

Supporting people with complex personality disorder

Screening for equalities impacts



Feedback collected before, during and after
the formal consultation period



Overview

Aim

The NHS conducted an equalities impact assessment screening to understand whether the models of care for people with complex personality disorder being consulted about between April and July 2009 required a full equalities impact assessment prior to making decisions about next steps.

Method

Information from document reviews, stakeholder workshops, consultation discussion groups, telephone calls with stakeholders and all feedback received during the formal consultation period was compiled and used as the basis for an assessment of potential impact using guidance from the Department of Health.

Screening

	Equalities issues
0 units	Low potential
1 unit	Medium potential
2 units	Low potential
4 units	Medium potential

	Positive impact	Negative Impact
Age	Low	Low
Disability	Low	Low
Ethnicity	Low	Med
Beliefs	Low	Low
Gender	Low	Med
Orientation	Low	Low
Human Rights	Low	Low

Recommendation

The screening process did not identify any high impact equalities issues but it is possible that some of the options could affect groups differently. It is recommended that a full impact assessment is not required prior to decisions about next steps but that a full assessment should be undertaken once an option has been chosen and the service specification is being planned, in line with national policy.



Background

The NHS has a duty and a desire to promote equality, eliminate discrimination and foster positive relationships between different groups of people. Promoting equality and diversity is a key priority in developing and improving services and models of care.

Between 20 April and 27 July 2009, the NHS sought feedback about the best way to organise services for people with complex personality disorder in the East of England, London, South Central and South East Coast regions. The four regions are working in partnership with service users, clinicians and other stakeholders to plan how Tier 4 services could be provided to ensure that people with complex personality disorder receive responsive services that are clinically and financially sustainable.

All policies, proposals and services within healthcare undergo equality impacts assessments to ensure that services promote equality and that no groups are systematically disadvantaged.

As a precursor to the consultation, an initial equality impacts screening was undertaken in December 2008. People and organisations responding to the consultation were also asked to consider whether any groups may be specifically disadvantaged by the proposals. Furthermore, following the end of the consultation feedback period, 100 organisations and stakeholder groups were recontacted to ask about equalities issues.

This document sets out the key messages related to equalities issues. The aim was to consider whether there is a need to undertake a full equalities impact assessment prior to making decisions about next steps.



Approach

People from all walks of life are affected by personality disorder. It is essential that any new models of care recognise and celebrate people's diversity, and do not disadvantage particular groups.

To understand the equalities implications of the options put forward regarding Tier 4 services for people with complex personality disorder, the NHS undertook an equalities impact screening

The NHS worked in partnership with service user and carer representatives, providers, commissioners and other stakeholders before, during and after the formal consultation period to understand any issues that might affect different groups.

The consultation team followed the Department of Health's *Equality Impact Assessment: Summary, Tool and Guidance for Policy Makers* (November 2008) as well as guidance from NHS West Kent, the host PCT for the consultation.

The methods used include:

- seeking feedback about equalities issues at discussion groups
- an equalities impact assessment workshop with a national policy focus
- a workshop with a group of stakeholders advising the consultation
- seeking guidance from NHS equalities leads
- seeking telephone feedback from voluntary sector equalities leaders
- asking a question about equalities issues within the consultation feedback form (92 responses made equalities comments)
- telephoning 100 organisations to discuss the draft consultation summary and seek further feedback about equalities issues
- reviewing service use data
- reviewing needs assessment data
- reviewing service specifications
- applying assessment templates

As outlined in the Department of Health's equality impact assessment guidance, the screening examined the extent to which the four options for models of care set out in the consultation summary document may impact positively or negatively on:

- Age
- Disability
- Ethnicity
- Gender
- Sexual orientation
- Religion or belief
- Human rights

The extent to which each option may impact on these groups differentially was considered as was any more general equalities impacts relating to each group. Acknowledging the important voice of service users, carers and other stakeholder groups, the screening process is built upon the feedback collected before, during and after the consultation period.

