

Supporting people with complex personality disorder

Independent summary of consultation themes



THE
Evidence
Centre

Consultation: 20 April to 27 July 2009

Setting the scene: a service user's story

“ I suddenly woke up one day in my late thirties and realised I was very different to other people. I had always had a suspicion that this was the case but now something had confirmed it. Having finally met other people who suffer with what has been so lovingly described as ‘personality disorder,’ I experienced ‘the black epiphany’- that moment when you suddenly gain a realisation of the sheer weight of pathology that has riddled your every waking moment and that has been there from your earliest disturbances in childhood to the numerous attempts I had made to end my life in my teens, twenties and thirties...

Signs of my emerging personality disorders started in early childhood. I was so disturbed that my adoptive parents had to put bars over my windows as I used to throw all my toys and bed linen out of the window every night and they were worried I would fall out of the window as I did this. I was told that I was adopted very early on and have no memory of ever thinking they were my parents as far back as I can remember. I used to pray to God that my real mum would rescue me one day. When someone came to the front door I used to rush forward shouting ‘is that my mum, has she come to get me?’...

I was a very disruptive, naughty child who wanted so desperately to be loved and accepted by my adoptive family. I had behavioural problems and used to rock backwards and forwards going into a trance-like state for hours every day. I had terrible insomnia from early on and would repeatedly bang my head on the pillow and make a droning noise to distract myself from the unbearable agitation that I felt. This ignited a cycle of physical and emotional abuse at the hands of my adoptive parents who did not understand the mental distress I had to endure on a daily basis and just beat me with increasing ferocity to get me to stop rocking and banging my head...

One time after I refused to rake up the back garden, I was beaten with the rake. I ran into the kitchen hoping my mum would protect me but she grabbed me so my dad could beat me some more. I grabbed a carving knife from the board and tried to stab her so she'd let me go. I was beaten severely for this and after that they contacted social services requesting I be put in a home for maladjusted children. I was 12 years old. Social services tried to work with the family to overcome our problems but my parents refused to attend the therapy sessions and I had to go on my own. When the decision was made not to send me away my father was so angry he just used to act as if I didn't exist. The rest of the family tried their hardest to get on with their lives but the silent aggression from both sides made me run away and spend hours on my own in the woods in my camp reading my comics. It was during this time that I started to feel suicidal and constantly tell my mum and dad that I wanted to die...

By 14 I had started sniffing glue to escape the misery I felt and also experimenting with cross-dressing. I was often sent home from school for wearing women's clothing. I started to alienate the few friends I had by doing this but I thought I was the messiah and they would all worship me one day. My father hated my emerging transvestism and completely smashed my make up box to pieces and forbid me from wearing any women's clothing around the house. The threat of being thrown out onto the street was put on me constantly. I decided to go on hunger strike and stopped swallowing my food. I used to store all the rotting mouthfuls of half digested food in shopping bags in my wardrobe...

A number of addictive behaviours started to enslave me from my mid teens: food (bulimia), gambling, spending and self mutilation, but alcohol and self harm became more prominent as the intensity of my emotional pain, depression, isolation, and self hatred magnified to unbearable levels during my late teens and early twenties. By my thirtieth birthday I had made a number of serious attempts to end my life, regularly slashing my arms with razor blades. I had also attempted to stab myself in the heart on a number of occasions and cut my nipples off...



After the end of my only relationship I started to drink heavily and self mutilate which led to my first contact with adult mental health services. After a lengthy assessment with a senior psychiatrist consultant I was told I presented symptoms of a condition that could not be treated with medication and discharged from services never knowing what was wrong with me... Although I constantly felt suicidal and my behaviour by that time was very extreme, people thought I had mild depression or was just an attention seeker...

Due to the 'untreatable' tag almost another entire decade would pass with an increase in all the aforementioned pain, distress and self-destructive behaviour until I finally entered [a residential unit]. The [unit] was the only thing that has made any difference, everything else was like water of a ducks back... I believe it is one of the only treatments available for people with a diagnosis of severe personality disorder that can make a significant and lasting difference to their condition. I'm not saying that out of any misplaced emotional attachment to the place as the regime there is very tough indeed and you can't view the [unit] with rose tinted specs. If you've been a resident there you know it's no tea party. I express that viewpoint with a strong conviction as I've had numerous other 'treatments' (both therapeutic and pharmaceutical) prior to that dating back to early adulthood.

Everyone I've known with personality disorder had no quality of life whatsoever prior to being treated at the [unit]. Living with personality disorder is like existing in a perpetual state of chronic mental torture, unending and unendurable depression, hopelessness, self hatred, despair, anger, frustration, extreme loneliness, paranoia ... One of the hardest things to endure having personality disorder is the contempt and lack of sympathy and ignorance that many mental health professionals hold towards a disorder that in many cases is a result of physical and/or sexual abuse in childhood...

I welcome personality disorder orientated [community] support networks as a step forward and an invaluable support to sufferers who have been in treatment but they could in no way replace residential inpatient treatment... The year long programme has actually changed me - the leopard not only changed its spots, I'm not even a leopard anymore - it has improved the quality of my life immensely. I no longer take medication all the time and the levels of psychological distress have diminished and I have also learned more adaptive coping mechanisms to cope with the more extreme feelings that arise from time to time. I live a more adaptive life and even though I would not say that I am cured my life now is better than it has ever been and I know that without the [unit] I would not have known what it's like to feel moments of true happiness and feel a growing sense of positivity about my life and myself.

The [unit] was a beacon of hope and is a literal lifesaver. To many it was their last chance to make a difference to a life that's not worth living. Many of the people I met in there (including myself) saw it as their only hope and would openly admit 'if I didn't get in there I would have committed suicide' ...

The vast majority of people with personality disorder that I've met live in very toxic domestic environments and need space away from them to break strongly fused co-dependent or abusive relationships that only worsen and maintain their symptoms. If I had attended a type of day programme but gone back to my mother's place in the evening I would have never been able to break the influence that unhealthy and mutually destructive relationship had on my life. It was only the year at the [unit] that was able to do that for me and I now live a much more independent life away from my mother. This was really helpful both during and more importantly after treatment. It enabled me to make some progress in developing my own inner strengths and helped me to understand myself, understand boundaries, to see the effect my behaviour had on others (a massive deterrent when you don't know why you have no friends), to start loving myself, and to have respect for myself and others. ”

Overview

As the preceding story demonstrates, people with complex personality disorders can face a lifetime of suffering and torment. The NHS wants to ensure that treatment and support is available for people with a wide variety of needs. A key part of this involves asking people using services, family members, health professionals and organisations what their needs are and how best to organise services to meet these needs.

Between April and July 2009, the NHS consulted about the best way to organise care for people with complex personality disorder in the East of England, London, South Central and South East Coast regions (ie people who might use 'Tier 4' services).

The key questions that the NHS is considering are:

- Should outreach teams be set up specifically for people with complex personality disorder in each region?
- Should specialist residential (live in) treatment centres be available for people with complex personality disorder?
- If residential treatment centres are used, how many should be provided across the four regions?

At this stage, the NHS is not considering what types of treatment and care should be provided by community outreach teams or residential unit(s).

The type of treatments to be offered, exactly where any units should be located and who should run them will all be considered once decisions are made about how to organise services.

Options

In total, 98% of responses to the consultation believed that some changes are needed to the way services are organised. There are currently two NHS-funded residential services for people with complex personality disorder serving the four regions (one of which is temporarily closed) and no separate specialist regional outreach teams.

The NHS asked people and organisations to provide feedback about the value of regional outreach teams, whether residential services are needed and how many residential services should be available.

Regarding the number of residential services, the NHS put forward four options which were developed by a group consisting of service user and carer representatives, GPs, specialist clinicians, black and minority ethnic group representatives and commissioners:

- no residential units
- one residential unit at an as yet undecided location
- two residential units at an as yet undecided location
- four residential units; one per region

In addition, all of these options also includes setting up one outreach team specialising in complex personality disorder per region.

The NHS also invited people and organisations to put forward alternative ways of organising care.



Who participated?

The NHS distributed a summary of proposals and feedback forms to more than 10,000 people and groups, sent press releases and updates to over 1000 organisations, ran five events to share information and listen to people's views and attended roadshows and conferences. People were invited to provide feedback by post, online, by telephone and in person.

There were 373 responses to the consultation. Of these, 181 were from health professionals and managers (49%), 106 were from service users and family members (29%), 59 were from NHS organisations, voluntary groups and other agencies (16%), 18 were from members of the public (5%), and 3 were from MPs and Councillors (1%). Six responses were from mixed groups of individuals and organisations.

It is not possible to say how many separate individuals took part because some people submitted more than one response and some of the responses represented numerous people or were on behalf of large groups such as health professionals' committees, local authorities and NHS organisations.

Overall, 20% of the feedback received was from the East of England, 28% was from London, 18% was from the South Central region, 28% was from the South East Coast and 7% was from other areas including the Midlands and Northern England.

Of the individual responses, 60% were women, 9% were from minority ethnic groups and the majority were aged between 20 and 60 years.

Feedback

All feedback was compiled by an independent organisation, The Evidence Centre, which specialises in collating people's views.

Should there be community outreach teams for personality disorder?

A total of 303 responses commented on whether outreach teams would be valuable. Of these 95% supported regional outreach teams.

Responses from all four regions were equally supportive of this idea.

Whilst people were generally in favour of this approach, some questioned the role of outreach teams and believed that they would be stretched to cover an entire region if they were providing hands-on treatment. It was suggested that these teams might more usefully focus on upskilling other staff to support people with complex personality disorder and signposting to other services.

Some suggested that 'managed clinical networks' may be more appropriate than outreach teams. It was not described how managed clinical networks may differ from the outreach teams proposed but the general concept of clinical networks involves professionals linking across organisational boundaries to share skills and knowledge.

Should specialist residential treatment centres be available?

A total of 276 of responses commented on the option of having no residential units. Of these, 16% supported the idea of having no residential units.

The reasons given included a lack of need, other priorities, the importance of investing in community services instead, and the potential to provide treatment in other ways such as through day centres, crisis homes, or spot purchasing of places from the independent sector.

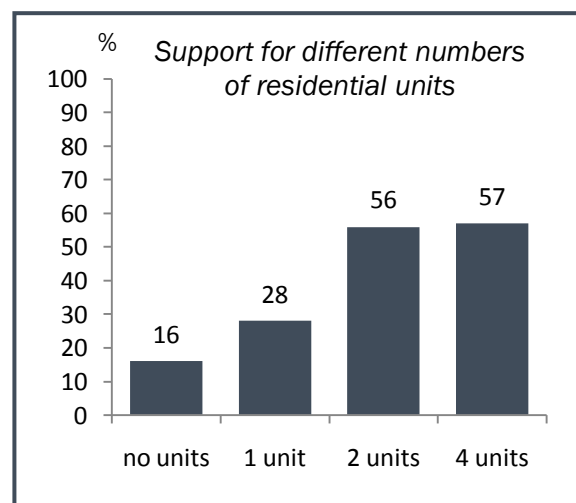
The top three advantages of having no residential units were thought to be saving money or diverting funds to community services, providing care closer to home and avoiding institutionalisation, stigmatisation and learning negative behaviours.

The top three limitations of this approach were said to be a lack of safety and containment, insufficient provision of treatment options and a lack of highly skilled specialist staff in outreach and community teams.

The majority of responses appeared to support having residential units of some nature. In fact, 92% of responses said both community outreach and residential units were needed. Responses suggested that it was important for service users and referrers to have a choice available. They said that some people with complex personality disorder needed to be away from their home environment while undergoing therapy and that some people required containment whilst receiving treatment. People said that residential care provides therapeutic approaches that are not possible within day units or other care in the community. Some said that if people are exploring complex emotions then it is better that they do not go back to their home environment until those emotions are fully worked through.

How many residential units should be provided across the four regions?

Whilst the majority of people and organisations that responded to the consultation generally supported both community outreach and residential care, there was no agreement about the number of residential units needed.



Around 250 responses commented on the value of having one, two or four units. Of these, 28% supported having one unit, 56% supported having two units and 57% supported having four units. Responses could support more than one option.

The top three perceived advantages of having one residential unit were ensuring that some live in facilities were available, developing a centre of excellence and ensuring consistency and good communication within and between regions.

The most commonly mentioned limitations were the distance between the unit and people's local communities and services, insufficient capacity to meet needs and not being able to offer different types of treatments or therapeutic approaches within one unit.



The top three advantages of having two residential units were thought to be an ability to provide a variety of therapeutic approaches and cater for different needs, greater bed numbers and the potential for care closer to home.

The top three limitations of this approach were said to be the potential for units to be far from people's homes which would necessitate travelling for service users and carers and make links with community services more difficult, having too few beds or not enough capacity to accept all referrals and being more expensive or less cost effective than some alternatives.

The three most commonly mentioned advantages of having four residential units were being able to offer care on a regional basis which may be closer to people's local communities, greater capacity of beds to meet identified needs, and the potential to provide a variety of different therapeutic approaches.

The top three limitations with having four residential units were concerns over cost and sustainability, the limited size of each unit which may preclude offering therapeutic communities and whether there would be a sufficient highly skilled specialist workforce to staff four units.

Feedback about the potential pros and cons of each approach was generally consistent throughout the four regions and amongst different types of respondents. In other words, service users, carers, health professionals, organisations and other stakeholders from throughout the regions tended to raise the same potential benefits and concerns.



Other options

Responses also suggested other ways of organising services for people with complex personality disorder, including:

Ideas for community services

- setting up more day centres or units where people stay 3-4 days per week rather than full residential units (this links to the option of having no residential units and strengthening community services)
- enhancing the support available in the community, including outreach teams, support groups, and recreational facilities (this links to the option of having no residential units and strengthening community services)
- adding specialists in personality disorder to community mental health teams or other existing community services rather than setting up separate outreach teams
- having a team in the community which holds and manages a commissioning budget and signposts people to available day centres, crisis treatment and other short term care (this links to the option of having no residential units and strengthening community services)
- ensuring a managed clinical network to help professionals work across organisational boundaries (this was suggested in addition to residential units not as a standalone option)
- having crisis houses in local areas available to cope with short term admissions rather than longer term residential care

Ideas for residential care

- having three needs-led units such as one for women only, one catering for families and one for a mixed group, or separate units for people with different types of personality disorder. These three units would not necessarily need to be located in different regions and could be of varying sizes
- partnering with housing associations and the voluntary sector to provide residential facilities
- setting up a number of smaller residential units, such as 8-10 units with 5-10 beds each



Next steps

In addressing the questions the NHS is considering, feedback from the consultation suggests that:

- people and organisations generally **support the idea of regional outreach teams**, though not all suggest that these need to be separate additional teams
- people and organisations generally believe that **both residential facilities and outreach support is needed** for people with complex personality disorder
- **there is no agreement about the number of residential units needed** to cover the four regions. More than half of responses supported having either two or four units to ensure that a wider range of needs could be met, to enhance capacity and to increase geographic spread

An NHS committee of representatives from the four regions has been set up to consider next steps in November 2009. The consultation documents issued by the NHS state that when making decisions, the committee will consider the feedback and stories received during the consultation period as well as the reasons for change, assessments of need, financial estimates and recommendations from NHS organisations.

Responses to the consultation said that the committee should prioritise clinical effectiveness and financial sustainability when differentiating between options.

Following the NHS committee's decision about next steps, the NHS has stated that groups from each of the regions will begin planning how to implement the decision and finalising the exact specification for the services required.



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About the authors

The Evidence Centre is an independent organisation specialising in ‘turning information into intelligence.’ It supports health, social care and other public services to make decisions and put evidence into practice by supporting consultation and engagement, conducting research and service evaluations, undertaking rapid reviews and working with teams to apply best practice.



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Background

Context

Between April and July 2009 the NHS consulted service users, carers, health professionals, organisations and members of the public about the future of services for people with complex personality disorder. This document provides an independent compilation of all consultation feedback. This section briefly describes the background to the consultation and how responses were collected and compiled. The next section outlines the number and type of responses. Following this, feedback about different options and potential next steps is presented.

Personality disorder

'Personality' is the pattern of thoughts, feelings and behaviours that make a person unique. It includes our approach to life and how we think, feel and react to others. An official psychiatric manual, the Diagnostic and Statistical Manual of the American Psychiatric Association, defines a personality disorder as an enduring pattern of inner experience and behaviour that differs markedly from the expectations of the individual's culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time and leads to distress or impairment. Personality disorders are characterised by long term, rigid patterns of thinking and behaviour that can cause personal and social difficulties.

The American Psychiatric Association defines three clusters of personality disorder (see Box 1). About one in ten people have a personality disorder. Most are able to live well day to day. A smaller number have a complex personality disorder which makes it difficult to live life well and can cause problems for people and their families.

People with complex personality disorders do not usually hurt other people, but they sometimes harm themselves as a result of the distressing feelings they experience. They might get angry, feel depressed, be impulsive, misuse alcohol or drugs, have an eating disorder, have volatile relationships, self harm or attempt suicide. Because our personalities develop early, personality disorder can take a long time to treat.

Box 1: American Psychiatric Association's three clusters of personality disorder

Cluster A - eccentric disorders

- Paranoid personality disorder: characterised by irrational suspicions and mistrust of others
- Schizoid personality disorder: lack of interest in social relationships
- Schizotypal personality disorder: characterised by odd behaviour or thinking

Cluster B - dramatic or emotional

- Antisocial personality disorder: pervasive disregard for the law and the rights of others
- Borderline personality disorder: instability in relationships, self-image, identity and behaviour and extreme 'black and white' thinking
- Histrionic personality disorder: attention-seeking behaviour and shallow or exaggerated emotions
- Narcissistic personality disorder: grandiosity, need for admiration, and a lack of empathy

Cluster C - anxious disorders

- Avoidant personality disorder: social inhibition, feelings of inadequacy and extreme sensitivity to negative evaluation
- Dependent personality disorder: psychological dependence on other people
- Obsessive-compulsive personality disorder (not the same as obsessive-compulsive disorder): rigid conformity to rules and moral codes and excessive orderliness



Treatment available

The NHS uses the terms ‘Tier 1’ to ‘Tier 6’ to describe the types of services for people with personality disorders. For people with mild to moderate personality disorders, Tier 1 to 3 services are provided in local communities, including support from GPs, community mental health services, nurses and voluntary groups and specialised day centres. People with more severe or complex personality disorders might need extra treatment and are offered Tier 4 specialist services. These people need more comprehensive help than can be offered by general community services and may be at risk of harming themselves. People with personality disorders who are at risk of harming others are offered Tier 5 or 6 services in hospitals or other secure facilities. People move from one tier of service to another as their needs change.

Between April and July 2009, the NHS consulted about how to organise treatment for people with complex personality disorders who might use ‘Tier 4’ services. About 100 people per year use these types of services spread across the East of England, London, the South Central region and South East Coast.

Currently Tier 4 services for people throughout these four regions are provided by two residential or ‘live in’ services located in London: the Cassel Hospital in Richmond and the Henderson Hospital in Sutton. The Henderson Hospital is temporarily closed. The NHS also uses services run by the independent sector.

