volunteers who translated the EIA tool in to Polish. The group ran two community awareness raising events, reaching over 250 people from the Polish community.
Outrite	Central and Eastern Cheshire	Sexuality – Gay and bi-sexual men	A project co-ordinator for Outrite an organisation that works to improve the sexual health of gay and bi-sexual men, ran an awareness raising event about IAPT with 10 gay and bi-sexual men. 10 one to one interviews were conducted separately with gay and bi-sexual men from Central and Eastern Cheshire.
Hyndburn Gypsy, Roma and Traveller Women’s Group	East Lancashire	Race – Gypsy, Roma and Traveller	<p>A project co-ordinator and a support worker supported 3 volunteers from the GRT community to interview 50 members of the community in Hyndburn. IAPT commissioning leads were also interviewed.</p> <p>An awareness raising day was organised around a ‘pamper day’ which attracted 45 women from the community. Local health professionals used the event to raise awareness about what they could offer and how they worked.</p>
Awaaz	East Lancashire	Race – South Asian	A project co-ordinator and 6 volunteers interviewed 80 South Asian people in Pendle and Hyndburn in a range of community languages including Urdu, Punjabi, Mirpuri, Pushto, Bengali and English. 3 awareness raising events were also held.
Knowsley Ethnic Minority Support Group (KEMS)	Knowsley	Race	A project co-ordinator and four volunteers interviewed 31 BME people who had been the victim of racially motivated crime. An awareness raising event was also held.
Age Concern	Salford	Age	A project co-ordinator and two older people working as volunteers interviewed 55 older people in Salford as well as the lead commissioner.
Age Concern	West Cheshire	Age	Age Concern worked in partnership with Dial House, the Disability Rights Centre and a number of adult service users. A project co-ordinator and 4 volunteers consulted with 49 older people aged between 50 and 80.

In most PCT areas a community workshop was held as part of the application process. This was a local event at which potentially interested community groups were invited to find out more about the programme and to ask questions to enable them to decide whether they wished to apply to take part or not.

Decisions about which groups to select were taken in partnership between ISCRI and local commissioners based on the information that groups provided in their application forms and the priorities of the local PCT.

An outline of the groups selected, the PCT they were based in, the equality strand that each of the groups focussed on and the methods that each group employed to carry out their equality impact assessment are set out in table 1.

Once they were selected, groups attended a two day training programme facilitated by ISCRI in which they were provided with background information about the IAPT programme and trained in how to undertake an EIA using a specifically designed toolkit (appendix 1).



Members of Age Concern West Cheshire attending the EIA training provided by ISCRI.



Members of the Polish Association of Crewe present their ideas for an IAPT service.

Key Findings

Monitoring

Although data such as ethnicity, age and sexual orientation is often collected and recorded as part of a minimum data set upon entry to service, such practice is not universal across all sites. Furthermore, the way that ethnicity data is collected is not always sensitive enough to capture information for all ethnic groups – for example no data was collected regarding the Gypsy, Roma and Traveller community in East Lancashire.

Even where data is collected at entry points it is rarely correlated with outcome data or satisfaction surveys. Thus even where it is possible to identify access to service by equality strand it will often not be possible to monitor experience or outcome across different groups.

Service user satisfaction surveys are conducted in some areas, but often use language that service users don't fully understand.

Access for some groups is lower than might be expected. For example, only 1 in 20 referrals to psychological services in Salford is for a person aged over 65. General population trend predictions suggest that we can anticipate a significant growth in both older and BME populations. There was little evidence that monitoring data was used to plan and develop services for specific groups.

Lack of awareness of services

Most people are unaware of mental health services and psychological therapies. This was true across all the groups.

'If I knew about that service 2 years ago, I probably wouldn't try to kill myself.'

Polish respondent.

The Knowsley group (KEMS) focussed on a very specific sample as this group provides support to Black and minority ethnic people who have been the victims of

racially motivated crime. There are specific psychological approaches (e.g. CBT) to treating the psychological symptoms of a wide range of conditions, including those that may arise as a result of traumatic attacks. None of the sample was aware of the possible help that psychological treatments might be able to offer however.