Quotes from discussion groups, feedback forms and telephone follow ups are used throughout to illustrate key themes.

For each individual option and each equalities group, the consultation team drew together all of the available feedback and rated the potential overall impact as high, medium or low.

Using the Department of Health guidance, 'high impact' refers to a policy or proposal that may have a significant effect on equalities groups, for example by reducing access or explicitly discriminating against some groups. Medium impact refers to a proposal which has the potential to affect some groups differently, but where this impact may be avoidable if modifications are made or where further information is required. Low impact refers to a proposal that is unlikely to affect equalities groups differently or policies which are likely to equally benefit or disadvantage different groups.

In all instances, impacts may be both positive and negative. Please refer to the Department of Health guidance for more information about how potential impacts are assessed and ranked.





Options

This section describes potential equalities impacts for each of the options set out in the consultation document in turn. The next section focuses on potential overall impacts for specific equalities groups.

In pre-consultation workshops, consultation discussion sessions, telephone calls and written responses, people and organisations emphasised the importance of acknowledging and supporting the diverse needs of those using services and their families.

“Diversity must be at the top of the list for any service model”

“Black and minority ethnic groups, women, older people those with a learning disability, homeless people etc must be planned for at the outset, not just an afterthought.”

People and organisations suggested that while people with personality disorders all have unique needs, some groups may be less advantaged by current and planned care models.

“Services need to be designed in a manner that is inclusive rather than inhibiting of supporting work with personality disorder clients as they are already marginalised by services. Careful consideration needs to be given to engage and maintain support for black and minority ethnic groups and outreach would be pivotal in building relationships in the community that decrease stigma and could enhance inpatient engagement and completion of treatment.”

However, whilst there was an acknowledgement of the importance of equalities issues, in thinking about the individual options proposed, the majority of feedback did not believe that any option would affect certain groups differently.

“I do not think that any of the options would be unfair to certain groups because I think each option has the potential to meet all groups and needs through careful and creative planning... the live in units can be planned and divided to meet the diverse range of people’s needs. The live in unit can include single sex annexes for example, and the specialist outreach teams can include an element that specialises with older people.”

In fact, out of 92 consultation responses that considered equalities issues, around one in ten believed that specific options may be disadvantageous to certain groups.

In 113 telephone calls to stakeholders during the consultation period and 100 further follow up calls with groups such as MIND and carers networks, no organisation suggested that particular options were biased in favour of some groups or particularly limiting for others.

In workshops and discussion groups, there was also more focus on changes as a whole and equality principles rather than suggesting that particular options were especially disadvantageous.

The small amount of feedback that was given about individual options is summarised here.



Outreach teams with 0 units

In commenting about equalities issues relating to having an outreach team in each region and no specialised residential unit, the most common feedback was that this would be “unfair to all groups.” People tended to believe that not having residential units would disadvantage many groups – but none more so than others.

One or two people commented that this approach may particularly disadvantage women who needed to break away from abusive or problematic home environments, or from carer responsibilities.

“No live in units would result in women having to be treated at home and continuing to act as mothers, wives etc. No break from home.”

Bearing in mind that impacts can be both positive or negative, some people felt that residential units could be problematic and that an approach focusing on outreach teams and strengthening community services could avoid negative impacts for some groups.

“As a service user with Borderline Personality Disorder who is also disabled physically and has a pet, living in a therapeutic community is not an option for me, so I do think that putting all the money into live in units will exclude the disabled, the elderly, those who have pets, women with children. With my physical disability I would not be able to cope with living in live in unit based on therapeutic community principles, due to my need for sleep and rest, but I would benefit from a specialist day programme that is long term and specific for trauma related personality disorders.”

Parents with young children were singled out for special mention as were the needs of other carers.

“All of the live-in proposals are potentially excluding, in that they will inevitably be remote for many people and their carers. Residential living does not suit the majority of people and almost always brings additional stress and tensions for individuals and groups. The closer to home that the service can be means that it is the least excluding, ie local outreach services are most inclusive, preferably within localities.”