People with a complex personality disorder might receive treatment at residential services for up to one year, with some follow up by specialist teams. There are 44 places or ‘beds’ spread across the two facilities.

Consultation purpose

The NHS is planning how to organise Tier 4 services in future. Sixty-two primary care trusts throughout the East of England, London, South Central and South East Coast regions undertook a combined consultation because these regions had historically used some of the same services. The focus of the consultation was on the general model of care, not on the pros and cons of individual services.

The key questions the NHS is considering are:

- Should community outreach teams be set up specifically for people with complex personality disorder in each region?
- Should specialist residential (live in) treatment centres be available for people with complex personality disorder?
- If residential treatment centres are used, how many should be provided across the four regions?

The consultation did not consider the exact type of treatments that should be provided by different services – just whether there should be more outreach care and how many residential units might be needed, if any.

The NHS consultation documents state that the consultation is not a referendum and that people’s feedback will be considered alongside other evidence such as the reasons for change, assessment of needs, financial projections and suggestions from primary care trusts. A joint committee of representatives from the four regions has been established to make decisions about next steps. This compilation of consultation feedback is **one** of the pieces of evidence the committee will consider.

Why change?

The consultation documents describe national guidance outlining how people with personality disorder should not be excluded from treatment and should receive good quality care. The consultation documents state there is no definitive evidence about how many people might need Tier 4 services, what models of care are best, or what type of changes might be needed, though people and clinicians sometimes hold strong views about this.

In the consultation documents, the NHS suggested that there are five main reasons why it is important to think about change rather than continue current ways of organising services. These reasons are replicated here to provide a context for the feedback received. All of the text in the yellow box on these pages is sourced from the consultation documents. (Further details are available on 'have your say section' of www.westkentpct.nhs.uk).

1. New community services are starting

In the past, residential services were the only type of care available for people with complex personality disorder but this is changing.

From 2003 it became government policy to create a full range of Tier 1-6 services to support people with personality disorders in the community and in residential facilities. Since then, community services have been set up in some areas to help people with less severe personality disorder.

The development of local Tier 3 services means the NHS has to think about how Tier 4 services fit in with the care pathway and how they interact and can best complement other services. This means the NHS is considering what type of residential services, if any, might be needed to supplement the local services planned or already set up.

2. Some people may feel excluded

The Tier 4 residential services provided at the Cassel and Henderson Hospitals are both 'therapeutic communities.' This means the therapeutic environment itself is one of the main ways of bringing about change, alongside intensive therapies. People receiving treatment have a key role in making decisions about the everyday running of these services. Relating to others on a day to day basis helps people challenge their thoughts and behaviours.

Therapeutic communities work well for some people but the 'therapeutic community' approach is not the only type of treatment available. This approach might exclude people who do not work well in groups or do not feel they fit in with other group members. Parents with young children, young adults and people from minority ethnic groups might find it more difficult to access these services or might not be as comfortable using therapeutic communities. A review from the National Specialised Commissioning Group (2008) suggested that there may be a need to build up a range of therapies and treatments, perhaps in addition to therapeutic communities, to make sure a wider range of people can get the help they need. For this reason the NHS needs to consider how best to organise care to cater for a wide range of needs.



3. Services might be far from home

The NHS aims to provide care as close to home as possible, although it can sometimes be helpful for people with personality disorders to receive care away from their local area too.

All Tier 4 services for the East of England, London, South East Coast and South Central regions are currently organised around two residential facilities in London. The NHS wants to consider whether this way of organising care is the best for people throughout the four regions or whether it may create problems for people living further from London.

It is important for people with personality disorders to have good follow up and outreach care. Having services closer to where people live might help to make this outreach support more accessible.

4. Approaches are not sustainable

The NHS estimated that the cost of Tier 4 services and other extra placements in the independent sector is probably at least £10 million per year. Full details of how the costs were estimated are provided on the consultation website (see the 'have your say section' of www.westkentpct.nhs.uk)

The way care is organised needs to be able to last long term or be 'sustainable.' The way that services are currently organised might not be able to be funded long term.

In recent years, changes to the way services are funded and developments in community services led to fewer people using Tier 4 residential services. There is no fixed or predictable income to keep residential services going. These changes mean that current services may not be stable and cannot be sure of their future. The NHS needs to develop a system to ensure more stability for treatment services.

5. Guidelines have changed

Previously it was not always acknowledged that personality disorder was treatable, but changes to government policies and the law mean that the NHS now recognises that people with personality disorder benefit from supportive treatment and care.

The NHS aims to provide 'appropriate medical treatment' for people with complex personality disorder. The appropriate care might not be a hospital or live in service. The NHS has to follow new guidelines and think about other ways of organising care, perhaps in addition to residential services.

New policy documents and guidance has been published over the past year and continues to emerge. The NHS needs to take account of all the new guidance and the best evidence when considering next steps.

In summary, the NHS is considering changes to the way Tier 4 services are organised because:

- new community services are being developed and the NHS needs to plan how everything might work together
- current services might not be meeting all needs or could exclude some people
- current services are all based in London so people outside London might be getting less support
- the way services are funded has changed and the NHS needs to develop a system to make sure that services are funded in a stable way in the long term
- changes to the law mean the NHS needs to consider a variety of approaches

'No change' is not an option because without change current residential services would continue to be unstable and would not be certain of their future. The care available would not meet the needs of all people with complex personality disorder and some groups would continue to be excluded.

Options

The NHS worked with people using services now and in the past (service users), family members and carers, voluntary groups, health professionals, commissioners and other interested organisations to develop potential new ways to organise Tier 4 services. The NHS invited people and organisations to comment on the options that were suggested by these stakeholders and to propose additional options of their own.

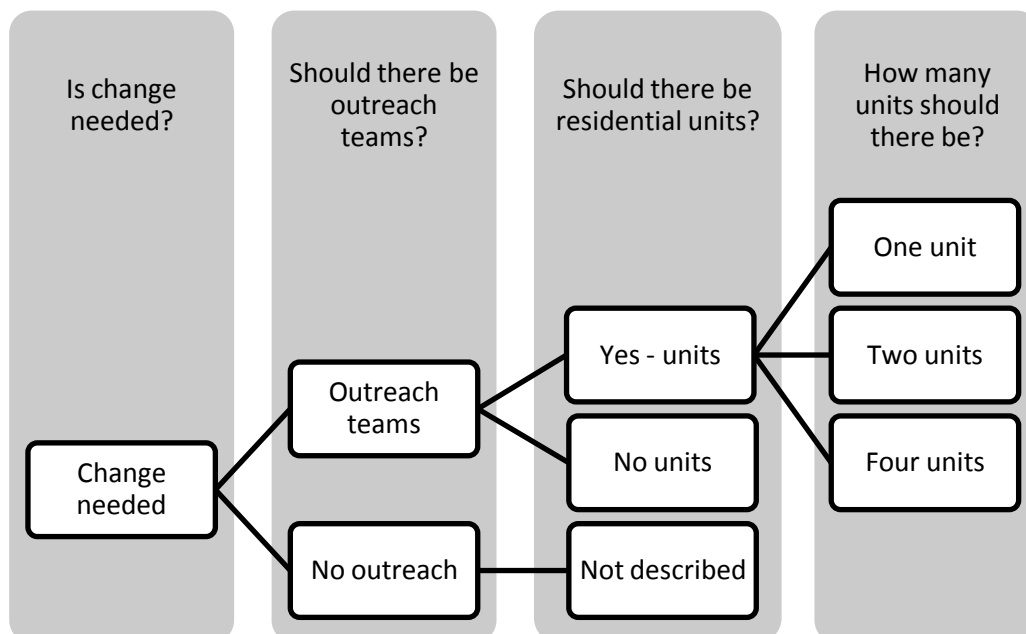
Figure 1 illustrates the decisions that the NHS will be making in November 2009, each of which the consultation asked people to comment about.

Outreach teams

The NHS proposed specialist 'outreach teams' working in the community regardless of whether or not residential units are provided. There would be one specialist outreach team for London, one for the East of England, one for South Central and one for the South East Coast.

These outreach teams would help identify people who might need Tier 4 services, signpost people and their families to appropriate care, train the people running local mental health services and offer follow up care. This would be a change from current services where most specialist treatment focuses on live in care.

Figure 1: Options being considered



Note: the figure illustrates options set out in the consultation document. Alternatives were also invited.



No residential units

An option is to have specialist outreach teams without any residential services. With this approach there would be no specialist live in Tier 4 treatment unit for personality disorder in the four regions.

The outreach teams would be hosted by local community services. Everyone would be treated in their local area and more local services would be developed to provide intensive day and outreach treatment in each of the four regions, but these would not be residential.

In a crisis when people could not safely be cared for within an outreach or day programme, they would be admitted to their local acute mental health hospital. There would be access to support 24 hours a day, for example from Community Mental Health Teams, Home Treatment Teams and hostels.

This option would cost about six million pounds per year. The NHS estimates that about 10 million pounds per year might currently be spent on Tier 4 services throughout the four regions.

One residential unit

Another option is to have specialist outreach teams plus one residential service covering all four regions. This would be quite a large unit, perhaps treating 20-30 people at any one time. The four regional outreach teams would all be linked to this one residential service. The outreach teams would provide follow up care when people leave the residential service and make sure that local services offer the support that people need.

There are no plans yet about where the residential unit would be based. This option would cost about six or seven million pounds per year, compared with an estimated 10 million pounds currently spent.

Two residential units

Another option is to have specialist outreach teams plus two residential services covering all four regions. These two services could each provide different treatment programmes to meet a wider range of people's needs. Each service could provide about 15-20 places.

The two residential services would act as a central contact point for the regional outreach teams. The outreach teams would refer people to the most appropriate of the two services and provide follow up care.

There are no plans yet about where the two services would be based. This option would cost about eight million pounds per year, compared to an estimated 10 million pounds currently.

Four residential units

Another option would be to have specialist outreach teams plus four residential units for people with complex personality disorders, one in each of the four regions. There would be between 10-15 beds in each.

Each outreach team might be linked to the regional residential unit.

This option would cost about 12 million pounds per year, compared to an estimated 10 million pounds currently.

Getting feedback

The NHS worked with service users and other stakeholders for about one year to consider needs, develop options, and test ideas. A formal consultation was launched on 20 April 2009 and the deadline for receiving feedback was 27 July 2009. The consultation methods included:

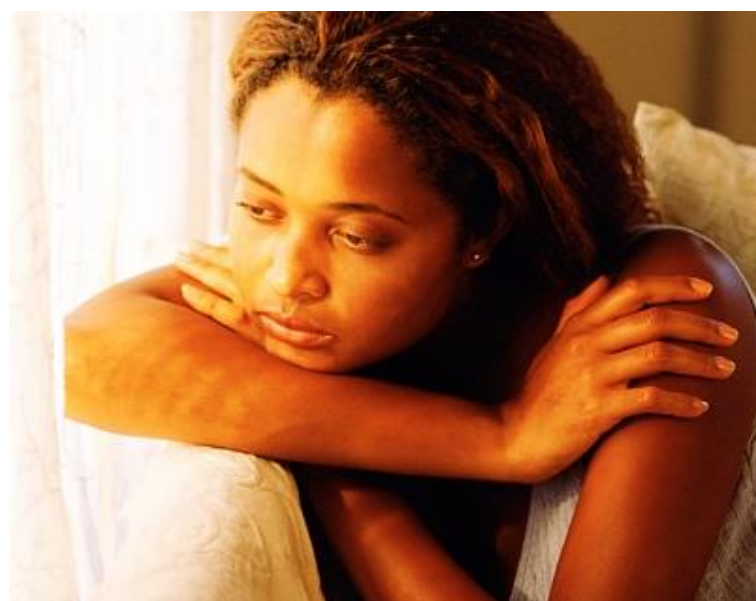
- circulating a consultation summary, feedback form and detailed documents
- making the consultation information and a feedback form available online
- distributing consultation information to more than 10,000 people and organisations across the four regions
- asking 66 NHS organisations to place alerts and updates on their websites
- providing posters and consultation summaries to NHS organisations, GP surgeries, the voluntary sector, libraries, local councils and other stakeholders
- monthly press releases
- sending email reminders and updates throughout the consultation
- running five discussion groups with 111 people
- attending national and regional meetings to promote the consultation
- offering to attend meetings or run discussion sessions for particular groups, including meetings with carers and Health Overview and Scrutiny Committees
- telephoning 113 voluntary sector and other stakeholder groups for feedback

Collating responses

People and organisations were invited to submit feedback using a posted or online feedback form, by submitting a personal story online, submitting a letter or email, providing comments by telephone or attending a discussion group.

NHS West Kent acted as the hub for receiving and logging all written and emailed responses and compiling notes from meetings and events.

Each letter, email, questionnaire, and set of notes from meetings and events was defined as a 'response' to the consultation. Thus, a response might represent one person or family or more than 30 people attending a discussion group. It is also important to note that some of the responses were from organisations or stakeholder groups that may represent many tens, hundreds or thousands of people (in the case of service user groups or local authorities, for instance).



Analysing responses

The NHS asked an independent organisation, The Evidence Centre, to compile the key themes from all feedback. The independent compilation team read all responses, identified key themes and created an electronic summary of every response. Demographic characteristics such as geographic location and gender were noted to allow comparisons.

The analysis used qualitative and quantitative methods. All the key points were converted to numerical codes to make it easier to quantify the most commonly mentioned issues. SPSS, the *Statistical Package for the Social Sciences*, was used to count the number of responses mentioning each theme and compare between different types of responses and people from each area. All of the differences described are statistically significant at the 95% level of confidence ($p < 0.05\%$).

The key themes were also analysed qualitatively to examine the strength of feeling and rationale for trends. Throughout the report quotes are used to illustrate points and stories from service users and carers provide a flavour of people's feedback. However **the material is not necessarily 'true' or factual**. All material is based on opinions and using this material does not suggest that the views expressed are accurate or unquestionable. It is also important to note that many of the stories mention the Henderson Hospital but the themes may relate to any similar residential unit.

The aim of the summary is to focus on the most common themes replicated throughout the feedback, not to explore the specifics of each response. It is the role of the NHS consultation team to read each response received and respond if appropriate.

Representativeness

The consultation did not aim to represent the views of all local people. It was not focused on finding out the proportion of people and organisations that support or oppose the proposals because the consultation methods aimed to be inclusive (gaining as many different perspectives as possible) rather than representative (generalisable to the views of all people living in the affected areas).

Obvious duplications, such as people submitting the same response by post and online, were removed. However, people were able to provide more than one different response. For example, someone might complete a feedback form, write an email and attend a discussion group.

This potential duplication does not matter for the purposes of the compilation. By its very nature, a consultation is not representative because people who feel strongly for or against certain options are more likely to respond. People who 'don't mind' may be less likely to share their views.

In the consultation documents, the NHS stated that the consultation should not be considered a vote or referendum. Instead, the NHS is interested in understanding the reasons why people supported a particular option and the potential pros and cons of different approaches. The NHS consultation documentation states that these pros and cons will be considered by the committee making decisions about next steps, rather than necessarily concentrating on the proportions supporting different approaches. For this reason, the analysis process focused on the most common themes and on exploring the reasons provided for favouring some approaches over others.



THE
Evidence
Centre



Responses

In total there were 373 responses to the consultation. These comprised:

- 149 online feedback forms (40%)
- 147 paper feedback forms (39%)
- 56 letters and emails (15%)
- 14 telephone calls (4%)
- 7 notes from discussions (2%)

There were responses from throughout the four regions (see Figure 2).

Around half of the responses were from health professionals or managers (49%), one quarter were from service users or family members (28%) and 16% were representing organisations. 5% were from general members of the public and 1% were from Councillors, MPs or other officials (see Table 1). Six responses were from mixed groups.

The organisations represented included mental health trusts, Foundation Trusts, the independent sector, voluntary groups, and local authority committees.

Of the individual responses, 60% were from women and 40% were from men. Four percent were Asian, 2% were Black, 91% were White and 3% were from other ethnic groups. This is broadly representative of the overall population, though demographics vary across the regions.

The majority of individual respondents were aged between 20 and 60 years (see Figure 3).

Figure 2: Location of responses

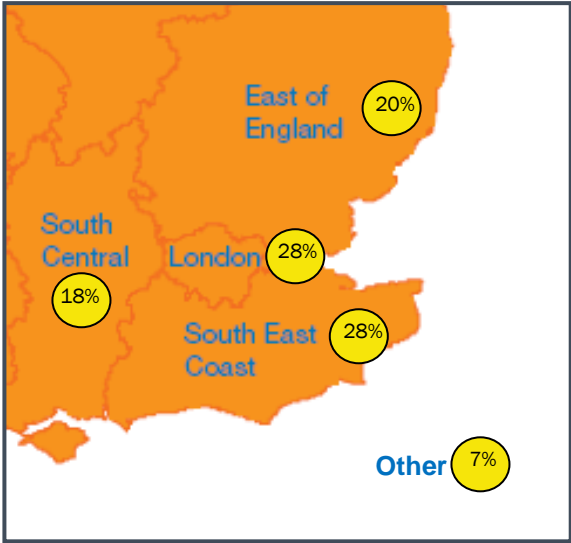


Figure 3: Age groups of respondents

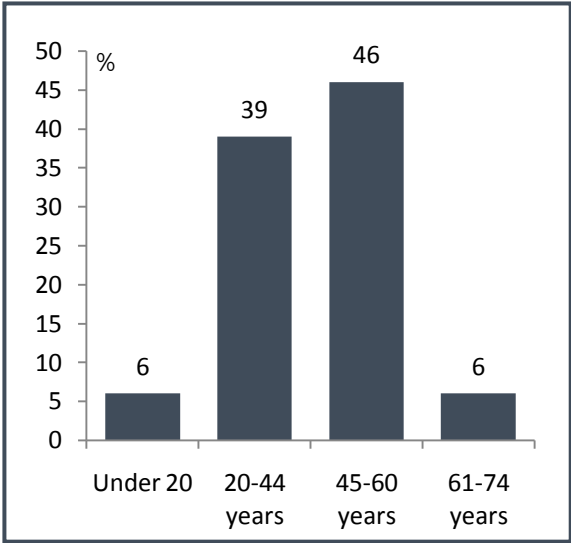


Table 1: Types of responses from different regions

	East of England	London region	South Central	Sth East Coast	Other
Service user / carer	29%	24%	25%	24%	54%
Member of the public	7%	4%	6%	5%	0%
Healthcare professional	44%	60%	57%	47%	29%
Councillor / MP	<1%	<1%	<1%	<1%	0%
Organisation	19%	12%	10%	24%	17%
Total number	71	102	64	102	24

Note: 10 responses did not state what region they were from



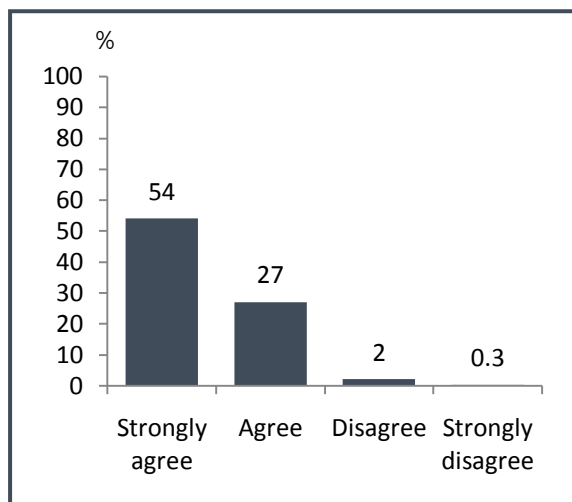
Outreach teams

Change is needed

The NHS asked people and organisations whether they think some changes are needed to Tier 4 services for people with complex personality disorders.