Language barriers

Language was an issue for most groups, although how this played out across each of the groups was often slightly different. For example, for the South Asian community in East Lancashire, many respondents complained that information was only available in English. This raised issues not only for how people would find out about the service, but also for how they would make use of the service if they needed it. Similar concerns were raised by the Polish community.

'My English is not enough to express my feelings.'

Polish respondent.

Older South Asian people in particular were often dependent upon younger relatives to interpret, but this was seen as wholly inappropriate in the context of the delivery of a psychological therapy.

'Even though I can speak English my mum can't, and I definitely don't feel comfortable taking her even to see the doctor, and I know she'd prefer there to be someone female translating for her, not her son you understand. I mean it's sometimes quite embarrassing, and this kind of service seems like one where privacy would be greatly needed.'

26 year old Pakistani male.

For other groups (e.g. the Gypsy Roma and Traveller Community, older people) the language issues were more about the complexity of the language used and the use of jargon. The Gypsy, Roma Traveller Community experienced considerable difficulties engaging with a

number of terms around mental health and the tool-kit that was developed to undertake the equality impact assessment needed to be substantially revised and re-written in order to allow the community to engage with it. There are existing examples of good practice (e.g. picture display boards) that have been developed to help communicate ideas to the Gypsy, Roma and Traveller community. The older people in the Salford sample also struggled with the jargon around mental health.

Perception of mental health, mental health services and stigma

Older people in particular often have an out-dated view of mental health services rooted in the days of old psychiatric institutions and the notion of asylums. For other communities mental health is heavily stigmatised and the implications of being seen as 'mad' can have far reaching consequences, not just for the individual but also for the family as a whole, including marriage prospects.

'English people don't know what it's like for us. If anyone in my family was to use this kind of service our whole family will be seen as pagals (mentally retarded). I have daughters, it's just not possible with our culture, I'd rather just go quietly to see a peer.'

Pakistani male.

Mental health was also a heavily stigmatised issue amongst both the Gypsy, Roma and Traveller community and the Polish community. The Polish community expressed concerns about how a diagnosis of a mental health problem would impact upon their work prospects.

There was concern that mental health problems may go undiagnosed amongst older populations with symptoms of depression being dismissed as simply a part of growing old.

Gay and bi-sexual men expressed concern that mental health services were likely to understand their needs poorly.

Pride as a barrier to seeking help

Older people in particular often said that they would not want to seek help because of pride. They had a sense that they should be able to cope and that they should be able to 'pull themselves together'.

'Older people are too proud to admit they have a problem. They have been brought up in an environment where you keep your private life private.'

(Male participant, West Cheshire).

Location of services and lack of community mobility

Some communities are relatively immobile. Others are quite parochial and insular and will not travel even short distances in to neighbouring communities in order to access services. This was true of older people in Salford and the South Asian community in East Lancashire. Although most communities therefore wanted services that they could access locally they also expressed concerns around anonymity and confidentiality.

Some communities said that they were required to travel considerable distances in to neighbouring districts in order to access services that were appropriate. This was true for the BME community in Knowsley who said that they often travelled to Liverpool to access culturally appropriate services and for gay and bi-sexual men in Central and Eastern Cheshire who often travelled to Manchester or Liverpool.

Some groups of service users (especially older people) requested home visits.

Multiple and complex needs

The equality strands often over-lap and people who fall in to more than one category will often have particularly complex needs (e.g. older people with disabilities; South Asian older people). Some communities are known to be suffering from multiple deprivations (e.g. the Gypsy, Roma and Traveller Community have generally poorer levels of physical,

mental and dental health, lower rates of GP registration, and higher prevalence of smoking and obesity). Particular thought will need to be given to the need to target groups such as these who may be simultaneously at greater risk of mental health problems whilst at the same time facing greater barriers to service access.

Access roots and referral pathways

For most communities GPs were seen as the most likely route in to services. Concern was expressed therefore about whether GPs were sufficiently well aware of the IAPT programme and about whether GPs were adequately trained to screen and refer for psychological services.

'GPs are gatekeepers and they don't always refer.'

Male aged 70, West Cheshire.