Weighing up all the feedback and suggestions using Department of Health guidance, the consultation team estimates that the option of outreach teams with **no residential units is unlikely to unfairly disadvantage some groups and may provide scope to develop localised services to meet diverse needs (low potential differential impact).**



Outreach teams with 1 unit

In discussion groups, workshops, and written consultation feedback, the option of having regional outreach teams along with one residential unit serving the four regions was the most likely to elicit concerns about equalities issues.

People believed that if only one unit was available, the service may meet the needs of a less diverse client group.

In particular, there were concerns about whether the different needs of men and women could be met in one unit.

“Many women may prefer single sex accommodation. Where there is one national unit this may not be possible. I lived in units ... and felt more comfortable with all residents being women, its only later I built confidence to be around men. It is true also where women have histories of abuse.”

Feedback before, during and after the consultation period suggested that there may be a need for a single sex facility. One unit could house men and women separately in different wings, but the practicalities of this would need to be carefully considered.

Another concern was that having one residential unit may necessitate more travelling and this could adversely affect those using public transport, the elderly, carers and those with young families.

“Having one or two live in units for the whole region would be unfair to any population which had to rely on public transport.”

Weighing up all the feedback and given the complex needs of those using Tier 4 services, the consultation team estimates that the option of outreach teams with **one residential unit may not address diversity issues as well as some of the other options but this could be mitigated with further development (medium potential differential impact).**

Outreach teams with 2 units

The screening found no clear equalities issues from having outreach teams with two residential units.

Some feedback to the consultation suggested that having two or more units would be more likely to meet diverse needs.

“Having a number of options available, in the form of live in units, day services with intensive treatment packages allows cultural needs of certain groups such as minority ethnic populations, women or elderly to be met and will reduce potential in unfairness in access.”

There were still some concerns about travel and access but weighing up all the feedback, the consultation team estimates that the option of outreach teams with **two residential units may be unlikely to unfairly disadvantage some groups (low potential differential impact)**.

Outreach teams with 4 units

The option of having four units elicited some concerns during the consultation period. A small number of people suggested that having four residential units could disadvantage people from certain groups as the small size of the units may mean that only one or two people from such groups would be present at any one time. Most commonly this was thought to be an issue for people from black and minority ethnic groups.

“Smaller units may mean that people from minority groups are more likely to be on their own, whether by ethnicity, age, class or for example parents whose children were in care.”

Weighing up all the feedback, the consultation team take on board the suggestion that the option of outreach teams plus **four residential units may have some impacts on minority groups and this would need further exploration if this option were selected (medium potential differential impact)**.

Other options

A number of alternative options were suggested during the consultation period including enhanced community services and three residential units. Those proposing these options tended to believe that the alternatives would better meet the diverse needs of people with complex personality disorder and no other equalities issues were raised regarding these options during the consultation period.

After the consultation period, once all responses had been compiled and information about alternative options was available, the consultation team telephoned 100 stakeholder organisations including carers groups, the voluntary sector, and NHS organisations to seek further feedback. The groups were asked for feedback about any perceived equalities issues with any of the original or alternative options put forward. These groups did not highlight any further equalities issues.





Broader issues

As described overleaf, almost all of the feedback received before, during and after the consultation and the consultation team's own assessment suggested that it is unlikely that any of the options proposed are specifically biased against certain groups, but that more detailed thought may be needed about how to ensure a wide range of people can benefit from any new services.

“It is important to remember the special needs of small subgroups of people with personality disorders and special needs such as mothers with new babies, frail older people, adolescents and young adults, people with a learning disability, people with a dual diagnosis of substance misuse and personality disorder, people from BME and other minority groups. There is currently very little provision for these groups...”

The groups that people and organisations thought should be considered when further developing new models of care include:

- people with dependents
- women
- men
- older people, aged 65+
- children and adolescents
- minority ethnic groups
- people in remote areas
- people using public transport
- people with drug and alcohol issues or other co-morbidities
- homeless people
- carers

This section examines potential impacts on each of the equalities groupings specified in the Department of Health guidance.