Of the 309 responses that explicitly commented about this, 98% thought there was a need for some change.

Figure 4: 'I agree some changes are needed'



However, eight responses, all from individuals, suggested that no change was needed. These people tended to focus on maintaining the specific services offered at the Cassel and Henderson Hospitals and felt that a 'status quo' option should be considered.

The majority of feedback suggested that change was definitely needed. The types of changes proposed ranged from infrastructural issues such as more robust funding, through to changes to the types of therapy offered and the number and type of facilities available. Suggestions for change are documented throughout this report.

There was a perception that there is a need for Tier 4 services and that there is much scope for development.

"There are a number of people whose distress is so severe and they're stuck on acute wards where there is a lot stigma which perpetuates further distress."
(Woman from the South Central region using services)

People spoke passionately about perceived failures in the system and how this signalled a need for improvement.

"I agree that more needs to be done for people with personality disorders and the whole mental health system needs to be looked at - there are never enough spaces in units for people who really need them, the doctors don't seem to be listening to the patients, and there seems to be not enough ongoing support outside of units and after recovery, which is why so many people keep returning to the units time and time again."
(Woman from the South East Coast using services)

"The route to funding for Tier 4 residential service is torturous and people are just left on the wards."
(Social worker from the South Central region)

Overall, 98% of responses supported the NHS' suggestion that there is a need for change to the way Tier 4 services are organised. This trend was consistent throughout the four regions.



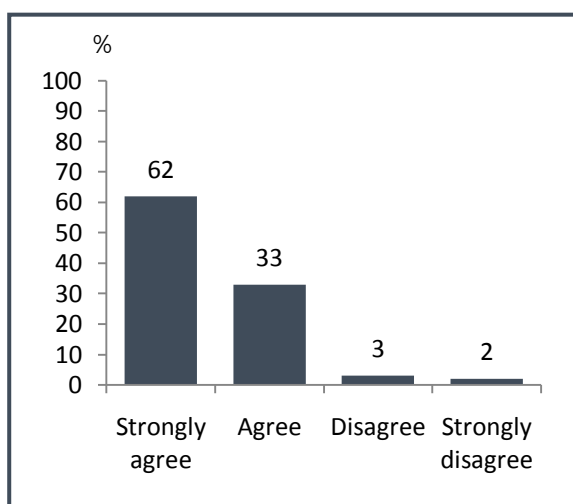
Outreach is supported

The NHS asked people whether they supported the idea of specialist outreach teams; one in each of the four regions. Of the 303 responses that specifically addressed this issue, 95% said they supported the idea of outreach teams. Support for outreach teams was similar throughout the four regions and from different types of respondents (see Figure 6).

People welcomed the idea of having specialist teams located in regions closer to where people live and the potential for more signposting and follow up support.

“Having worked in an Intensive Support Assertive Outreach team with a high number of service users with personality disorder, I have seen firsthand that specialised community teams with good supervision and small case loads are able to show good outcomes for people with complex personality disorders. We managed to reduce A&E admissions, acute mental health admissions and improve people’s quality of life and recovery.” (Health professional from the East of England)

Figure 5: ‘I support the idea of outreach teams’



However, responses were also concerned about the extent to which outreach teams would be able to provide hands on care or cover the vast regions suggested.

Figure 6: Regional support for outreach



“In terms of staffing levels the community outreach teams are relatively small given that one outreach team will be covering the entire region. There is strong possibility that they will not be able to deliver what is proposed or what we would expect from them. At very most they might provide a gatekeeping role into Tier 4 services and a signposting role after patients exit from Tier 4 services.” (Committee of health professionals from the South East Coast)

It was suggested that the outreach teams might best fulfil an educational and signposting role rather than providing clinical care.

“Because of the enormous size of the catchment areas, we do not think the four community outreach (specialist) teams should have a caseload. Instead, they can have a useful role in the provision of advice and consultation. They can also function as gatekeepers or filters of the latest good practice advances, providing local teams with training that focuses on practical and constructive ways of better managing personality-disordered individuals despite some restrictions in resources.” (NHS Foundation Trust)

Some responses believed there is a danger with developing outreach teams as ‘yet another specialist team.’ Some suggested that specialist skills should be more widely disseminated throughout general clinical teams (such as having a specialist based within community mental health teams). It was felt that outreach teams might create a danger of silo working and that all health professionals should be equipped with the right skills to treat the people they come into contact with.

Overall, 95% of responses supported the NHS’ suggestion of developing regional specialist outreach teams but there were concerns about how these teams would operate in practice. This trend was consistent throughout the four regions.

Sharing stories

Box 1: A carer from the South Central region reflects on her son’s journey

After the year-long inpatient stay at the Henderson, my son has come a really long way. He now lives independently from me in his own flat and takes responsibility for his day-to-day living. His raised levels of self insight, self worth and self acceptance have empowered him to express his experiences ... to a very wide audience through the voluntary work he does for a number of personality disorder service user organisations.

Although I see the Henderson as the bedrock to his increased awareness and greatly improved ability to function in the world, he still struggles emotionally and this is compounded by the fact that all support for him was withdrawn within a week of his leaving treatment by our local community mental health team. His discharge summary on leaving the Henderson included a care plan of ongoing support to make sure that the gains he made continued during the difficult period of adjusting the outside world, this was deliberately ignored by local mental health team, even though a senior member of the clinical team from the Henderson Outreach Service went to the trouble of visiting them in person to ask them to reconsider their decision. Sadly they still refused and it was heart breaking to see this lead to another extended period of self harm and destructive drinking that only started to abate when he paid to see a private counsellor out his own money and started to attend AA meetings.

I do feel that if given the support the Henderson had suggested he would have continued to make gains after his discharge and wouldn’t have had to suffer the frustrations and downturn in his behaviours that he did. It would appear inpatient treatment is essential in turning around the behaviour of his disorder, but it’s important that it is seen as part of the treatment plan and not the finite solution. Support and further psychological input when required are vital if someone like my son is to continue and to strengthen the gains made in a robust residential service like the Henderson.





Residential treatment

No units

The NHS invited people and organisations to comment on the potential for having no residential treatment units and relying instead on specialist outreach teams and ad hoc placements. Of the 276 responses that specifically addressed this issue, 16% said they supported the idea of having no residential units. Around half were strongly opposed (see Figure 7). The lack of support was similar across the regions and different types of responses, though those from London were most opposed (see Figure 8).

Figure 7: 'I support having no live in units'

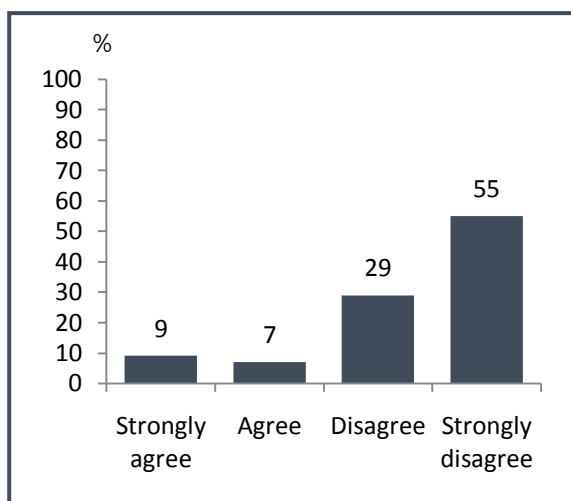


Figure 8: Regional support for no units



In the consultation documentation, the NHS stated it is most interested in considering the perceived pros and cons of different ways of organising services, rather than merely the proportion of people who support different options. The NHS asked people to describe in detail the potential pros and cons of each model regardless of whether or not they supported it (see Table 2).

A total of 143 responses suggested one or more advantages with having no residential units. The top five perceived advantages were:

- cost effectiveness, saving money, allowing funds to be diverted into Tier 3 and other community services (42%) and sustainability (4%)
- providing care closer to home, reducing travel (31%) and ensuring equality of access to care (7%)
- avoiding institutionalisation, reducing stigma and ensuring that people do not learn problematic behaviours by interacting with others in residential facilities (29%)
- better integration and communication between services and consistency between regions (14%)
- more convenient for families and carers (6%)

The main themes were similar across the four different regions and among different types of responses such as service users, carers, health professionals and organisations.



Some suggested that there may not be a need for residential services.

“Live-in psychological treatment units may help some people with personality disorder, but are not appropriate for the majority. Day care gives the opportunity for more flexible interventions according to the nature of people's difficulties and needs, and keeps a focus on helping people to manage themselves in the real world more effectively.” (Health professional from London)

Around two fifths believed that this approach would save money and that having no residential units would allow more funds to be diverted into community services and Tier 3 provision.

“All the money will be available to put into outreach support and day programmes providing long term support to reach a much wider amount of people in the community with complex personality disorder. Money can be put into easier out of hours support which is currently lacking. Also higher support levels will enable people to live in their own homes without becoming institutionalised in a live in unit.” (Woman from South East Coast using services)

Around one third of responses, including those from health professionals and service users, suggested that residential units have the potential to be stigmatising and may not support people to develop the skills needed to live within their local communities. It was proposed that having enhanced community services rather than residential facilities would provide more seamless care and help people integrate more fully and quickly.

“The reality is people have to be able to find a way to live within their community and residential units risk making that harder. I have spent 20 years working on inpatient acute mental health wards as a clinical psychologist ... so a significant advantage is people don't become isolated or if they are their isolation can be addressed in situ - they can learn how to manage and be supported in this.” (Health professional from the East of England)

It was emphasised that if no residential units were present there would need to be a focus on upskilling community teams and more emphasis placed on prevention and whole systems planning.

“It is important to build into this option robust planning around prevention, identification, assessment and support for people with a personality disorder, alongside crisis resolution teams and a comprehensive out of hours service.” (Health Overview and Scrutiny Committee)

A total of 214 responses suggested one or more limitations with having no residential units, whether or not they supported this approach. The top five perceived limitations were:

- no services for people who need to be contained / unsafe (53%)
- insufficient access to appropriate types of treatment (25%)
- a lack of expertise or shortage of highly trained staff to provide outreach services (17%)
- insufficient capacity and expertise within Tier 3 services to support people with complex personality disorder (14%)
- not cost effective because there will be impacts on other services such as the acute sector, private sector, prisons and social care (9%)

About half of those who suggested a problem with this approach mentioned the need to provide safe and secure placements for some people with complex personality disorder.

“People with borderline personality disorder, including myself in the past, need a place that is containing and safe. Often inpatient units and acute wards don’t provide this and when they do it is a holding area until we go out and the next crisis erupts. It is no solution. Also inpatient beds in adult services have been cut to a minimum, it is only those on sections that would probably get admitted.” (Woman from South East Coast using services)

Issues of safety and containment were mentioned by both service users and health professionals.

“When assessing clients for an outpatient therapeutic intervention we have to consider the capacity of the individual to keep themselves safe between sessions, taking into account level of risk, ego strength (resilience) and support networks. Where the level of disturbance is severe the risks are usually prohibitively high, coupled with a prohibitively low level of ego strength. Such individuals are often isolated or in abusive situations which compound their risk. The risk of harm to self and others may then be such that it requires the containment of a therapeutic residential environment.”
(Personality disorder service from the West Midlands)

About one quarter suggested that having no residential units would severely limit the types and effectiveness of treatment available for people with complex personality disorders.

“There is a significant group of patients who are chronically excluded from society and exclude themselves, who may find that a residential therapeutic community concretely houses them and metaphorically provide a home for their mind. This experience is unlikely to be replicated in a day service or outpatient clinic. The same patient group may not be able to engage in therapeutic work without the containment of a residential setting.” (Health professional from London)



There was a focus on providing environments which allowed people to work through any issues in a structured and contained manner.

“Intensive therapy can be done in residential care, particularly around dynamics, as residents have little option (unless they leave) than to stay and work the dynamic out. Such work cannot be done so well, in my opinion, if there are no live in units.” (Woman from the West Midlands using services)

Responses were concerned that not having residential units would limit choice and viable alternatives (4%), may be inequitable to people who are homeless and may lead to inconsistencies and inequalities of care across the regions (8%).

“I think the option of not having residential services would be unfair to everybody as this is denying ‘what works and is known to work’. Once again the NHS is going round in circles due to politics. I ultimately believe there should be a choice of services to meet individual need and where this is not available locally, there should be provision to refer to the nearest service and trusts should be prepared to pay for this treatment.” (Health professional from the East of England)

“Already acute wards and forensic units struggle to meet the needs of those with personality disorder who do not fit in with the predominant medical model for treatment in mental health. There needs to be an alternative of which the secure units do not meet, as very few individuals need that level of security.” (Health professional from London)

One in ten responses said that not having residential units was unlikely to be cost effective in the long term as there would be impacts on use of acute mental health hospitals, private sector placements, social care, prisons and Tier 5 services.

“This option is unlikely to save money as PCTs will most probably still spot purchase places for those in need of residential treatment. These places would undoubtedly be in the independent sector as, without PCT support for Tier 4 services, the NHS will not be able to finance them. Spot purchasing does not allow the advantage of commissioning a specialist therapeutic unit into which commissioners can input, and people may be placed in general psychiatric units which do not necessarily cater for their therapeutic needs. (Woman from London using services)

Some were worried that beds purchased from the private sector on an ad hoc or as needed basis would not have the same quality control as NHS run facilities.

“Spot purchasing is not commissioning and beds can be bought anywhere. Therefore people placed in the independent sector can be placed in beds not suitable to their needs.” (Health professional from London)

Table 2: Perceived pros and cons of having no residential units

Suggested positive points	Suggested negative points
<p><i>Location (31%)</i></p> <ul style="list-style-type: none"> • Could provide care closer to home <p><i>Development / choice (6%)</i></p> <ul style="list-style-type: none"> • Services will have to be developed locally to support people with complex needs • May result in more local choices • May result in improved Tier 3 services • More scope for outreach and follow up • May support areas with limited Tier 3 services • May create a sense of local ownership <p><i>Capacity / need (3%)</i></p> <ul style="list-style-type: none"> • May meet the current level of need • Dedicated beds may not be needed: when you develop beds people are more likely to use them <p><i>Clinical / treatment (14%)</i></p> <ul style="list-style-type: none"> • Smoother transition / pathway with other services • May strengthen cross agency and cross lifespan working • Could employ more staff and see more patients because not paying for buildings <p><i>Carers (6%)</i></p> <ul style="list-style-type: none"> • Closer to home so may benefit carers <p><i>Equalities (7%)</i></p> <ul style="list-style-type: none"> • Reduce geographic inequalities <p><i>Expertise (3%)</i></p> <ul style="list-style-type: none"> • Outreach team would be trained to a higher level • Tier 4 services could train up Tier 3 teams <p><i>Cost / sustainability (46%)</i></p> <ul style="list-style-type: none"> • More financially viable and sustainable • Least expensive option • May reduce amount spent on beds / placements • May be more money to spend on Tier 3 services • Reduced travel costs for service users and carers <p><i>Other (31%)</i></p> <ul style="list-style-type: none"> • May result in less institutionalisation and stigma • Until Tier 1-3 is developed we don't know the demand for Tier 4 • May be the most flexible option • Quick to implement 	<p><i>Location (1%)</i></p> <ul style="list-style-type: none"> • May involve more travelling for outreach teams • Some people need time away from the local environment during their recovery • Insufficient capacity to meet demand may lead to more out of area placements <p><i>Choice (4%)</i></p> <ul style="list-style-type: none"> • Limited choice of treatment options <p><i>Capacity / need (18%)</i></p> <ul style="list-style-type: none"> • Does not meet patients' needs • Only a short term solution • Could lead to burnt out staff in community teams • Unfair on tier 3 services if no beds • Assumes adequate Tier 3 services <p><i>Clinical / treatment (79%)</i></p> <ul style="list-style-type: none"> • People with personality disorder need exposure to socialisation in treatment • Community services are not suitable for people with complex disorders • Can't 'contain' people • Unsafe for people at high risk • Patients may be pushed into inappropriate care • Unless operating 24/7, these teams couldn't provide the intensive therapy needed • Lack of consistency in care offered across regions • Difficult to access crisis beds due to gatekeeping <p><i>Carers (3%)</i></p> <ul style="list-style-type: none"> • No opportunity for 'respite' for family and users <p><i>Equalities (8%)</i></p> <ul style="list-style-type: none"> • Excludes certain client groups such as homeless • No equitable access across region <p><i>Expertise (17%)</i></p> <ul style="list-style-type: none"> • More difficult to build and develop skills • No centres of excellence • Dilution of specialist service <p><i>Cost / sustainability (10%)</i></p> <ul style="list-style-type: none"> • Greater burden on acute services • Based on financial model rather than safety • Not financially viable because of hidden costs <p><i>Other (6%)</i></p> <ul style="list-style-type: none"> • More risk of institutionalisation • Building up reliance on private and acute sectors • This may be an untested approach • Spot purchasing allows no commissioning input

Note: percentages are based on 143 responses that suggested advantages and 214 responses that suggested limitations



Supporting live in care

There was a preference for a mix of residential and outreach services. Of the 307 responses that specifically addressed this issue, 92% supported the idea of having both residential and outreach treatment (see Figure 9).

Service users, carers and some clinicians wrote and spoke passionately about the need for residential treatment. Some of the stories provided by service users are included in boxes throughout the report. The level of support was similar across the regions and different types of responses (see Figure 10).

Figure 9: 'Outreach & live in services are needed'

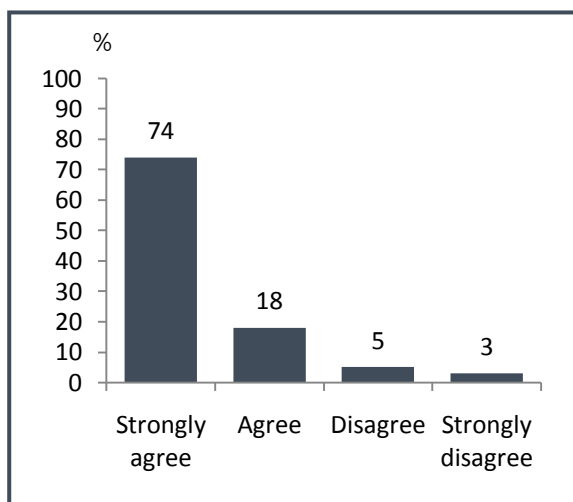
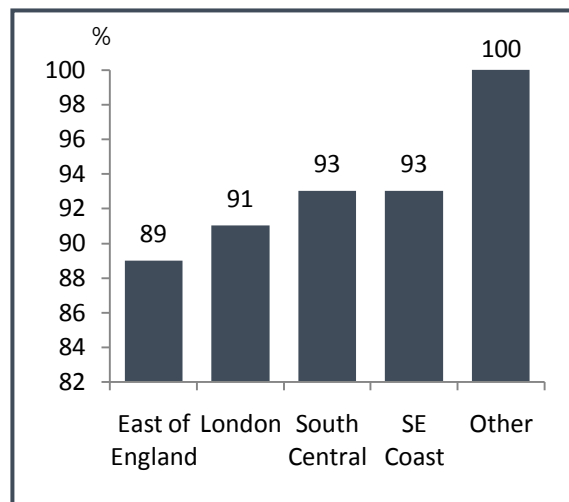


Figure 10: Regional support for outreach & live in



Overall, 16% of responses supported to some degree the idea of having no residential units.