IAPT services that rely on GP referral will inevitably disadvantage communities that have low GP registration rates. Other professionals based in a wide range of non-mental health services may be in a stronger position to identify and refer people with mental health problems. In some areas there were plans to provide low intensity services from a range of community settings, often in partnership with a local community or voluntary sector organisation. This was seen a good thing that was likely to promote wider access to services, especially when combined with extended open hours either in the evening, early morning or at weekend.

Eligibility

Some recent immigrant communities were unclear about whether they were eligible for state healthcare services. Confusion around this on the part of both communities and services creates an additional barrier. Older people were concerned that they may not be eligible for help as the IAPT programme has been closely linked to improving employability and getting people back to work.

Gender

Men from the Gypsy, Roma and Traveller community were more difficult to engage than women. The fact that the GRT community itself had problems engaging men means that services are very likely to encounter similar problems. Males from the GRT community may therefore have specific needs over and above the needs of the GRT community as a whole which need to be thought through and taken in to account when designing services that are accessible to all. South Asian communities in particular articulated specific religious and cultural needs in relation to the provision of gender specific services.

Specific cultural and religious needs

The South Asian community said that they wanted to be sure that the staff who treated them were fully cognisant and supportive of their religious and cultural needs. This would include the provision of gender specific services and an understanding of the key role that faith can often provide in both understanding and interpreting concepts of mental health and in the provision of treatment and the promotion of recovery. Many of the BME respondents in the Knowsley project were practicing Christians and many of them saw their religion as something that could provide comfort and understanding and that could promote recovery and well-being.

Within South Asian communities there was concern that the struggle for identity could impact upon the mental health and well-being of young people in particular who often straddled both traditional and Western cultures, with strong pulls in both directions. The backlash against Islam in the wake of 9/11 was a further dynamic.

The Gypsy, Roma and Traveller community felt that they had a particular way of life that was seldom understood and valued by service providers which made accessing services difficult for them.

Older people were concerned that younger people may have a different world view to them, and that services may not be planned and delivered at an appropriate pace.

Heterogeneity

All communities expressed concerns about being stereo-typed and homogenised. The experiences of, for example, all BME people or even all Pakistani people are not the same, however. The same holds true for all communities.

Recommendations

- There is a need for community based education and awareness campaigns that will raise the communities awareness of mental health, well-being, and mental health conditions as well as of the range of services that are available to offer help and support. Such awareness raising campaigns need to take account of the fact that some communities will have inaccurate and out-dated perceptions of mental health and that mental health is often a heavily stigmatised subject. Thought should be given as to how campaigns that aim to promote awareness of IAPT might perhaps be delivered in partnership with other organisations who run successful campaigns aimed at specific groups (e.g. Age UK [formerly Age Concern]).
- Uniform approaches need to be developed for monitoring access to, experience of and outcome from psychological therapies. These approaches need to be sophisticated enough to pick up on differences between different groups.
- Staff coming in to contact with people in non-psychological settings should be trained to screen and refer to mental health services. For example, staff dealing with chronic health conditions such as diabetes and respiratory conditions may come in to contact with older people suffering from depression and anxiety and would be ideally placed to screen and refer. Models of brief interventions have been trialled with GPs in the context of alcohol for example and could be replicated and used by other professionals in different spheres.
- Consideration needs to be given as to how best to provide local points of access for communities that either cannot or will not travel. Home visits might be appropriate in some circumstances.
- Equality and diversity training should be embedded in to the training provided to both low intensity and high intensity therapists.
- Information about psychological therapies should be developed in a range of different languages and formats. Interpreters should also be available to support the delivery of psychological interventions to people whose first language is not English. Provision of such support might best be developed regionally rather than locally as the cost for replicating such services in every locality may be prohibitive. Practitioners will need to be trained in the effective use of interpreters.
- Commissioners should plan for the challenges that we know lie ahead with respect to the provision of services to both an increasingly ageing and an increasingly ethnically diverse population. In so doing, care should be taken not to homogenise and over-simplify population groups, but to recognise the diversity that exists within them. Some groups will face multiple barriers – such as age, ethnicity and gender.
- Commissioners need to ensure that they develop services in partnership with service users and community organisations that understand the different needs of different communities.