Age

Feedback before, during and after the consultation suggested that the new models of care were unlikely to have a significant impact on different age groups for the population considered (those aged 18-60 years).

Some suggested that the proposals should be broader to consider young adults with personality disorder, those making the transition from children's to adult services and older adults.

“From my experience of the Henderson and the Cassel neither could really offer appropriate facilities for older people with personality disorders and their needs are cared for by mainstream mental health or older persons units.”

It was also suggested that small residential therapeutic units may have a potential to be alienating for some age groups. For example in small facilities there may be a large disparity in the ages of service users, leading to less identification with others as well as less integration, interaction and communication.

These are potential issues for consideration with all of the options suggested in the consultation.

If focusing on the scope of the consultation itself, rather than other issues that could be included, the consultation team estimates that the options themselves may have a **low potential impact according to age.**

Disability

The equalities screening found that the proposals were unlikely to discriminate against those with a physical or learning disability. All of the options would need to consider accessibility issues for those with physical disabilities, especially when considering venues for residential care.

In workshops prior to the consultation stakeholders suggested that some current services may have issues with physical accessibility such as unsuitable buildings, insufficient wheelchair access, or no lifts. It was noted that patients with severe hearing disability using hearing loops or sign translators may be excluded.

Stakeholders also suggested that attention should be given to people with learning disabilities when developing future services.

During the consultation period, no responses suggested that some options would be more or less advantageous for people with disabilities. Follow up calls to 100 stakeholder organisations also found no suggestions of differential equalities issues in this regard.

Whilst acknowledging the need for all new models of care to cater appropriately for people with different physical needs and those with learning disabilities, the consultation team estimates that proposals about new models of care would not positively or negatively impact on people with disabilities any more than the status quo so this was given a **low overall impact rating.**

Ethnicity

The screening suggested that the consultation options had a medium possibility of impacting negatively on people from black and minority ethnic groups.

Consultation responses and feedback from stakeholder groups suggested that while the consultation options themselves may not lead to more disadvantage or harm, there were still significant steps to be taken to address ethnic diversity within current and future services.

During workshops and discussion groups stakeholders suggested that very few people from minority ethnic groups are diagnosed or referred to personality disorder services. The reasons for this require further exploration. The workforce caring for people with personality disorders may also benefit from more ethnic diversity.

People were also concerned about the extent to which intercultural issues were dealt with within very small services. Some feedback to the consultation suggested that therapeutic community approaches may find it difficult to work effectively with those who do not feel they 'fit in' to the group.

"I think current forms of live-in unit, which depend on the therapeutic community model, are more difficult for some groups to make use of, including vulnerable women, elderly people, children and people from some ethnic backgrounds."

As outlined overleaf, for this reason some people questioned whether having four small residential units would potential disadvantage people from ethnic minorities.

There were a number of comments about how to improve current and future services in order to be more inclusive of people from various ethnic groups. For example, during workshops focused on equalities issues, it was suggested that future services should include trained outreach teams and volunteers recruited from various ethnic backgrounds, should target services to make them more accessible to people from a wider range of ethnic groups and should include translation of leaflets or provision of information in easy read formats to support those who have English as an additional language. These suggestions apply both to current and future services and are not specific to proposed changes in the model of care.

Some responses to the consultation felt that when a new model of care is selected and implemented, it will be important to assess the extent to which ethnicity equalities issues have been addressed.

"I think it would be important to have an audit of how patients from ethnic minority groups are able to access these services."

Because there is a significant amount of work to be done in this area, the consultation team and stakeholders involved in the screening felt this should be given a medium impact rating to ensure the issues were considered further.

Gender

The screening assessment concluded that some of the consultation options may impact differently on women and men.