The main perceived advantages of having no residential units were saving funds or having more resources for community services, providing care closer to home and reducing institutionalisation and the learning of problematic behaviours in residential units.

The most commonly mentioned limitations were not having a safe place to contain people with complex personality disorders, insufficient provision of appropriate treatments and a lack of expertise within regional outreach teams and community services.

In total, 92% of responses believed the NHS should provide both outreach and residential services for people with complex personality disorder.

These trends were consistent throughout the four regions and amongst different types of respondents.

Sharing personal stories

Box 2: A woman based in London describes how residential treatment supported her

I have had difficulties since childhood and began self harming at the age of seven and tried suicide at the age of eight as a result of the extensive physical, emotional and sexual abuse I had suffered and continued to suffer from until I left home at 18. Throughout my teens I had severe emotional and social difficulties, although I excelled at school. I was diagnosed with an eating disorder when I was 14 and throughout my childhood I was under the care of social services and spent 8 years on the 'at risk' register. I left home at 18 to go to university and struggled enormously to interact with my peers as my social skills were severely undeveloped. I had a full breakdown in my final year, after provoking fights with strangers in the street and punching walls. I was diagnosed with depression and psychosis. After university I threw myself into work and although I was drinking heavily at the time, I managed to hold down three jobs at a time, often working 20+ hours a day...

This was a pattern until 2002 when my drinking and self harming escalated and I attempted suicide. I was referred to a CMHT who tried to admit me to an acute unit... I had a terrible time in the acute unit. I detoxed from alcohol without any specific help and suffered horrendous nightmares and was extremely disturbed with frequent psychotic episodes. Prior to the assessment for the residential drug and alcohol treatment I attempted suicide again. I was accepted for the 4 month programme and completed it, however, although my remained abstinent from alcohol my self harming was increasing and I actually felt no better despite the psychological input. I spoke to my consultant psychiatrist at the time, who said I was getting the 'gold standard' treatment for drug and alcohol issues, but when I said it wasn't helping any of my other difficulties, he said there was nothing he could do and I should be satisfied with what I was getting. It was clear to me that my issues with alcohol were only a symptom of a greater problem not the problem itself. However I went to second stage drug and alcohol treatment for a further seven months. During this time I made slight progress however, I was still very unstable and slipped into a crippling depression which resulted in a further suicide attempt and discharge from the second stage drug and alcohol unit. I was again admitted into an acute ward where I stayed whilst I was referred to the Henderson Hospital. I had to remain on the unit, though the crisis of the suicide attempt had passed as I was deemed too unsafe to live in the community.

I went to the Henderson ... I made huge progress and my self harming and suicidal behaviours were minimised greatly. The elements of the service that proved most beneficial in terms of my cessation of personality disordered difficulties were:

- being in treatment with others with similar difficulties allowed me to understand both what triggered my own behaviours and gain insight into the effect and impact of my behaviour on others
- the value of the 24 hour contained environment enabled me to feel safe to explore difficult issues during the therapeutic programme and access support outside the group programme where necessary. If I had to go home, it is likely that I would have turned to self harm or alcohol to deal with difficult feelings whilst alone and isolated in the evening or at weekends
- the integrated therapeutic programme (using different types of therapy; CBT, DBT, psycho-drama, art therapy, community tasks) allowed for progress across a number of emotional and social difficulties
- the unstructured part of the service (weekends and evenings) allowed the development of social skills and other non-destructive coping mechanisms that proved vital to the sustained cessation of self harm after treatment
- the provision of service user involvement opportunities allowed the development of work skills that proved essential and hugely valuable in terms of my progress in returning to full time work



Since leaving the Henderson, I have had no attendances at A&E for self harm / suicide attempts nor being admitted to an acute ward. My social functioning and social skills have increased greatly. I moved out of supported accommodation in 2006 into my own flat, and have managed on my own for over three years which is a significant improvement from the time when I could not bear 24 hours on my own. I returned to full time work in 2007 after 5 years on benefits...

Although I deem my treatment at the Henderson to be very successful, I do however advocate the need for further treatment post the Henderson. Indeed my discharge summary from the Henderson made this suggestion, one which has been met with ambivalence from my community team. There is an assumption that a year at the Henderson cured everything, and although it greatly reduced my behaviours I still struggle with some emotional problems that need further psychological input specifically around gender dysphoria, identity issues and sexual problems that resulted from many years of trauma and abuse. It is essential that residential services are seen a portal on a care pathway and there is some integration with community therapeutic services post discharge from Tier 4 services.

I would like you to consider some elements of my story under the following headings:

Financial outcomes: Although the cost of treatment per person seems very high, most people who go onto receive treatment at services such as the Henderson have spent most of their lives in a revolving door pattern, frequently accessing and sometimes draining the resources of ill-equipped services such as A&E, primary and secondary care and acute mental health services...

Worthwhile outcomes: How do you measure if a service is worthwhile? Is it all about how much money will be saved? What difference does a service like the Henderson make to people's lives? In my case I believe that services like the Henderson saved my life as I am sure that without this treatment, I would have continued with the destructive patterns that frequently resulted in serious self harm and suicide attempts. As a result I would likely be either dead or in hospital or prison. Instead I am in full-time work, looking towards a bright future rather than at a bleak past. Not only was my treatment life saving, it helped me work towards a future, with optimism and a sense of recovery...

Centres of excellence: Services such as the Henderson or the Cassel are centres of excellence in terms of their collective knowledge base around personality disorder. Many of the newer pilot services are influenced in part by the Henderson and the model of treatment it delivers or by training and consultation from the outreach team...

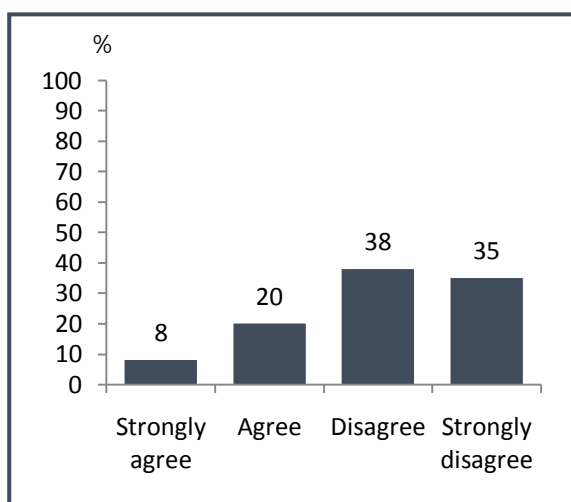
Need for residential care: Why can't everyone be treated in the community? Why have residential treatments? It is true that some would benefit from treatment offered in the community, but there will always be some whose behaviours and symptoms are so severe that they could not be contained in a community setting. I was deemed too unsafe to live in the community prior to my time at the Henderson, hence my extended period on an acute ward and this scenario was all too familiar with other residents' histories...

Although it is quite evident that I am fairly passionate about the Henderson, It is entirely possible I would have been as equally passionate if I had received treatment at the Cassel or another residential service. Although this could be interpreted as bias, I feel that it is moreover a passionate plea for appropriate residential service provision. Many people who I meet in the course of my work, (users, carers and professionals) maintain that some people cannot be contained in the community and end up in and out of acute wards that do nothing but entrench difficulties and make users feel worse in the long run. I doubt I would have cared what the service was called, where it was or what the therapy was called when I needed it as long as I knew it was specifically designed for people with my type of difficulties and that anecdotal evidence from previous users said that it worked.

One unit

The NHS invited people to comment on having one residential treatment unit shared across the regions in addition to a specialist outreach team in each region. Of the 232 responses that specifically addressed this issue, 28% said they supported the idea of having one residential unit. One third were strongly opposed.

Figure 11: 'I support having one live in unit'



The level of support was similar across the regions and different types of responses.

Figure 12: Regional support for one unit



A total of 159 responses suggested one or more advantages with having one residential unit, whether or not they supported this approach (see Table 3). The top five perceived advantages were:

- having some residential treatment available (40%), including social support and peer engagement (16%)
- developing a centre of excellence with high quality training and staff (27%)
- ensuring better integration of services, including communication between outreach teams and the residential facility (18%)
- being cost effective (16%)
- having enough referrals to ensure the model is sustainable in the long term (15%)

Service users, carers and some professionals provided many stories about how residential services had helped in the past and said having a least one residential unit was therefore essential.

"One unit would provide a contained safe place which can specifically address the emotional and behavioural issues that cannot be contained in the community or appropriately on an acute ward."(Organisation from the East of England)



People talked about how residential care provided an important opportunity to share experiences and undertake therapy in a safe and contained environment.

“It is my belief that one of the main reasons this core change was achievable was because it was a residential service. I am convinced that if he had returned home every evening and at weekends, he would not have had the containment to break his destructive patterns of drinking and self harm, as these coping mechanisms were what he used to anaesthetise his mental distress, escape the harsh realities of his life and a very toxic home environment. The safety and containment that the therapeutic community provided was another essential component to his success and without it any lasting changes would not have been developed or sustained.” (Woman from East of England whose partner attended a residential unit)

Some suggested that having one unit would ensure enough beds and space to provide specialised care to different groups, such as women or parents with young children.

“Some people would be able to be treated in a unit large enough to provide robust peer involvement and empowerment. If there were more beds then a range of treatment options could be provided.” (Organisation from London)

Others suggested that having one residential unit would ensure that the demand for such services is met whilst not providing too much additional capacity.

“If there was a small amount of people needing residential treatment this would ensure that that only the top end of the spectrum were referred for treatment. By having one unit it would stop smaller units all running on half capacity, the tendency would be that the one unit would be more in demand and would be running always at full capacity.”
(Organisation from London)

It was also felt that having one unit could provide consistency of services across the four regions and robust interactions with regional outreach teams.

“One live in unit would create a core base and a consistent approach which would also be generated out to the outreach teams. One live in unit could be designed into a large unit that would accommodate the diverse range of groups and people needs.” (Organisation from the South Central region)

Table 3: Perceived pros and cons of having one residential unit

Suggested positive points	Suggested negative points
<p><i>Location (4%)</i></p> <ul style="list-style-type: none"> Centralised access to care May help maintain local services <p><i>Capacity / need (41%)</i></p> <ul style="list-style-type: none"> Some residential treatment is available Having one unit is better than none May meet existing level of need <p><i>Clinical / treatment (31%)</i></p> <ul style="list-style-type: none"> More socialisation and peer group treatment available Unit could include sections for women only etc There would be a larger group of both staff and patients which could work well for some types of treatment such as therapeutic communities <p><i>Carers (1%)</i></p> <ul style="list-style-type: none"> Better for carers and family <p><i>Equalities (4%)</i></p> <ul style="list-style-type: none"> Equity of access to care across different regions <p><i>Expertise / integration (43%)</i></p> <ul style="list-style-type: none"> Can develop a centre of excellence / specialised team Easy exchange of experience between clinicians Potential for less fragmentation and competition Could encourage development of more holistic services, focusing on a cradle to grave approach Could use existing expertise in this model ie current service providers <p><i>Cost / sustainability (31%)</i></p> <ul style="list-style-type: none"> Less expensive than having more units May be more likely to be sustainable in the longer term 	<p><i>Location (65%)</i></p> <ul style="list-style-type: none"> There may be accessibility issues May only benefit people who live close to the unit The service might be based in London so it may be of limited value for those outside London Concern that a focus on four regions focus might close off the services to other areas eg Ireland Distance between unit and outreach teams <p><i>Capacity / need (44%)</i></p> <ul style="list-style-type: none"> Fewer beds than currently One unit would not address the existing need May not be able to meet a range of diverse needs Insufficient capacity for containment Could result in long waiting lists Could increase stress on local teams because there may not be enough residential services to cope <p><i>Choice (8%)</i></p> <ul style="list-style-type: none"> Limited patient choice No comparisons are possible between units and no competition to improve standards <p><i>Clinical/ treatment (31%)</i></p> <ul style="list-style-type: none"> One size fits all model may not suit all people Unit may be selective about who to include This model could be counter therapeutic because people could learn maladaptive coping methods from other people who self harm. There should be more units so people can be separated out Unit may be too small to provide for all needs <p><i>Carers (11%)</i></p> <ul style="list-style-type: none"> Carers may be unable to visit or visiting would have significant cost and time implications <p><i>Expertise / integration (6%)</i></p> <ul style="list-style-type: none"> Not enough expertise and training takes time Difficult to support continuity of care Difficult to coordinate community teams from unit Admission to a unit could undermine existing relationships and support networks <p><i>Cost / sustainability (4%)</i></p> <ul style="list-style-type: none"> Based on resources / cost, not patient needs Not sustainable or cost effective <p><i>Other (<1%)</i></p> <ul style="list-style-type: none"> May be more stigmatising to go out of area to a unit Danger of one service becoming too elitist The effectiveness of this model depends of the development and effectiveness of Tiers 1-3

Note: percentages are based on 159 responses that suggested advantages and 196 responses that suggested limitations



In total, 196 responses suggested at least one potential limitation with having one residential unit, whether or not they supported this approach. The five most commonly mentioned were:

- the residential unit being located far from people's local communities, Tier 3 community services (39%) and outreach teams (13%)
- having too few beds and insufficient capacity to meet current needs (32%) which may result in long waiting lists (11%)
- not having the capability of offering different types of treatment or catering for the needs of diverse groups (24%)
- being less accessible and having restricted or stringent entry criteria (13%)
- a potential negative impact on carers (11%)

There was a real concern that sharing one unit between the four regions would mean that the unit would be located far away from many people's local communities and the Tier 3 services and outreach teams providing follow up.

"It will take people a long way from home and the outreach teams will be remote making it difficult to build up local knowledge and partnerships." (Member of the public from the South East Coast)

Both service users and health professionals were concerned about the implications of travel if there was one residential unit.

"A limitation is the distance people have to travel. I only came home once a fortnight and effectively my home life stopped for 14 months and it was difficult to pick up when I came home and took quite a length of time." (Woman who used services and lives outside the region)

Responses also suggested that having one unit would limit the type of treatment available and the diversity of the people who could be supported.

"There would be a lack of range of treatment options, therefore less opportunity to meet the diverse needs of this population. The size of the unit may restrict what modalities can be delivered, for example the large number limits capacity to function as a therapeutic community." (Health professional from the South Central region)

A key issue was a lack of choice and variety in the type of support available.

"The most significant limitation is the lack of choice with regard to the treatment model. For example the 'Cassel model' uses predominantly individual therapy whereas the Henderson model used primarily 'group approaches'. It is clear from accumulated clinical evidence that some people would benefit from one approach and others from the other." (Health professional from London)

Some pointed out that people with different types of personality disorder may be best supported in separate facilities.

“A limitation would be putting too many people of varying problems together. The spectrum of personality disorder is wider over symptoms and severity. You can’t bundle all people labelled like this one place. They need different things.” (Woman using services who lives outside the four regions)

Others were concerned that a lack of capacity would limit the number and type of people able to gain access to residential treatment.

“Individual hospitals/trusts will prioritise their most severe/neediest/hard to deal with/likely to get benefit from - leaving a huge swathe of individuals who could still improve greatly given live in treatment.” (Woman from the South East Coast using services)

“Not enough beds. If only the most severe cases get places the situation will never be turned around. Help needs to be given sooner.” (Carer from the East of England)

It was thought that long waiting lists might result and this may frustrate both service users and referrers.

“There will be so few places available as to make it a treatment option in theory only. Referrers will get frustrated when they can never secure a place for their patients. They will start to forget about live in care as an option and thereby the service will die due to lack of funds.” (Health professional from the East of England)

To summarise, 28% of responses supported the idea of having one residential unit.

The main perceived advantages of having one residential unit were ensuring that some live in facilities were available, developing a centre of excellence and ensuring consistency and good communication within and between regions.

The most commonly mentioned limitations were the distance between the unit and people’s local communities and services, insufficient capacity to meet needs and not being able to offer different types of treatments.

These trends were consistent throughout the four regions and amongst different types of respondents.



Sharing personal stories

Box 3: A woman shares her experiences about the value of residential care

Prior to spending a year at Henderson Hospital I had no understanding of how to deal with my feelings, no sense of responsibility for my actions and the effect I had on other people and no respect for myself. I had an eating disorder, obsessive compulsive disorder, was suicidal and my self harm was out of control.

At Henderson I began to work on difficult issues from my past and learned how to make good respectful friendships. My closest friendships from Henderson continue today and I have been able to build on these and make new friends since Henderson and re-engage with family.

As I had lost my accommodation when I was admitted to a psychiatric hospital. I was homeless when I went to Henderson and it the residential aspect of Henderson was necessary for practical reasons. The 24 hour nature of Henderson means that in terms of the therapy there is little opportunity to hide destructive foibles from your peers and nothing goes unnoticed. That Henderson was residential was also essential for my personal safety, as I had little ability to keep myself safe and no chance of learning to manage feelings without a containing environment. If had I stayed in the town I had lived in prior to admission to hospital I would have been drunk or stoned, and a risk to myself in terms of suicide or serious self harm. Instead the peer support, containment and challenging from peers combined with the psychotherapy meant I was able to learn to feel the feelings and manage them, engage safely in therapy and develop emotionally.

The democratic community ethos of Henderson taught me a lot about responsibility to myself and others, self discipline (dinner still needs to be cooked for the community even if you're in distress), self respect and I saw others learning new skills through it too.

I learned a lot from Henderson, it saved my life. Now over 10 years on I have a responsible job, hobbies, live independently (which none of my peers would have thought possible at the beginning of my stay) and I am on the edge of the psychiatric system, rather than using acute services as a revolving door patient.

Henderson may not be appropriate for everyone, but it gave me and others who might otherwise have been consigned to the scrap heap a second chance when others services did not.

Two units

The NHS invited people and organisations to comment on the potential for having two residential treatment units in addition to a specialist outreach team in each region. Of the 246 responses that specifically addressed this issue, 56% said they supported the idea of having two residential units. One fifth were strongly opposed. The level of support varied across the regions with responses from London being most in favour (see Figure 14).