Outcomes

This report summarises the individual reports produced by each group and presented to its own local PCT. Each group has presented its own report to its own local PCT however with the result that the following local outcomes have already been achieved.

In East Lancashire, commissioners and service managers have recognised the value of working in partnership with a local organisation that is trusted by and has

access to the community. Discussions are underway about how they might work with AWAAZ to target South Asian men in particular. A pictorial display board has been developed to promote services to the Gypsy and Roma Traveller Community. Commissioners have recognised the limitations of their systems for monitoring service uptake across the different equality strands and are taking steps to address these.

In Knowsley, discussions have commenced around the links that need to be established between IAPT services and faith organisations, based on the finding that most BME people who were interviewed were more likely to approach a religious organisation for help in the first instance.

In West Cheshire, the importance of the GP as a first point of contact to older people was highlighted and work is now planned to build closer links between IAPT services and GPs as a result. Further training is to be developed for IAPT therapists around some of the specific needs of older people.

In Salford, a discussion is underway about the establishment of an older people's forum that might enable older people to have a greater say in how services are run.

Across the North West, partnerships have been established with 7 community organisations who have acquired considerable knowledge and expertise around IAPT. They have already provided information and outreach to more than 500 people.

Appendix 1

Improved Access to Psychological Therapies - Equality Impact Assessment Pro-Forma

Please Note: - A good quality impact assessment report will

- a. Include the best information available at the time
 - b. Be clear, concise, balanced and proportionate to the policy's general impact and equality relevance
 - c. Be a self-contained document
 - d. Use plain and clear language
-

Background Information

1. Name of organisation conducting the EIA.	
2. Names and roles of people involved in conducting EIA.	
3. PCT/area being equality impact assessed. Please describe geographic area that is covered by the IAPT service/s.	

Information about the IAPT Service/s

4. Please provide a brief description of the IAPT service /s that is being EIAd. (e.g. how can it be accessed, where is it located, what times is it available etc)	
5. Which equality strand (s) is/are the focus of your equality impact assessment. (Race, gender, disability, age, sexual orientation, religion and belief)	
6. Please provide an upto date demographic profile of your equality area. (You may need to ask your PCT whether they have upto date demographic profiles. You may research the Office for National Statistics website. Alternatively your support worker may be contacted for further guidance)	

<p>7. Does the IAPT service/s collect equality data in relation to the equality strand. (i.e does the service collect data on the profile of their patients e.g. in relation to race, gender, sexual orientation, disability, age and religion and belief)</p>	
<p>8. What does the data tell us about</p> <ul style="list-style-type: none"> a.) access to the service b.) experience of the service c.) outcomes from the service <p>(You will need to compare the data with the local demographic profile to assess whether there may be some disproportionality)</p>	
<p>9. Are there any specific provisions that are made by the IAPT service/s to take account of the equality strand that is the focus of this eia. (e.g. availability of interpreters, therapists from different backgrounds, literature available in different formats, venues for the service etc)</p>	
<p>10. Are there any good practice issues that the IAPT service/s implements in relation to equality issues, and that others could learn from?</p>	

Information that has been collected

<p>11. Please describe the consultation that has taken place. (Who was consulted and how)</p>	
<p>12. Please describe the outcomes of the consultation. (What did people tell you about the service)</p>	
<p>13. Please describe how your equality target group might have different needs, experiences or priorities in relation to IAPT service/s. Please provide details.</p>	

<p>14. Has any adverse impact been identified through the data or consultation. Please list details. (Is your equality target group subject to any disadvantage, barriers or less positive outcomes than others)</p>	
<p>15. Can any adverse impact be justified? (Is there a valid reason for that unjustified impact)</p>	
<p>16. What further consultation or research is required in order to reach a more definitive view of any differential impact on the equality target group. Please state full details.</p>	
<p>17. If any identified adverse impact is not justified then state what mitigating actions need to take place to minimise the adverse. Please complete recommended action plan below.</p>	
<p>18. What data or information is needed to help to continue to monitor the impact of this policy in relation your equality group and how should this be implemented.</p>	
<p>19. Are there any other equality issues that have come to light during the course of your research?</p>	

Recommended Action Plan

Action	Responsibilities	Timescales

Signed _____ Dated _____

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