During stakeholder workshops prior to the consultation it was suggested that there were some potential gender inequalities within current models of care and that these may need to be redressed in developing new approaches. In general, women outweigh men in contact with mental health services 2:1. Women are more likely to be in contact with mental health services while men are more likely to be in contact with the criminal justice system or drug and alcohol services.

This concern was replicated during the consultation process itself. When asked about potential equalities issues, gender was one of the most frequently mentioned concerns. As outlined overleaf, people were worried that having one residential unit might mean that women would not have the space and time needed to receive treatment in a supportive and potentially single sex facility.

Others mentioned that men also had special needs that may not be met by current or planned models of care.

“Men will tend to miss out as they are more likely to be dealt with by forensic services. It is therefore important to continue to maintain contact even when clients are in contact with prison/probation services. They are also more difficult to engage and are perceived to be more of a risk to staff.”

“Most services are unfair to men. Women who act out are seen as vulnerable and requiring extra treatment, support, protection etc. Men who act out are seen as too aggressive, unsuitable for the service, or requiring management by the criminal justice system.”

There was also concern that all of the proposed models of care may not cater adequately for parents.

“Live in services will always be likely to be difficult for mothers with children unless accommodation for the children is provided as well. The balance between separating mother and child should be weighed up against the benefits for the mother (in terms of her mental health and her ability to mother)”

For these reasons **gender issues were assessed to have a medium potential impact and may need to be considered further when developing the service specification for new models of care.**

Religion or belief

The screening found that proposed new models of care were unlikely to have a different impact on people with various religious beliefs.

People taking part in workshops to discuss equalities issues noted that those who think they may be ostracised from society or their family due to cultural or religious beliefs may be less likely to access personality disorder services. This is an issue regardless of the model of care selected.

The consultation team estimate that **religion or belief may have low potential differential impact** regarding the consultation options.

Sexual orientation

Screening found that the consultation options were unlikely to affect gay, straight or bisexual people differently.

It was suggested that whatever the model of care, services should be accessible and equally welcoming to all. One of the roles of proposed outreach teams may be to undertake further work to understand how services could be adapted to better meet the needs of people regardless of their sexual orientation. Thus the consultation team estimate that **sexual orientation may have low potential differential impact** regarding the consultation options.

Human rights

Screening found that the consultation options may be unlikely to impact human rights compared to current service provision.

Several potential shortcomings in current and future care were brought to light such as:

- the length of time that people must spend in residential units takes them away from their family and impacts on finance, employment, education and childcare
- people have to be knowledgeable to access the services so more information and signposting is required for service users and primary care
- the Mental Health Act prevents access to some services based on medication
- stigma of diagnosis

It was suggested that literature about Tier 4 services should reflect principles of care and take into account Human Rights legislation.

However, these are issues that span all of the potential consultation options so the consultation team estimate that **human rights issues may have low potential differential impact**.



Summary

To summarise, the potential for proposals to impact positively or negatively on different equalities groups was rated as low, medium or high, as tabulated below.

	Equalities issues
0 units	Low potential
1 unit	Medium potential
2 units	Low potential
4 units	Medium potential

	Positive impact	Negative Impact
Age	Low	Low
Disability	Low	Low
Ethnicity	Low	Med
Beliefs	Low	Low
Gender	Low	Med
Orientation	Low	Low
Human Rights	Low	Low

The screening did not identify any potential 'high' impact areas which means it is recommended that a full equalities impact assessment is not required prior to making decisions about next steps. However, once an option for the future is chosen, another screening will be required in line with Department of Health guidelines.

Given that the screening identified potential equalities issues with current provision and some areas for further consideration, it is recommended that a full equalities impact assessment is undertaken once a model of care is chosen and planning is underway.

Other suggestions include:

- collating demographic information about all of the equalities groups prioritised by the Department of Health as a requirement in new service specifications
- considering staff demographics and recruitment as well
- building in an audit process for new services to ensure ongoing consideration of equalities issues on a regular basis

Keeping equalities issues high on the agenda as new models of care are developed will help the NHS meet its aim of providing accessible and acceptable care for all.