Figure 13: 'I support having two live in units'

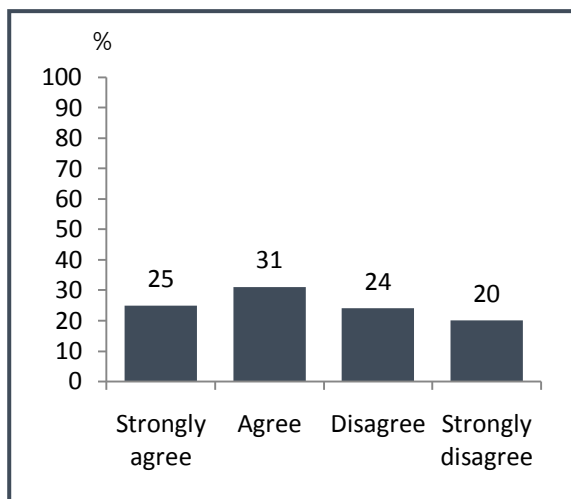


Figure 14: Regional support for two units



In total, 177 responses suggested one or more advantages with having two residential units, whether or not they supported this model (see Table 4). The most commonly mentioned advantages were:

- having the potential to provide a variety of different therapeutic approaches and treatment for different subgroups (51%), with a firm focus on residential treatment (14%)
- greater capacity and numbers of beds so more people can benefit from residential services (33%)
- providing more localised care closer to home if situated in different regions (19%)
- providing more choice for service users and referrers (18%)
- allowing better communication and integration between residential services themselves and with community and outreach services (13%)

Responses felt that at least two units were needed to ensure that residential services could use a range of therapeutic models, thus catering for the needs of a wider range of people.

“The Committee should favour two residential units as there is a clear need for the retention of some specialist residential provision, and two units allows a choice of different therapeutic models, which may be important given the heterogeneity of the population served.” (Health Overview and Scrutiny Committee)



Organisations, health professionals and service users and carers were similarly positive in suggesting that two residential units would cover a variety of needs.

“We believe that two in patient units is probably the best option, offering units of a size which can effectively offer all the evidence based interventions, the opportunity to have two different diagnostic intake profiles, the potential for more people to be treated within a reasonable distance from home, some competition and facility for patient choice. It is also more possible for local personality disorder services to relate closely, remain engaged and support the treatment of their patients in two units than four.” (NHS Foundation Trust from the South East Coast)

“It may be useful to offer two residential units which provide a different service to each other. We would like to see one of these units catering for the low end of forensic needs and anti-social personality disorder. Whilst we recognise the need for a women's only service, we also feel that it is important to offer a mixed service as this gives scope for individuals to work through their issues with members of the opposite sex and gives a balanced demography reflective of wider society. There will also be opportunities for single sex groups within a mixed sex environment.” (MPs from South East Coast)

Some argued that it would be important for the two units to be located in different regions to enhance accessibility and reduce travel time.

“The two live in units can be situated so that it is easy access to travel to within the four regions. Having less than four live in units enables better consistency and approach, easier access and greater partnership working with outreach teams.” (Organisation from the South Central region)

People felt it would be essential to ensure close liaison between the units and between the units and outreach and community services.

“It would be important that there would be close liaison between the two residential units so that service users needs are kept in the forefront and they are referred to the appropriate service and that the services are not set up to be in competition with one another but are there to compliment the other by having different emphasis in their work.” (Medical Advisory Committee from the South East Coast)

Table 4: Perceived pros and cons of having two residential units

Suggested positive points	Suggested negative points
<p><i>Location (19%)</i></p> <ul style="list-style-type: none"> • Having two units is more balanced (distance wise) • Closer to home / less travel <p><i>Capacity / need (33%)</i></p> <ul style="list-style-type: none"> • Increased bed numbers are possible • Able to cope with number of referrals <p><i>Choice (18%)</i></p> <ul style="list-style-type: none"> • This would increase patient choice <p><i>Clinical / treatment (72%)</i></p> <ul style="list-style-type: none"> • Some residential services would be available • Could have two different treatment models • It would be possible to have a female- only centre • Ability for different client groups to engage who may not work well in one residential unit • Treatment outcomes may be better for more homogeneous patient groups in each unit • Allow peer support and socialisation <p><i>Carers (2%)</i></p> <ul style="list-style-type: none"> • Better for carers and family <p><i>Expertise / integration (20%)</i></p> <ul style="list-style-type: none"> • Could create centres of excellence • There could be interaction between the staff at each unit which would strengthen expertise and aid ongoing development • There would be more continuity between outreach teams and units which means that this option could be more consistent and coherent overall <p><i>Cost / sustainability (11%)</i></p> <ul style="list-style-type: none"> • More sustainable financially • Less expensive than having four units • This would not take too much funding away from community services • This might be realistic in terms of what funds would likely be outlaid by PCTs <p><i>Other (1%)</i></p> <ul style="list-style-type: none"> • This model is the closest to the existing situation / status quo approach • Competition and comparisons would be possible 	<p><i>Location (35%)</i></p> <ul style="list-style-type: none"> • It may be difficult to manage the transition to Tier 3 services because the units could be far from home • Large area is covered so may be a lot of travel <p><i>Capacity / need (29%)</i></p> <ul style="list-style-type: none"> • May not meet identified need for beds • Long waiting lists <p><i>Clinical / treatment (10%)</i></p> <ul style="list-style-type: none"> • Might not address the needs of men / forensic • Units may be too small for some treatments • May not allow for enough flexibility in treatment types or services for different groups <p><i>Carers (4%)</i></p> <ul style="list-style-type: none"> • There should be a unit in each area for regular family access which assists in recovery <p><i>Equalities (9%)</i></p> <ul style="list-style-type: none"> • Inequitable access to units across the regions <p><i>Expertise / integration (19%)</i></p> <ul style="list-style-type: none"> • Staffing two units may be difficult • There may be competition between units • More highly skilled local teams are needed • Problems with communication between units <p><i>Cost / sustainability (39%)</i></p> <ul style="list-style-type: none"> • There were questions about whether the PCTs would be committed to funding this number of beds / units • The money needed to fund more live in services may take away funding from local services • This model may lead to duplication and twice as much facility overheads • Lack of referrals may limit sustainability <p><i>Other (2%)</i></p> <ul style="list-style-type: none"> • Could be better to have one larger unit • May draw attention away from developing excellent community services • Linking the outreach teams to beds may introduce bias and create a conflict of interest such that community outreach teams feel the need to 'fill' the beds • Live-in services require extensive step down community care to support the maintenance of gains that have been made • This is the same sort of model as now – so there are questions about whether it would be any better than current arrangements

Note: percentages are based on 177 responses that suggested advantages and 143 responses that suggested limitations



In total, 143 responses suggested potential limitations with having two residential units, including those who supported this approach. The most commonly mentioned limitations were:

- being too far from home and local Tier 3 services (33%)
- having too few beds or not enough capacity to accept all referrals (27%)
- being more expensive than some other options or not being cost effective (22%)
- the potential for communication problems or rivalry between services (19%)
- the possibility of not being sustainable due to not having enough referrals to warrant two residential services (17%)

These limitations were common to responses from all of the different areas and were equally likely to be mentioned by service users and carers, health professionals and organisations.

One third of the responses that suggested a disadvantage were concerned about the placement and locality of the residential units.

“Would have to think carefully about where to place the two units in the country so as not to disadvantage too many people who may want to work there or use the services.” (Health professional from London)

“There would still be quite substantial travelling times for some people, and two units would not adequately allow for patients to be divided according to needs.” (Health professional from East of England)

People were worried that those living in the region(s) where units are located would have greater access and that this might cause geographic inequality.

“The live in services would be quite far from home for many people. People who live nearby might get better access to care, which would be unfair to those living further away.” (Organisation from the South East Coast)

About one quarter wondered whether having two residential units would meet the demand.

“30-40 beds would not be enough considering the number of beds being used in 2008/9 across the region.” (Health professional from London)

“I don't think two units would be enough. I just wish people would understand the complete confusion and the feelings of helplessness of this horrible disorder. Understanding is all they want and us families need backup and support as well.” (Carer from the South Central region)

On the other hand, almost one fifth wondered whether there would be enough referrals to sustain two units.

“Might not be enough people using services to keep two services stable and well funded.” (Person from the South East Coast using services)

Around one fifth were worried about the cost effectiveness of this option and the sustainability of funding available.

“Still heavy on resources - rent, staff, furniture and yet only the same number of places.”
(Organisation from the South Central region)

“Both will be expensive (because of size needed) and therefore constantly be under threat of closure.” (Health professional from the South East Coast)

Another concern was how the units would interact with one another and with community services and outreach teams. About one fifth of those who suggested limitations felt that consistency and communication were issues that would need to be thought through carefully.

“If the units are different all four outreach teams would need to relate to both services which could impede efficacy in providing responsive services. There would need to be mechanisms to ensure good communication, for example regular actual or virtual meeting of all outreach teams and the units.”
(Health professional from London)

To summarise, 56% of responses supported the idea of having two residential units.

The main perceived advantages of this approach were the potential to provide a variety of different therapeutic approaches, greater capacity and numbers of beds so more people can benefit from residential services and providing more localised care closer to home if the two units were situated in different regions.

The most commonly mentioned limitations were the distance between the unit and people's local communities and services, having too few beds to accept all referrals and being more expensive or less cost effective than alternatives.

These trends were consistent throughout the four regions and amongst different types of respondents.



Sharing personal stories

Box 4: A man reflects on how residential care changed his life

The Henderson Hospital saved my life and transformed the lives of those around me.

For many years I was in and out of psychiatric hospitals and regular hospitals dealing with the repercussions of my self harm and attempts to take my own life. I wanted to die and to be honest those around me would have it easier if I could just get my act together and do it properly.

I saw so many therapists and used so many different services they are mostly a blur in my mind. Then I heard about the Henderson. I spent a year at the Henderson and today, many years later my wife, my family, my friends, my PCT and the psychiatrist I no longer see all breathe a sigh of relief and recognise that the Henderson changed all our lives and kept me here.

Now instead of using day services and periodically being kicked out into different services because I was too disruptive - I work full time. My colleagues wouldn't even recognise the person I am writing about here. I contribute to my family. I am in love with my wife and she knows I cherish her because I express that clearly and unambiguously and I support her when she is having a tough time.

People rely on me - and I shoulder up to the responsibility. I am alive. I have similar ups and downs to most people and I recognise in times of stress my old patterns rear up and I battle with old habits to deal with the stress in healthy ways. I win. I do that because I have friends who I can turn to and family who are no longer scared of me and my emotions.

I do all these things and I have all these things because of the Henderson. Because of what the staff and residents there gave me and what I was taught there. It was the most challenging time of my life but it gave me a life worth living.

I had been to so many different therapies, services, models and approaches and avoided myself throughout them all until I went to the Henderson and had to face up to who I was and why. The Henderson is a unique place which offered me a chance and should be re-opened so others are given a chance too. Years on I still know many people whose lives were transformed by the Henderson.

My story is not unique, there are many of us now quietly getting on with a life we couldn't have dreamt of before we went to the Henderson. I also still remember many people who left early - feeling the place wasn't for them or the community feeling they were not ready. I know too many people who have died to be all starry eyed and unrealistic about the Henderson. The Henderson offered a unique environment and approach which worked for many but of course could not work for everyone. No one service will suit everyone's needs.

The Henderson is not the answer for everyone and it needs to be one of a range of choices available for people to try and find what works for them. But it should be there as an option - properly funded and sustained and open to people from across the regions - to give others a chance at life too.

Four units

The NHS invited people and organisations to comment on the potential for having one residential treatment unit in each region as well as a specialist outreach team per region. Of the 250 responses that specifically addressed this issue, 57% said they supported the idea of having four residential units. 16% were strongly opposed. Those from the East of England were most likely to be supportive, with the South East Coast more likely to be opposed.

Figure 15: 'I support having four live in units'

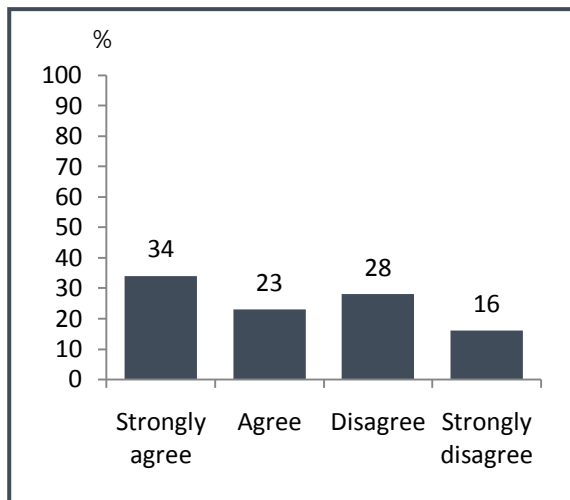


Figure 16: Regional support for four units



A total of 191 responses suggested one or more advantages with having four residential units, whether or not they supported this approach (see Table 5). The most commonly mentioned potential advantages were:

- providing care closer to home (57%)
- having greater capacity and bed numbers so more people can receive treatment (33%)
- providing a range of different therapeutic approaches and treatment for specific subgroups (24%), thus allowing greater choice for service users and referrers (10%)
- more integration and consistency within regions because residential units, outreach teams and community services will be co-terminus (19%)
- better access and support for carers (9%)

More than half of those who suggested an advantage believed that providing care closer to home was important. While it was acknowledged that units would not be 'local' to most people because the regions covered are each large, there was a feeling that having a residential unit in every region would reduce travel for people using services and their families and ensure more equitable access to treatment across the regions.

"There will be wide access of treatment for people with severe personality disorder from all regions and the outreach team will be near people's homes." (Health professional from London)



Regional units were thought to have benefits for family members and carers regarding access and travel.

“Units would be closer to where people live and thus easier for visiting for most partners. I imagine the units would be smaller and hence less formal and intimidating.”
(Member of the public from the South Central region)

People also felt that being closer to home might help to speed discharge or make the transition from residential treatment to community care smoother and more seamless.

“Much more local, therefore personalised service and much easier to graduate return to home.”
(Woman from East of England using services)

Around one quarter suggested that having four units would provide more scope to specialise or target specific groups.

“More scope for catering for excluded groups with different approaches and targeted populations, for example one unit for older adults, one for people with sexual offending backgrounds or risks (and severe personality disorder but not requiring secure accommodation), one for aggressive and chaotic individuals, one for anxious / avoidant / hyper-aroused people with a post traumatic stress type presentation.” (Health professional from the South Central region)

One third of those who suggested advantages mentioned that this option would provide the greatest number of beds. It was stated that this level of capacity would help more people with complex personality disorder access effective treatment more promptly.

“The prevalence of personality disorder is high; much higher than realised... People who are motivated and ready for treatment would be able to access it quicker without losing hope and motivation on a waiting list and getting caught up in cycles of self and other harm.”
(Health professional from East of England)

“There is a better likelihood of people who need it getting a place as not competing with patients from other PCTs for funding. Four units means more beds. Therefore more people getting treated. Will hopefully cut down waiting lists. In the meantime, there will hopefully be more specialised knowledge and support from the unit to help providers in the local community. The unit should be part of the local community. The more people you can treat, the sooner you can help personality disorder sufferers earlier and hopefully fewer people will get to the crisis stage and this will have a positive impact on our whole society. People may also be more willing to use them if they're closer to home.” (Woman from East of England using services)

Other perceived benefits were the potential to specialise, develop centres of excellence, upskill teams and provide high quality training and support in local areas.

“More interchange of information, research findings etc between units, and possibility of variety of treatments. Could be closer to patient's home and to staff wishing to specialise in this area. More possibility of providing training for mental health staff across the country.” (Health professional from South East Coast)

The NHS estimates that more than 30 million per annum may be spent across the four regions supporting people who may be eligible for Tier 4 services of this nature. A conservative estimate is that at least 10 million of this is currently spent providing care for people who could use the proposed new models of care. The consultation website contains full details of these cost estimates (see the ‘have your say’ section of www.westkentpct.nhs.uk).

Whilst responses acknowledged that, at an estimated 12 million pounds per annum, having four units was the most costly option proposed, it was suggested that this would be an investment in overall cost savings. People argued that having four residential units would decrease the pressure on acute units and the private sector, reduce the inappropriate use of Tier 3 and 5 services and alleviate other costs within the criminal justice and social welfare systems.

Service users and some health professionals were equally likely to hold this view.

“Would save money long-term with reduction in inpatient admissions for the more risky clients.” (Health professional from outside the region)

In total, 182 responses suggested one or more potential limitations with this approach, whether or not they supported it. The most commonly mentioned limitations included:

- concerns about costs, including overheads and the need to develop new facilities (54%)
- with 10-15 beds, the units may be too small to offer some approaches such as ‘therapeutic communities’ (24%)
- whether there would be enough highly skilled professionals available to staff all four units appropriately (21%)
- a potential lack of referrals which may impact on sustainability (19%)
- insufficient appropriate treatment including outreach and community support, especially if funds are channelled into residential units at the expense of other approaches (16%)

The most commonly perceived limitation was the potential cost of establishing and running four units. Some responses questioned whether this expense was justified in the context of the continued development of community services.

“Very expensive, probably unnecessary especially once more local outpatient services have been developed better.” (Woman from the South Central region using services)



In the consultation documents, the NHS proposed that each of the four residential units would have 10-15 places. Around one quarter of responses that mentioned a limitation with this approach felt that this may be too small to provide for a wide range of people's needs or provide appropriate treatment types.

"If the four units need to provide for everyone in their region then 10-15 beds is too small a number to provide for such a heterogeneous group who are likely to have widely differing needs." (Health professional from London)

There were concerns that a unit of 10-15 people would not be an adequate size to provide a therapeutic community treatment approach.

"The smaller size of the units would make it much harder to offer some interventions including therapeutic community model, no matter how modified." (Health professional from London)

Some service users were concerned that smaller units may lead to a greater dependence upon staff and limit the types and effectiveness of treatment available.

"The small number of patients per unit is likely to result in more dependence on staff rather than the peer involvement and empowerment that is beneficial for their development. This could result in an increase in regressive behaviour instead of a reduction." (Woman from London using services)

Around one in five responses were concerned about whether there was adequate demand for four units. It was suggested that there may be insufficient referrals to sustain a separate unit in each region.

There may not be enough patients to make four units sustainable. There may not be adequate numbers of specialised staff, or amounts of resources to make each unit successful. (Health professional from East of England)

Some also mentioned that the level of need in each region may vary, such that some regions may require larger units.

About one in five responses that considered this issue mentioned a concern with staffing. It was suggested that residential units require highly trained and experienced specialists and that these professionals may be in short supply.

"The specialist staff skills and resource required may take considerable time to develop." (Organisation from outside consultation region)

"To get the right staff for four units would be difficult without losing the excellent staff that you already have, they may be spread too thin. It takes a certain type of nurse for this line of work." (Woman from another area using services)

About one in six responses that considered the limitations of this option were concerned that emphasising residential units may lessen the quality and quantity of other support available.

“I don't see this as a good option as it will mean that other much needed services will not be provided as live in units cost far more than outpatient services and a handful of people will benefit as opposed to the many people with complex personality disorder who are not receiving the levels of care and support that they need and therefore will deteriorate leading to more local psychiatric admissions and increased risk of suicide amongst the vulnerable.” (Carer from South East Coast)

To summarise, 57% of responses supported the idea of having four residential units.

The most commonly mentioned advantages of this option were being able to offer care on a regional basis which may be closer to people's local communities, greater capacity of beds to meet identified needs, and the potential to provide a variety of different therapeutic approaches.

The most commonly mentioned limitations were concerns over cost and sustainability, the limited size of each unit which may preclude some forms of treatment and the availability of a highly skilled specialist workforce to cover four units.

These trends were consistent throughout the four regions and amongst different types of respondents.

Sharing stories

Box 5: A woman shares her experiences

I started self harming when I was 11 and after a suicide attempt at 14 I was sectioned and placed in an adolescent psych unit for about 18 months... When I was 25 I started to get unwell again although I didn't realise it at the time. My behaviour and thinking changed and I started to use alcohol and amphetamines. My relationship with my partner broke down and I began self harming again. I started acting and feeling exactly the same way as I had when I was 14. I could not control my feelings or my behaviour and I thought I was going crazy. It got to the point where I just wanted to die again so I had another suicide attempt and was again sectioned except this time I was put on a locked ward of a psychiatric hospital. I was referred to a therapeutic community called the Henderson where I stayed for a year. The Henderson helped me in so many ways. When I went in I felt suicidal, my life was a mess and I could not see any other way out. Being a resident there for a year gave me the time and space I needed to get myself back together. I didn't have to think about everything at once such as my flat, bills, travelling, my job, my daughter, etc...

Living as part of a community and being around other people with similar or the same problems as me was sometimes like being shown a mirror of myself and I started to see how my behaviour affected others. Being confronted with my behaviour by others was sometimes really hard to take but it made me start to take responsibility for myself again. When I left the Henderson I was really scared that I would not be able to cope on my own in the real world but I have surprised myself by how well I have done! Life is going really well for me... I have not had a drink or drug for 18 months, I am almost at the end of a computer course and I have my daughter back three nights per week. I have not self harmed for over six months and am looking forward to going back to work. I really believe that therapeutic communities like the Henderson give people a new start in life.



Table 5: Perceived pros and cons of having four residential units

Suggested positive points	Suggested negative points
<p><i>Location (57%)</i></p> <ul style="list-style-type: none"> • Providing care closer to home • Reasonable regional coverage • Less travel for service users and carers • Beds would be available outside London <p><i>Capacity / need (33%)</i></p> <ul style="list-style-type: none"> • Sufficient bed space to meet the need <p><i>Choice (10%)</i></p> <ul style="list-style-type: none"> • Greater range of units to choose between <p><i>Clinical / treatment (33%)</i></p> <ul style="list-style-type: none"> • Could have separate units for particular groups • More access to different treatment models • Ability to compare different approaches • Better aftercare may be possible as units would be linked to community teams • Residential treatment allows peers support and socialisation <p><i>Equalities (8%)</i></p> <ul style="list-style-type: none"> • The greater flexibility could support the inclusion of minority ethnic groups • Geographic equality of access to care <p><i>Carers (9%)</i></p> <ul style="list-style-type: none"> • Carers have better access and support • Having local support may be an aid to recovery • May allow provision for 'respite' periods for carers <p><i>Expertise / integration (21%)</i></p> <ul style="list-style-type: none"> • Distributes expertise geographically • Better links between live in services and local specialist outreach teams and community services • There may be more opportunity for placements, training and networking of staff and teams • There may be a possibility of greater networking • A high level of expertise would be developed • This approach could be used to develop core skills and train up local services <p><i>Cost / sustainability (3%)</i></p> <ul style="list-style-type: none"> • May cost less in the long term: invest to save • Could reduce the use of independent sector beds if the four units provided enough variety 	<p><i>Location (5%)</i></p> <ul style="list-style-type: none"> • Assumes that 'local services' are good but some people need to escape situations in their locality • Area covered is large, so units will not be 'local' • Outreach teams might have to work beyond their host region if each area is very specialised <p><i>Capacity / need (25%)</i></p> <ul style="list-style-type: none"> • Not sufficient bed spaces across all four regions • Insufficient referrals to sustain four units • Assumes demand will be the same across all areas <p><i>Clinical/ treatment (25%)</i></p> <ul style="list-style-type: none"> • The small size of each unit may restrict the service model ie therapeutic communities • This could result in four different models, not one co-ordinated approach across regions • Less scope for differentiation (eg female/male) if everyone has to fit within 15 beds per area • Not enough beds to do different treatments • Smaller units may encourage dependency on staff rather than each other • Units may be too small and intense for some <p><i>Expertise / integration (33%)</i></p> <ul style="list-style-type: none"> • Expertise and communication could be diluted • Unhealthy competition between units • Lack of cross fertilisation across units • May be difficult to find enough skilled staff • Model is not cohesive across the four regions • Communication and integration problems <p><i>Cost / sustainability (54%)</i></p> <ul style="list-style-type: none"> • Too expensive • This could detract resources from Tier 3 services • This model may be unlikely to be funded long term <p><i>Other (16%)</i></p> <ul style="list-style-type: none"> • There is a risk of creating a culture of admission rather than admission based on need. With beds so readily available, people may admit more readily than seeking out other options • Resources could be watered down because they are spread across many services • This approach may not be politically acceptable. There could be public outcry at spending such a lot on this specialist service, especially in the context of cutbacks in other areas

Note: percentages are based on 191 responses that suggested advantages and 182 responses that suggested limitations

Sharing personal stories

Box 6: A woman describes the value of residential care for her

I had reached a dead end by the time I got to [the Henderson Hospital]. I had been assessed by several other professionals and services including intensive therapy whilst living at home, but all those people felt they would not be able to provide the amount of support I needed to work on my issues, let alone the time.

I was lucky enough to have been granted the funding for my year there, but I met other people who had wanted to go and had been referred - and as far as I know accepted - but were never given the chance due to funding not being granted, so I do not believe that there was insufficient demand.

I have also had the opportunity to see how the place was properly working and had a chance to benefit from it. For the first time in my life I was able to learn to put words to what was going on for me and not be on a self destruct mission and I had the opportunity to work on my problems and gain understanding whilst not being then 'left to my own devices' once the sessions were over. Considering almost all of us had histories of abuse or other trauma I feel this was the most important aspect of my year there, as it is very common for all those negative things to haunt you at night or otherwise quiet times, so it was absolutely invaluable to feel supported at any time of day or night and not just Monday till Friday during office hours. Dysfunctional behaviour doesn't just happen when it suits professionals. It is with us all the time and often when least expected! Some of the residents during my time were also still living in abusive situations. For those it would have been extremely unhelpful to have to return home at the end of each day, and they needed the actual physical distance and safety to work out how best to move on with their lives.

The model of a therapeutic community is also entirely based on service user involvement and residents were part of all decisions made. This is something almost any organisation or part of the NHS is trying to achieve nowadays. I therefore do not believe the argument that the model is outdated...

For people like us who have a personality disorder some sort stability and consistency are extremely important. We feel so out of control and full of chaos most of the time that we desperately need the structure around us to be stable and supportive, just to be able to function to some level...

I do seriously believe that residential services are needed, even with the slowly improving local services, and it would be so much better if the situation got assessed only on need rather than how many people are allowed the money to go.





Other options

Local services

The NHS invited people to suggest alternatives or adaptations to the options put forward within the consultation document. The consultation documents state that the NHS decision making committee will consider any alternative options put forward when planning next steps.

A total of 79 responses mentioned a possible alternative or adaptation. These were divided into two categories – those focused on the development of local community, outreach or support services and those focused on residential treatment models.

Alternatives about local community, outreach or support services reinforced and built on the original proposals, rather than suggesting completely new ways of organising care. Proposals included:

- enhancing the support available in the community, including outreach teams, support groups and recreational facilities (this links to the option of having no residential units and strengthening community services instead) (5 responses)
- setting up more day centres or units where people stay 3-4 days per week rather than full residential units (this links to the option of having no residential units and strengthening community services) (13 responses)
- adding specialists in personality disorder to community mental health teams or other existing community services rather than setting up separate outreach teams (16 responses)
- having a team in the community that holds and manages a commissioning budget and signposts people to available day centres, crisis treatment and other short term care (this links to the option of having no residential units) (2 responses)
- ensuring a managed clinical network to help professionals work across organisational boundaries (this was suggested in addition to residential units not as a standalone option) (4 responses)
- having local crisis houses available to cope with short term admissions rather than longer term residential care (15 responses)



Enhancing Tier 3

Five responses, including notes from discussion groups, suggested that there should be a focus on strengthening Tier 3 and other community services, rather than developing residential units. This is similar to the 'no units' proposal put forward by the NHS, but the no units option includes outreach teams which some responses thought might be unnecessary.

The perceived benefits of enhancing Tier 3 services rather than using specialist outreach teams with or without residential units included:

- improving existing services
- increasing local capacity
- providing care closer to home
- focusing resources on Tier 3 services rather than splitting resources between Tiers 3 and 4

Some argued that if Tier 3 services were built up, there may be no need for a dedicated Tier 4 service and that residential placements could be made on an ad hoc basis.

"If there is money to invest in personality disorder services this would be better placed in Tier 3 and outreach services rather than residential units. There must be support for day centres and community resources." (Health professional from South East Coast)

As in the 'no units' option, people who supported this approach suggested that it would be appropriate to rely on spot purchasing from the private sector to ensure residential services are available on an as needed basis.

Day units

Thirteen responses were more specific about the type of community services they would like to see developed, with a focus on providing more day treatment centres or units that people could stay in for a few nights per week.

The perceived advantages of this approach were:

- enhancing existing services
- catering for the majority of people's needs rather than setting up services suitable for a minority
- cost containment

"In our view, the preferred model of care for personality disordered clients is one of day care/day programmes, rather than live-in units. This day care should encompass a range of possible care pathways, including intensive treatment, but also support, psycho-educational interventions and crisis planning interventions. We recognise that there is a tiny minority of personality disorder patients whose behaviour escalates to such a degree that they require inpatient containment, usually in challenging behaviour services. However this is not the same as psychological therapies residential services." (NHS Foundation Trust from the South Central region)

However some service users suggested that day centres alone may not be sufficient to provide the treatment they need (see Box 7).

Sharing stories

Box 7: Service user discusses day care

As an adolescent I could not conceive of a tenable future, and was under much stress to overcome personal problems and fit in to society. At university I started hearing voices, and eventually left to become a near recluse living back at my family home. It was not for some years that I received any treatment from mental health services, and when I did approach them I ended up being sectioned.

Then a new phase of my life started, attending day centres. This kept me busy and gave me back some confidence with people. But when I eventually left to get a job, the support disappeared. Once again I was overwhelmed by stress, and suffered both mentally and physically. This leaves me as I am today, pretty much incapacitated by others' standards, but doing each day what I can.

My problems seem to come from within and without, so I am fighting a battle with myself and with other people. This leaves me so drained, angry, sad, and lonely that I can't move beyond where I am. I think there should be treatment available for people like me with personality disorders: focused, intensive, residential if necessary, that will make a real difference to someone's life.

Support in the community can only go so far, and often ends up maintaining a status quo rather than taking a risk and moving forwards.

Specialists in teams

Sixteen responses suggested that rather than developing a specialist outreach team, one or two specialists in personality disorder could work within every community mental health team. The specialists would fulfil the same research, awareness raising, training, diagnosis and signposting services as proposed for the outreach teams, but would be more localised because they would be based within community mental health teams. It was suggested that this configuration could be feasible regardless of how many, if any, live in services were provided.

The perceived advantages with this approach included:

- making best use of existing resources
- upskilling current teams
- reducing travel for outreach teams
- cost containment

“Our preferred option would be that funds for community support were ring-fenced for the development of local expertise and that good care co-ordination from local teams underpin the care pathway. It would seem wasteful to have a small highly expert team that would spend most of their time driving around the Country.” (Organisation from the East of England)



Brokerage services

Two responses, including notes from a meeting, suggested that the proposed outreach teams could fulfil a signposting and brokerage service or that resources could be used to help existing Tier 3 services purchase the specialist residential placements they may need.

In this model, the outreach teams would have a dedicated budget to identify and fund short term residential placements. The perceived advantages were:

- a defined role for the outreach team
- not overlapping or competing with existing services
- the potential to use ad hoc placements to keep people closer to home

This configuration could be feasible regardless of how many, if any, live in services were provided.

“The consultation seems to take no account of building on existing specialist services around the regions. I think that although many places do not have specialist services quite a few do. Where these exist surely Tier 4 functions could be added onto their remit. An option would be for teams with chiefly outpatient functions to be resourced to buy in such inpatient provision (for example from the private sector) as they needed. Responsibility for buying these services in and for managing a budget to do so would sharpen the minds of the purchasing team and also help them to enforce their own standards and plans on the provider unit.” (Health professional from the East of England)

Clinical networks

Four responses suggested that rather than outreach teams ‘managed clinical networks’ might be more appropriate. However responses did not tend to define what they meant by clinical networks or to state how this would differ from the outreach model proposed.

In general, managed clinical networks involve linked groups of health professionals and organisations from primary, secondary and tertiary care working in a co-ordinated way, unconstrained by professional boundaries. Such networks aim to offer a new way of delivering services, designed to focus on treatment and service users rather than upon buildings and organisations. Managed clinical networks work across the boundaries between the different professions and parts of the health service.

Crisis units

Fifteen responses suggested that rather than setting up residential units to provide long term treatment, shorter stay ‘crisis houses’ or units should be set up. It was suggested that regardless of the number of residential services available, such crisis units should form an integral part of the care model for people with complex personality disorder.

“I strongly disagree that those in crisis should be admitted to hospital. There should be crisis houses operating to cope with crisis admissions. Psychiatric admissions are unhelpful and damaging to those with personality disorder and other patients.” (Health professional from the South East Coast)

Residential services

The majority of the alternatives suggested relating to local community services focused on adapting or further specifying how outreach teams should work or how specialists should be integrated with existing community services. The alternatives relating to residential facilities tended to focus on the most appropriate number of units to offer.

Alternative options related to residential care included:

- having three needs-led units such as one for women only, one catering for families and one for a mixed group, or separate units for people with different types of personality disorder. These three units would not necessarily need to be located in different regions and could be of varying sizes (17 responses)
- partnering with housing associations and the voluntary sector to provide residential facilities (6 responses)
- setting up a number of smaller residential units, such as 8-10 units with 5-10 beds each (3 responses)
- adaptations of the options proposed in the consultation document, such as having one London-based unit or maintaining the status quo (5 responses)

Three needs-led units

Seventeen responses, including notes from meetings, suggested that three units could be set up to focus on people with different needs.

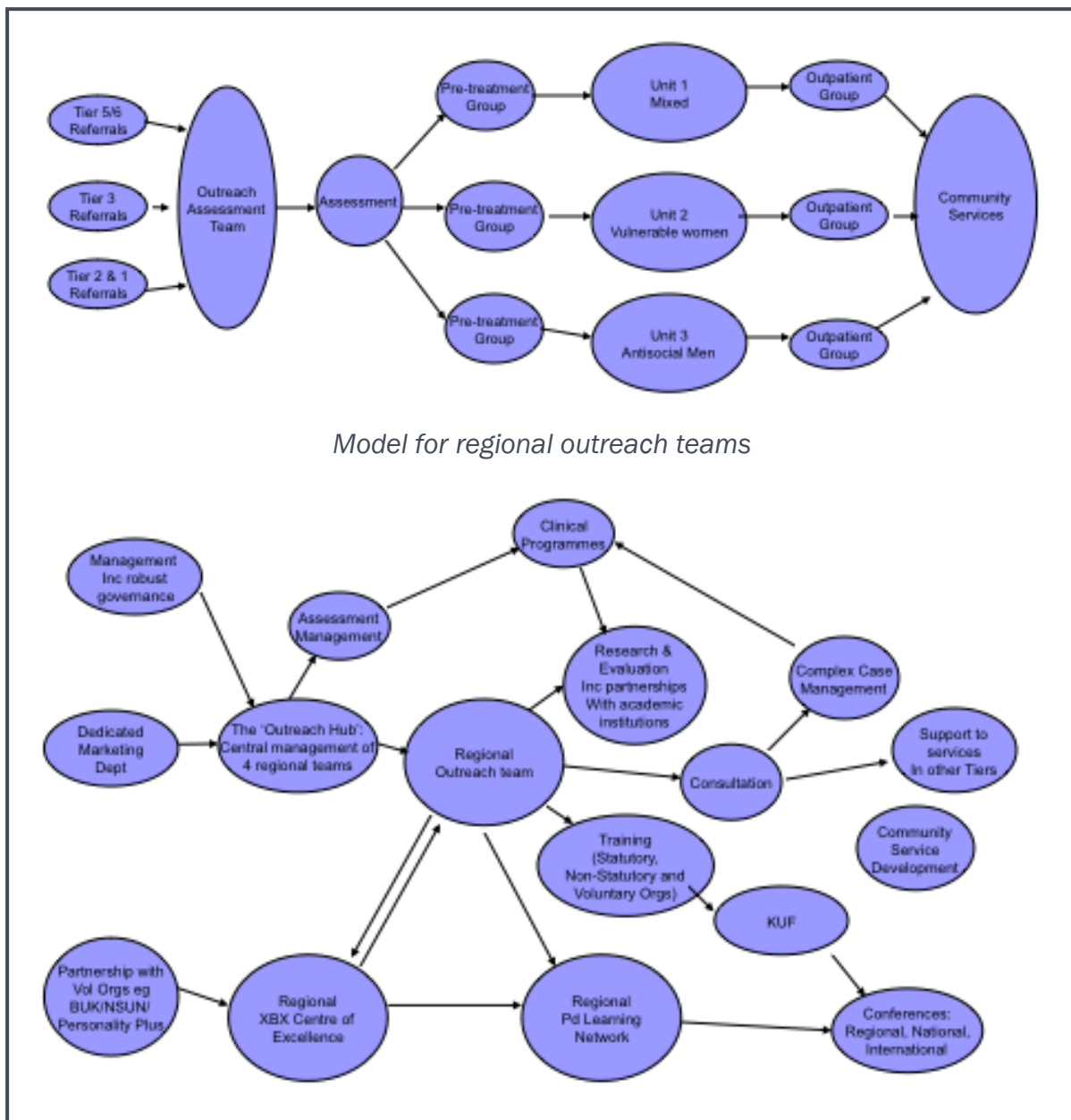
“There could be three needs-led (rather than geographically-led) units of 20-25 beds, each providing for one of the categories of patient identified in the consultation documents ie complex cases at high risk with unstable lifestyles, vulnerable women needing separate accommodation and men moving down from Tier 5.” (Woman from London using services)

It was envisioned that the three units in this option could be provided as part of one integrated service, and that there would be four regional outreach teams as originally suggested by the NHS (see Figure 17).

The three units may or may not be provided in different regions. This approach would allow for a critical mass of beds in each unit, thus allowing robust peer involvement and a range of therapeutic approaches. Integral to this model is collaboration with service users or experts by experience.



Figure 17: Model for three needs-led residential units submitted by responses



In this model, referrals would be directed towards a central assessment team and service users would be supported to attend the unit most suitable according to their needs. This central assessment team would help to manage the four regional outreach teams to ensure consistency and collaboration.

The regional outreach teams would help prepare service users to attend treatment and support them after leaving the residential programme, including offering leavers groups in each region. These outreach groups would also provide training and support to Tier 3 services, research and evaluation and regional networks.

More units

Three responses suggested that it would be more useful to have a greater number of units, each with a smaller number of beds. These would be similar to the 'crisis houses' described earlier but would provide longer term care. The perceived advantages of this approach were:

- providing care closer to home
- greater numbers of beds
- increased access to care

The responses that put this option forward did not elaborate on how this model may work in practice.

Partnerships

Six responses, including notes from discussion groups, suggested that the NHS should think more creatively about partnership working with the voluntary sector, local authorities and housing services. The specifics of how this could work in practice were not detailed.

"The NHS is not willing to pay for 'hotel' services. What about a new idea for a partnership with other groups such as housing services. They could provide food and board and the NHS could provide treatment. We need to get more creative."

"Sharing care with voluntary and third sector organisations (like housing associations) - so maybe they can get B&B costs through housing benefit. Also they have a less 'authoritarian' and paternalistic culture than the NHS." (Health professional from South Central region)

Adaptations

Five responses suggested variations to the options put forward by the NHS rather than completely new approaches. For example, it was suggested that a status quo option may be useful, whereby the NHS provides residential services at the Cassel and Henderson Hospitals as in previous years. In discussion groups, people suggested that the Cassel and Henderson Hospitals provided good services and that any new model may adversely affect the Cassel as well as the Henderson Hospital.

Another suggestion was having one residential unit as proposed by the NHS, but with a variety of different 'wings' or streams within it. One larger unit could have different wards or areas catering for people with various needs. For example, there could be an area for people with substance misuse issues, an area for parents, women and people with different levels of complexity. Some suggested that this residential unit should be set up as a centre of excellence.

"The best model would be to have a centre based in London linked to an inpatient unit and also the outreach team. The centre could be linked to academic departments and act as hub by providing training to all the local teams." (Health professional from London)

A final suggestion was to have two residential treatment services working collaboratively under one clinical management structure, along with four managed clinical networks, one in each region. One of the residential services could provide safe containment for people who may be detained under the Mental Health Act. The other could provide a more intensive treatment programme for those assessed as being able to work towards taking responsibility for their lives.





Making decisions

Criteria

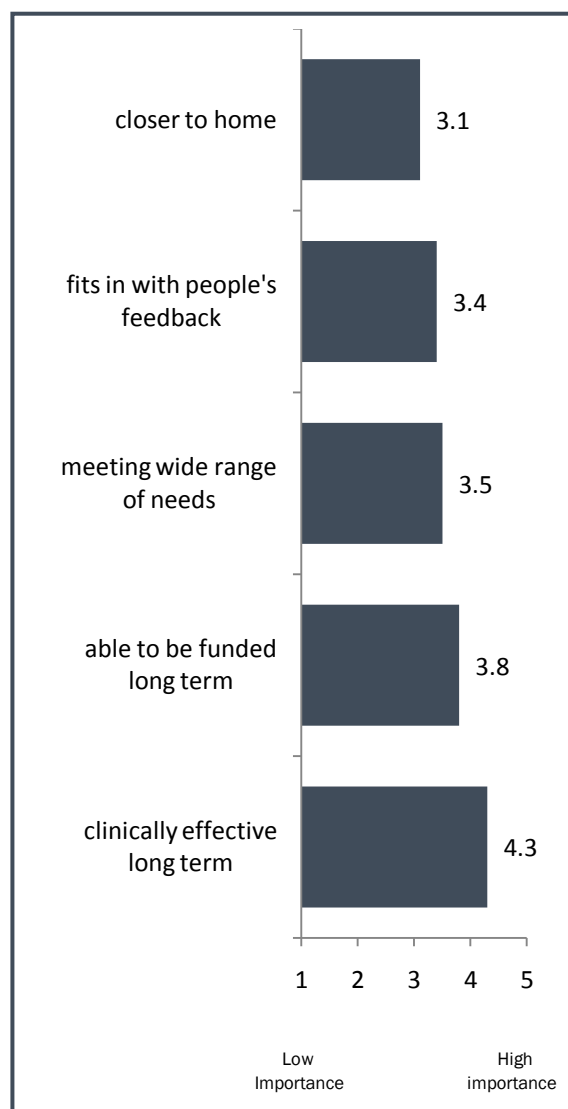
The consultation documents state that the NHS will weigh up the pros and cons of proposed options when deciding on next steps, including the alternatives put forward during the consultation. To assist with this decision making process, the NHS asked people to consider the factors that should be used to differentiate or decide between different options. People were asked to rate the importance of potential decision making criteria, including:

- Can the option provide care closer to home / accessible services?
- Can the option meet the needs of a wide range of groups and will it disadvantage any groups?
- Will the option be clinically sustainable? (provide good care long term)
- Will the option be financially sustainable? (funded long term)
- What do people and organisations think of this option?

A total of 286 responses rated the relative importance of these potential criteria. Clinical sustainability, or the ability to provide good long term care, was the criteria that responses felt was most important for the decision making committee to consider when weighing up the pros and cons of different options.

Financial sustainability, or the ability to ensure models of care are able to be funded long term, was also seen as important.

Figure 18: Perceived importance of criteria



Note: The graph shows the average rating out of 5 on a scale where 1 = low importance and 5 = high importance (for clarity of presentation the figures have been recalculated from those on the consultation feedback form which used the reverse order)



Of less importance was the ability to provide care close to people's homes. Although responses felt that this was important and often mentioned it when describing the pros and cons of different options, the location of treatment was seen to be a less important criteria than clinical and financial sustainability (see Figure 18).

“A view expressed by residents ...is that being close to home is less important than having an appropriate, effective treatment. Some people need to be away from a problematic or abusive environment (which may not be evident at initial assessment) in order to progress.”
(Woman from London using services)



People were also invited to suggest other criteria that the NHS should consider when deciding on next steps (see Box 8). A total of 160 responses made suggestions for additional questions that the NHS should ask when judging each option, including:

- How does the option fit with the evidence base and emerging national guidance? (27%)
- Does the option ensure a choice and range of treatments, including therapeutic communities? (21%)
- Does the option take account of broader costs and impacts, including long term costs to acute services, social care, prisons, families and community services? (20%)
- Does the option allow a choice of location / ease of access? (11%)
- Does the option build in prevention and follow up to ensure an integrated pathway of care? (8%)
- Does the option include good communication and governance structures, including communication between any residential units and outreach teams? (8%)
- Does the option include greater involvement of service users and carers? (8%)
- Does the option include treatments for dual diagnosis and those with co-morbidities such as drug and alcohol issues? (6%)
- Is the workforce sufficient to staff the model? (7%)
- Will the option meet needs or allow an adequate needs assessment to be completed? (6%)
- Will the option allow the enhancement of Tier 3 and other services? (6%)
- Does the option include more support for carers? (5%)
- Does the option ensure culturally appropriate services and equitable access across the regions? (3%)
- Will the option allow people to be contained if needed / be safe? (3%)

Box 8: Recommended factors to consider when making decisions

Need

- Will the option cover the number of people referred to Tier 4 services?
- Does the model meet assessed needs (prevalence of personality disorder and occupancy of beds)?

Choice

- Does the option provide choice of location?
- Does the option provide choice of treatments?

Access / location

- Does the option address geographic spread?
- Will the option provide care as close to home as possible?
- The length or duration people will be expected to stay as inpatients, as this may affect family access
- Will people from outside the area be able to use services?
- Does the model recognise that being away from the local environment might be a helpful part of treatment?

Treatment approaches

- Is a health and wellbeing model used rather than an illness model?
- Will there be access to residential services?
- Will the proposal ensure patient choice?
- Is the option flexible enough to support people different needs?
- Is the approach based on evidence about the most effective treatments?

Organisation

- Does the option work well for all three current contexts: well developed Tier 3 services, not so well developed Tier 3 services and no Tier 3 services – or does it rely on established community services?
- Will the model fit within the current system?
- Does the model allow a linked up service with community, GPs etc?
- Will the option ensure a planned and sustainable service rather than haphazard placements?
- Is there a coherent way of organising care that makes sense to service users?

Equalities

- Will the option ensure that people in different regions gain equitable care?
- Will the option address issues surrounding gender and ethnicity?
- Will the option allow gender-specific services to be provided?
- Will the option cater for disabled people and other physical issues?
- Will the model allow access to those excluded currently eg homeless?

Carers

- Will the option have an impact on families?
- Will the option impact negatively on carers' costs and time?

Expertise

- Is there potential to develop the workforce?
- Will there be expertise to support local services?
- Does the option include an aspect of research and development?
- Will the option allow for the creation of a centre of excellence?
- Can the service be jointly planned and run with service users? ('experts by experience')
- Does the model ensure availability of trained and experienced staff?
- Does the model include appropriate time and funding for training?
- Does the model allow expertise to be developed in diagnosis and treatment?

Cost

- What is the impact of funding decisions on Tier 3 services?
- Will the option be viable in the longer term?
- Will 62 PCTs commit to funding this option?
- Does the model have accurate costings, with no hidden costs (eg extra acute placements)?



Other issues

Assessing needs

The NHS invited people to comment on any other issues that they wanted to raise. In open ended feedback, about 10% of responses suggested that it would be difficult for the NHS to move forward without undertaking a comprehensive needs assessment to understand the number of people who might benefit from Tier 4 services. An independent needs analysis was undertaken as part of the consultation development process but this concluded that there were insufficient data available on which to calculate the number and type of services required (see the 'have your say' section of www.westkentpct.nhs.uk).

Some service users, clinicians, NHS organisations and local authorities argued that it was not possible to decide on the number of residential units and beds needed until a full needs assessment was completed.

“How do we determine the need for the number of beds and how much are we missing because people are going into the private sector rather than the NHS? There needs to be a good understanding of what the need is.” (Health professional from the South East Coast)

“Across the four regions, the numbers of patients requiring specialist residential treatment has yet to be established. As such, there is insufficient information on which to base a rationale decision for future service provision for this patient group.” (NHS Foundation Trust from London)

Some responses provided their own informal needs assessments. In discussion groups and written responses, some argued that the need for Tier 4 services is increasing and cited historical referrals rates and the interest generated by the consultation as evidence. Others believed that referrals to current services had been decreasing in recent years and that this might suggest that extensive residential services were not needed. But some professionals and organisations were uncomfortable in using historical referral rates to estimate the need for services, especially as changes to funding in the recent past may have led to less people being able to access services.

“We believe it is mistaken to assume that the more recent reduction in referrals to NHS-based Tier 4 services such as to Henderson Hospital reflects a reduced need for such services given that the prerequisite funding requirements asked for by commissioners on a cost per case basis led many referrers to look elsewhere to treat such patients whose needs remain.” (NHS Foundation Trust from outside the four regions)

Responses were also eager to understand the characteristics of people who may be eligible for any new services. There were questions about the criteria that would be used to assess need and whether the profile of service users might match those who have recently used the Cassel and Henderson Hospitals.

It was emphasised that people with personality disorder often have other issues such as eating disorders, drug and alcohol misuse and other comorbidities. Responses suggested that when planning for the future this wide variety of needs should be accounted for.

“As a significant number of individuals with borderline and anti-social personality disorder also have a substance misuse problem, it is necessary to consider drug and alcohol rehabilitation provision within Tier 4.” (Health professionals committee from the South East Coast)

“One size does not fit all. Having a range of services that can take people with different needs will be crucial.” (Man from the South East Coast using services)

A local authority Health Overview and Scrutiny Committee suggested that it may be problematic to make decisions about next steps for the four regions given that national guidance and needs assessments were underway.

“In view of the new guidance in relation to personality disorders, issued in June 2009, and the fact that further work is likely to be undertaken across the country in relation to assessing further future need, it would seem premature at this point to determine what level of residential service is required.” (Overview and Scrutiny Committee)



Care pathways

There was a strong feeling that services for people with complex personality disorder should not operate or be planned in a vacuum. Service users, clinicians and commissioners alike felt that future planning needed to acknowledge the role of other services and concentrate on how other Tiers would be part of the solution.

“The problem of tier 4 service provision is not simply one of how many units, but how patient care across the tiers is managed. The routes of entry into specialist services are disparate and entirely dependent on Borough funding approval. This effectively results in a random range of care pathways (including no care) – a process which may not be informed by local need. We would recommend that the care pathways for patients with complex personality disorder are appropriately managed at a local level in tandem with any changes being made to Tier 4 provision.”
(NHS Foundation Trust from London)

“We realise the consultation is about Tier 4 services but it is also essential to have consultations about best practice for the remaining tiers and other complex personality disorder specialist services, to promote a vision of how these attempt to provide a comprehensive service for people with complex personality disorder”
(Service user group from the South East Coast)

In open ended comments, 10% of responses focused on seeing Tier 4 services as part of a pathway.

“Regarding the number of residential units, this decision needs to be informed by an understanding of the importance of transitions between tiers 3 and 4. Transitional periods are particularly difficult and risky for this patient group and require careful attention as a central component of risk management. In light of this we would recommend that residential facilities are located as close as possible to local non residential / Tier 3 services.” (NHS Foundation Trust from London)

People suggested that it is important to define the relationship between different tiers of service.

“We should be using an integrated approach rather than examining Tier 4 in isolation.” (Commissioner from London)

It was acknowledged that Tier 3 services are variable in different areas and people suggested this should be considered when planning for the future. Responses felt that one model of provision across all four regions may not account for the wide variation in the quality and quantity of Tier 3 services.

“The effectiveness of Tier 4 personality disorder services will be influenced by the level of Tier 3 services in the regions. At present there is great deal of discrepancy in the robustness of Tier 3 services being provided with many areas not having an adequate Tier 3 service. The four commissioning groups will also need to consider investing more money into developing Tier 3 services. Any model that is introduced will need to be seamless, with smooth and effective transition from Tier 3 to Tier 4 or Tier 4 to Tier 5.” (Health professionals committee from South East Coast)

In particular, some organisations and professionals were keen to ensure that investment in Tier 4 services was not at the expense of Tier 3 services. It was suggested that developing local services may eventually lessen the need for Tier 4 residential units. Organisations and professionals from the South East Coast region were more likely to hold this view.

“It is important that the creation of specialist services is contextualised in the overall work which is already in progress to make these local services more therapeutic and responsive in a person centred way. Progress and investment here will, over time, make them potentially a better option - even for people with complex severe personality disorder who we would now regard as needing Tier 4 interventions - offering better opportunity to maintain community and social connections.” (NHS Foundation Trust from the South East Coast)



Treatment approaches

Some responses said that it was difficult to comment on the proposed options since the NHS has not provided information about the type of services that will be offered by outreach teams and residential units. In open ended feedback, 5% of responses suggested that the type of treatments should be determined first and then the best structure for organising them considered.

“This approach is backwards. How are you going to provide treatment and then decide the structure?”
(Health professional from London)

Responses commented on the components of treatment they would like to see considered including the importance of human relationships within treatment, coaching in coping techniques and providing vocational support and assistance for people to build their confidence and get back to work.

“There is nothing out there to help people to get back to work and engage in society. The work programmes are being forced out of the National Health Service as the NHS is not in the ‘work’ business. What they don’t seem to get is that these work programmes are moving people forward toward integrating back into society.” (Councillor from the South Central region)

Whatever therapeutic interventions are offered, responses were keen for treatments to be evidence based and to take account of the most recent guidance.

“The proposed options do not say anything about the type of treatment so it is not possible to judge them against the clinically effective criterion, though this is the most important. Therapeutic communities were the only type of residential treatment whose evidence was considered in the NICE guidelines for people with borderline personality disorder.”
(Woman from London using services)

Service users, carers, health professionals and organisations from all four regions suggested that ensuring a variety of treatment approaches was essential. In open ended feedback, 10% of responses emphasised the importance of patient choice.

“One size does not fit all at any Tier level, it is important, within the evidence base, to include a diversity of treatment types and settings within Tier 4.” (NHS Foundation Trust from outside the four regions)

“There must be a choice for patients – the stigma is still there and patients must be able to choose treatments.” (Man from London using services)

Equalities

During discussion sessions and in written responses, people 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” (Health professional from London)

Responses suggested that while people with personality disorders all have unique needs, some groups may be less advantaged by current and planned care models. The NHS explicitly asked people to comment on any groups that may be disadvantaged by the options put forward. Ninety-two responses suggested subgroups that should be considered when planning or commented on equalities issues. Most of these responses did not believe that the options proposed were specifically biased against certain groups, but rather than more detailed thought may be needed about how to ensure a wide range of people can benefit from any new services.

“We also think 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 and we do not believe they are likely to be included on equal terms in the Tier 4 provision in any of the options currently proposed.” (NHS Foundation Trust from the South East)

The groups that responses thought should be considered further include:

- people with dependents (35 responses)
- women (25 responses)
- older people, aged 65+ (22 responses)
- minority ethnic groups (17 responses)
- people in remote areas (10 responses)
- children and adolescents (8 responses)
- people with drug and alcohol issues or other comorbidities (7 responses)
- men (3 responses)

Most responses did not suggest that a particular option or options would disadvantage certain groups, but there were two exceptions. Some responses felt that the option of having one residential unit would disadvantage vulnerable women because there may not be the potential for a single-sex facility.

“Many women may prefer single sex accommodation. Where there is one residential 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.” (Woman from the South East Coast using services)

Others suggested that having four residential units could disadvantage people from minority ethnic groups as the small size of the units may mean that only one or two people from minority ethnic groups would be present at any one time.

The NHS consultation team telephoned 113 voluntary and special interest groups to seek further feedback about equalities issues but no other issues were highlighted.



Carers' needs

In open ended comments, 9% of responses highlighted the importance of supporting carers and considering the needs of family members.

“Carers must be taken into consideration when planning the services and involved in the care pathway. Working with carers might even reduce the need for hospital admissions sometimes.” (Carer from the East of England)

Responses suggested that residential treatment could place a strain on families in terms of travel time and costs. In discussion groups carers said that new models of care should have good communication with families built in. It was suggested that some community teams already work alongside carers and that this approach should be rolled out more widely.

Carers and service users said that any outreach teams should be well trained in how to work effectively with carers and provide support to families.

“Fragmented care is unacceptable. Focus on the whole family and you have a better chance of allowing someone to recover at their own rate not the systems.” (Woman using services, area unknown)

Some suggested that residential approaches where service users could maintain contact with their local communities by returning home at weekends may be beneficial for both service users and carers. Others suggested that inpatient options should include somewhere for families to stay.



Funding

At discussion groups and in written feedback there were a number of comments about ensuring appropriate investment in Tier 4 services.

“There is a need for Tier 4 services but the question is how much? Decisions should be based on clinical issues but PCTs also need to think about providing value for money. Are we investing to save? Are we providing a positive experience for service users? And is the service sustainable”
(Commissioner from the South East Coast)

People acknowledged the complexity of the issue and the competing priorities facing the NHS.

“PCTs come under great local pressure to finance or underwrite inefficient but popular medical and surgical services. Scarcely a week goes by without some story in the press about local campaigns supported by councillors or MPs to save a well-loved NHS facility, some Maternity or A&E department, for example. Reports continue of how such PCTs struggle to balance their books by taking funds away from less glamorous services such as mental health, leaving mental health trusts to struggle even more to meet their mandatory requirements... In these circumstances neither mental health trusts nor PCT can be expected or relied upon to commission specialist Tier 4 services in a reliable fashion.”
(Health professional from London)

Others suggested that there was not enough information available about the potential budget available and that this made it difficult to provide suggestions about how to best invest funds.

“I would be comfortable discussing this if we had a cost envelope. If we had £10-16 million or £30 million we should look at Tiers 1-3 and shore them up first. We don't know how much money we have to design our services.” (Health professional from the South East Coast)

Service users and health professionals were keen to ascertain that the NHS was committed to following through on whatever model of care is selected. There were concerns that PCTs may not be committed philosophically or financially to supporting the selected model.

To remedy this, there was a desire to see centralised funding to ensure that models of care would be sustainable, rather than based on the decisions of individual primary care trusts. In fact 12% of responses suggested regional or centralised funding of some sort.

“Unless reliable NHS regional funding with teeth is put in place or unless consistent national public funding is re-established for the Tier 4 option to be chosen by this public consultation, it risks being consigned to some NHS fantasy wish-list so that truly effective residential services for this seriously disadvantaged patient group might tragically never see the light of day.”
(Health professional from London)



Training

Finally, there was heavy emphasis on ensuring that appropriate training, research and development was built into new models of care. In open ended feedback about one third of responses made comments about the workforce, training or research needs (35%).

“People with severe personality disorder see a whole range of people in their lives and we should look at the whole care pathway. The people in contact with these patients must have the skills to treat them.” (Health professional from the East of England)

Responses believed that those supporting people with complex personality disorder needed specialist skills and the opportunity for training and ongoing development. This was seen as an important component of any future model of care.

“The attitude of staff is of central importance in all services for people with complex PD so particular emphasis should be placed on selection and involvement of people with complex PD in recruitment (there is research to support this). Sensitivity and excellent engagement skills are crucial.” (Service user group from the South East Coast)

It was suggested that currently mental health services are not good at diagnosing personality disorder so more upskilling in the area of diagnosis and assessment is needed.

Others argued that community teams and other local staff would need to be adequately prepared for any changes, especially as all of the proposed options have significant implications for how community teams will work in future.

“When care in the community started the communities were not prepared. It seems we are moving in the same direction with the same issues. We need to ensure the communities are prepared and trained.” (Member of the public from the South Central region)

Others said that community mental health teams do not have the knowledge, skills or confidence to deal with people with personality disorder. People commented that there should be more attention paid to enhancing Tier 3 services through training, support and developmental work and encouraging investment from local PCTs.

“Teams in the community are extremely challenged and need to be supported with training. There are huge gaps in training within the community teams.” (Woman from the South Central region using services)

People believed that future models of care should focus on building expertise within both local and specialist teams.

To summarise, responses acknowledged that the NHS had difficult decisions to make regarding the future of Tier 4 services for people with complex personality disorder. Those who responded tended to feel passionately that there was a need for improved services.

Responses urged the NHS to make decisions based on clinical effectiveness, evidence and experience-based practice, funding and sustainability.

Whilst the importance of offering care close to home was acknowledged by some, people tended to rate this as of less importance than receiving specialist care designed to meet individuals' needs.

Other issues that responses wanted the NHS to consider when planning for the future included locating Tier 4 services as part of a comprehensive pathway, providing adequate training and development, and ensuring a sustainable funding model to avoid ongoing changes and uncertainties. People did not generally believe that any of the options disadvantaged particular groups but there was a call to ensure that choice was offered and services were developed to address a wide range of needs.





Consultation issues

Positive feedback

Forty-five responses made comments about the consultation process or content itself. Most of this feedback was positive or neutral.

People and organisations recognised the importance of the consultation, suggesting that it may have far reaching implications.

“We regard this consultation as timely and helpful in shaping the necessary structure and function of Tier 4 services for people with personality disorder according to their clinical needs within a tier based system of services and care.”
(NHS Foundation Trust from outside the four regions)

Organisations from outside the four regions suggested that the outcome may influence what happens in their own areas.

“I believe the outcome of this consultation is likely to influence commissioning of services all over the country.” (Personality disorder service from the West Midlands)

The NHS consultation team telephoned 113 voluntary groups and stakeholder organisations to ensure that they had received copies of the consultation material and to gain their feedback. These groups were very positive about the quality of the consultation materials and their accessibility to general audiences.

The most positive feedback about the way the consultation had been developed and managed came from NHS organisations and health professionals, particularly those in London and the South East Coast.

“We are optimistic that this review will build on the excellent services provided by the Henderson and Cassel and provide us with opportunities to deliver a range of effective therapeutic interventions for this client group.” (Health professionals’ committee from the South East Coast)

Overall, about one in ten responses commented that the consultation information was clear, easy to understand and well presented (9%).

A similar number suggested that the consultation had sought to engage with a variety of people, and that events were well run and inclusive (8%).

“The Trust welcomes this review of the way Tier 4 services for people with complex and severe personality disorders are provided which we believe is timely and helpful. We believe the process seems to have been thoughtful and inclusive. The information provided on the [consultation] website has been very helpful and we strongly support the introduction of a range of options for providing responses.” (NHS Foundation Trust from the South East Coast)



Areas to improve

Two complaints were received during the consultation period.

The first, from a service user, took issue with the description of personality disorder used in the consultation document. This description, which suggested that the behaviours of people with personality disorder tended to fall outside usual societal or cultural norms, was based on an official psychological definition. The service user suggested that using this definition made people with personality disorder sound 'odd' or 'labelled.'

The second complaint was from a health professional who believed that the images used in the consultation document should show people in greater distress or 'less normal' looking.

"There is a problem with the consultation document. A number of pictures of apparently normal people showing little signs of distress is shown. This is similar to a consultation document for a treatment of say, eczema, with lots of pictures of people with normal skin. It gives a confusing message which could easily be interpreted as that the real problems of the patients cannot be coped with. This could be stigmatising and reinforce an unhelpful message that the patients are untreatable." (Health professional)

Both complaints were investigated by the Chair of the NHS organisation hosting the consultation and individual responses were sent.

Other issues

In addition to these two issues, other responses provided helpful suggestions about how to continue to ensure the consultation is engaging and inclusive.

There was a desire to actively engage service users in the consultation, including being part of the final decision making committee. Two out of the five consultation discussion groups recommended that the NHS decision making committee should be able to meet service users and carers to hear their stories first hand. They requested that the NHS committee should involve service users in the decision making process and hear the stories and concerns of service users in person, perhaps as part of the decision making meeting.

Some responses said that it is important for commissioners to be involved in the consultation process, including attending discussion groups to hear what service users and other stakeholders have to say. It was also noted that GPs are important in caring for people with personality disorder and they should be represented at consultation meetings.

Others were worried that decisions may be made on financial grounds rather than clinical grounds and suggested that service users and carers should be at the centre of decisions to avoid this.

People also wanted assurance that their feedback would be taken into account by decision makers and that the outcome of the consultation would be implemented without question by all 62 PCTs.

"How do we know that the views of the service users will be heard and not spun into an option that just prioritises costs?" (Man from London using services)

Specific services

About 2% of responses believed that the consultation should have more explicitly addressed the role of the Henderson Hospital or have been conducted prior to the hospital's temporary closure.

"It is disappointing that this consultation on service models is taking place after the Henderson Hospital has temporarily closed, rather than prior to the commissioning decisions which led to that closure. If specialist residential provision for complex and severe personality disorder is to have a secure future, this will necessitate commissioning through a risk-sharing agreement rather than pure spot purchasing." (Health Overview and Scrutiny Committee)

However, the majority of these responses felt that specific types of residential treatment should have been explored rather than focusing on a particular building or entity itself.

"We would like to be very clear that although there is a great deal of strong feeling about the Henderson, the feeling is for the service and the community and not the building itself." (MP from London)

A number of service users, carers and health professionals provided heartfelt stories about how the Henderson Hospital had offered support and high quality treatment in the past.

"I want the decision makers and the government to listen to the voices of people who have had treatment at the Henderson and how substantially different their lives are post treatment there is no substitute for the type of treatment the Henderson offers... I'm not saying that out of any misplaced emotional attachment to the place as the regime there is very tough indeed and you can't view the Henderson with rose tinted specs if you've been a resident there you know it's not tea party." (Man from London using services)

In fact, in open ended feedback, about one in three responses suggested that residential services such as the Henderson Hospital had helped them or their family (29%). Examples of the stories and descriptions provided are included in boxes throughout this report. However, there were also some less than positive accounts (see Box 9).



Sharing personal stories

Box 9: A family member's reflections

Following two brief episodes of depression as a teenager and subsequently a breakdown after two significantly negative life changes, we were told that her particular symptoms fitted the DSM diagnostic conclusion for borderline personality disorder.

Prescribed drug therapy brought inadequate relief for her, from the multiple symptoms of borderline personality disorder and the obsessive compulsive disorder which took the form of continual phone calls leading to debts, which ran out of control on a very meager benefits income.

She was accepted at the Henderson Hospital for inpatient treatment. She discussed the options with her psychiatrist and with us; she understood the seriousness of this option of treatment. She also understood there was a strong possibility of progress for her, so she entered the Henderson Hospital happily, off her drug regime, and was looking forward to a positive outcome.

She kept in contact with us during her stay, voluntarily also she visited our home during her stay. Distressingly, over the weeks she became more and more distressed. She self harmed (something we had never witnessed her do before her stay). She was thrown out with all her possessions in black bags, no transport and no home to go to. One member of the Henderson's staff rang us and expected us to 'pick up the pieces.' There was no offer of support or guidance for us in how to cope with her terrible ongoing distress, and none followed.

The staff had been unwilling to discuss her deteriorating health until they decided she was to leave. That optimistic young person returned unable to talk, unable to sit still and continually wandered. She stayed with relatives until her worsening state of mind meant she had to spend time in the safe house under her local mental health team. What was meant to provide a safe therapeutic healing environment, felt disastrous and highly damaging.

Years on she and we are still alive and all living with the many complexities of this disorder. As a family we have had a *terrible* struggle insuring she has finances and that she continues to have a home. We maintain contact with her mental health team through formal annual updates. We asked for, and now have maintained contact with a carers' support worker. It was a fight to get adequate help.

Our relative said putting all types of people with different difficulties together in one place did not work. The degree of the severity of the various clients' disorders needs to be taken in to account when inpatient care is decided. This client group needs by the very nature of their difficulties long term, planned, consistent help and support.

Tier 4 care should not be seen in isolation, but move and be supported through the other Tier levels. The Tier 4 care needs to be thoughtful, caring, encouraging, free from abuse and enhance every individual's autonomy. By their very nature these clients may be disruptive, changeable and hard work. Short term fixes do not seem to work. What would help is a supportive approach at all Tier levels, and the awareness that in many cases families can be a positive part of the change for health.

Note: this feedback is provided as an example of how not all descriptions of the Henderson Hospital and other residential facilities were positive. As with the positive descriptions scattered throughout the report, it is based on opinions and perceived experiences.

Perhaps most importantly, many who had used services in the past emphasised that they supported specific types of residential therapy rather than a particular unit itself.

“Although it is quite evident that I am fairly passionate about the Henderson, it is entirely possible I would have been as equally passionate if I had received treatment at the Cassel or another residential service... I doubt I would have cared what the service was called, where it was or what the therapy was called when I needed it as long as I knew it was specifically designed for people with my type of difficulties and that anecdotal evidence from previous users said that it worked.”

In summary, around 12% of responses provided one or more comments about the consultation process or management.

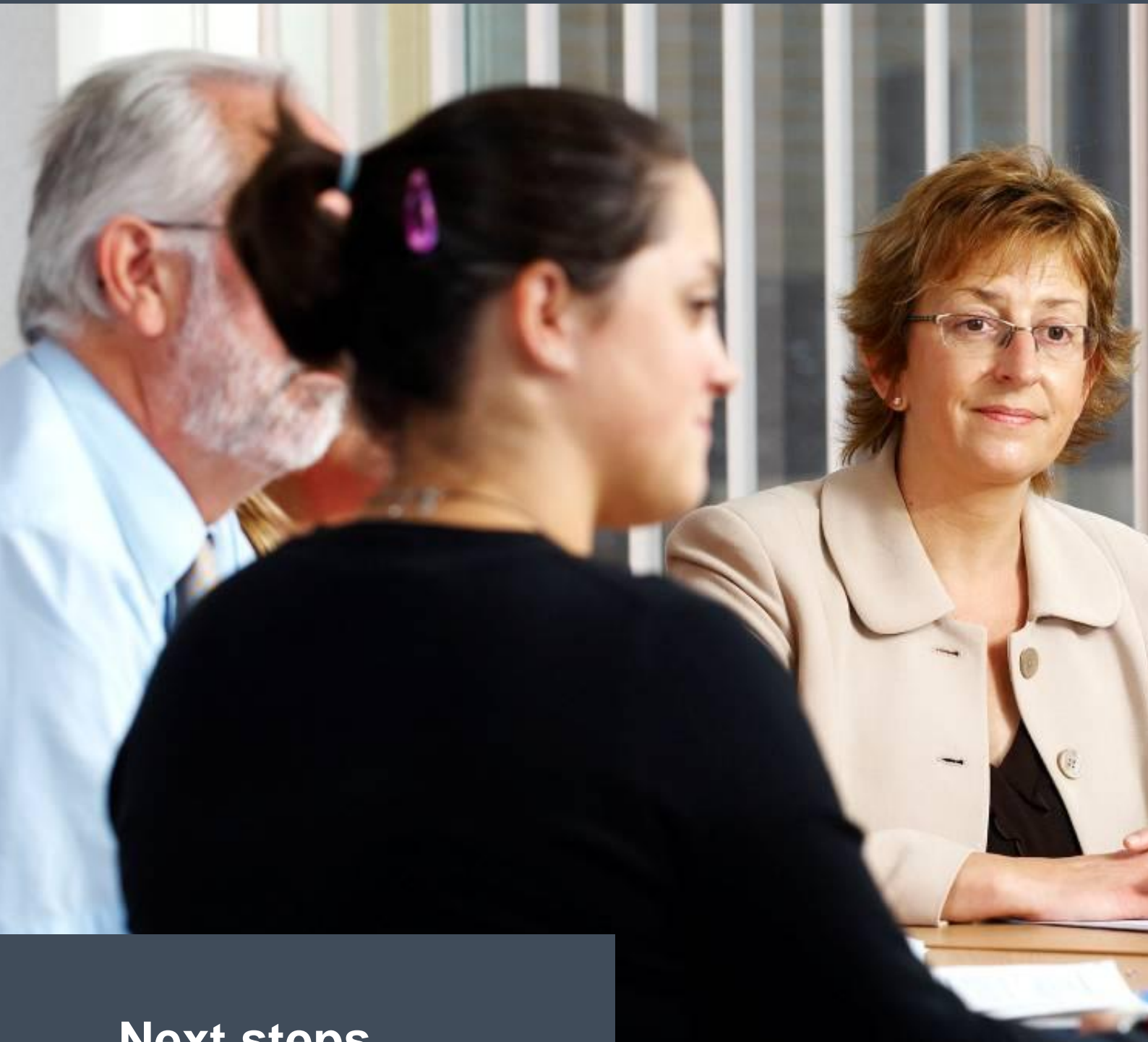
Most of these were positive or neutral. Some felt the consultation information was well presented and accessible. Others believed the consultation was inclusive and well organised.

The most common concern was how people's feedback would be considered and incorporated by the NHS. Some were vocal about the need for the decision making committee to include service users and carers, or fully hear the stories and experiences of local people. Overall, though the consultation process appeared well regarded.

Reinforcing this, following the close of the formal consultation period the Joint Overview and Scrutiny Committee met to consider the appropriateness and extent of the consultation process and materials.

“The committee concluded that it was content with the way that the consultation had been conducted and noted the positive comments of those present who had participated in it. [A Councillor] commented that she believed the Consultation Advisory Group had worked very well and that there had been an open-mindedness of approach. The consultation had been conducted with rigour and had given a welcome opportunity to share knowledge and expertise and discuss Tier 4 services.” (minutes of JOSC meeting, 6 October 2009)





Next steps

The consultation aimed to help the NHS consider three key questions:

- Should community outreach teams be set up specifically for people with complex personality disorder in each region?
- Should specialist residential treatment centres be available for people with complex personality disorder?
- If residential treatment centres are used, how many should be provided across the four regions?

The consultation documents state that NHS will consider feedback to the consultation as one of the pieces of evidence when addressing these questions.

Almost all of the responses that commented on this issue believed that **some change is needed** in services for people with complex personality disorder (98%).

The majority supported regional outreach teams (95%), though there were differences of opinion about the most effective way to run and manage such teams or how they should interlink with existing services.

The majority believed that some residential services should be available (84%), with just 16% supporting having no residential units.

The majority believed that both outreach and residential services should be provided (92%).

There was less consistency in opinions about how many residential units should be offered. About one quarter of responses supported having one residential unit (28%) and about half supported having two (56%) or four units (57%). Responses could favour more than one option. Responses suggested a range of advantages and limitations with each option (see Table 6).

Table 6: Proportion of all advantages and limitations that focused on different topic areas

	0 units - % pros	0 units - % cons	1 unit - % pros	1 unit - % cons	2 units - % pros	2 units - % cons	4 units - % pros	4 units - % cons
Location	31	1	4	65	19	35	57	5
Capacity / need	3	18	41	44	33	29	33	25
Choice	6	4	0	8	18	0	10	0
Clinical	14	79	31	31	72	10	33	25
Carers	6	3	1	11	2	4	9	0
Equalities	7	8	4	0	0	9	8	0
Expertise	3	17	43	6	20	19	21	33
Cost / sustain	46	10	31	4	11	39	3	54
Other	31	6	0	<1	1	2	0	16



The two most commonly mentioned alternative options were greater integration of outreach support with existing community services and setting up three needs-led residential units to cater for a range of specific subgroups.

Responses felt strongly that whatever decisions are made should be based on clinical effectiveness and the needs of people using services.

“The starting point should be what is best for the patient and then services should be designed around that. We should be looking at evidence of what works best clinically and then arranging services to fit in with that, no matter how much it costs. This should not be about costs, it should be about patient care.” (Health professional from the South East Coast)

The importance of diversity and equity was highlighted. People suggested that whatever model is chosen should ensure the availability of female-only services, allow access for minority ethnic groups and encourage use by previously excluded groups such as the homeless.

They also wanted to ensure that Tier 4 services are not considered in isolation, that further information about levels of need and demand is available and that the views of service users and health professionals are fully examined when making decisions.

The NHS will consider next steps in November 2009. Service users and health professionals spoke and wrote passionately about the benefits of specific residential facilities. Whilst there was sadness and anger about the temporary closure of the Henderson Hospital and uncertainties for the Cassel Hospital, there was also a sense of optimism about the potential to make positive changes.

Service users and health professionals throughout the four regions encouraged the NHS to make the most of this opportunity to develop a sustainable model of care for people with complex personality disorder.

“We need real ‘vision.’ It takes time for services to evolve and for people to change. We should not be looking for a quick fix. We have an opportunity to do something good for the future. We should take that opportunity and focus on what we want.” (Health professional)

