

Equality Analysis

Government Response to: Liberating the NHS - No decision about me, without me

December 2012

Equality Analysis

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1. Introduction

- 1.1. This Equality Analysis accompanies the Government's response to the consultation Liberating the NHS: No Decision About Me Without Me Further consultation on proposals to secure shared decision making ¹. The response document confirms the Government policy to increase opportunities for patients and their representatives to have more involvement in decisions about their care all along the patient pathway.
- 1.2. The development of the Government policy on patient choice and involvement in decisions started with the vision set out in the White Paper, Equity and Excellence: Liberating the NHS². It included proposals to ensure that there would be a presumption of choice, including choice of treatment and choice of any qualified provider for patients in the vast majority of NHS-funded services by no later than 2013/14.
- 1.3. In October 2010, the consultation document, *Liberating the NHS: Greater Choice and Control A consultation on proposals* ³, sought the views of patients, the public and healthcare professionals and the NHS on the choices that people want to make, when they want to make them and what information and support they need to be able to have more say and to share in decisions about their care.
- 1.4. In May 2012, Liberating the NHS: No decision about me without me Further consultation on proposals to secure shared decision making proposed a model for giving patients and their representatives more say in decisions about their care and treatment. The model was organised under four broad headings where choice would be expected to be available: in primary care; before a diagnosis; at referral to secondary care; and after a diagnosis.
- 1.5. An Equality Impact Assessment and an Equality Analysis were published alongside the respective consultations in October 2010 and May 2012. Both cover many of the issues that relate to this policy. Therefore, we have attempted to resist duplicating earlier documents. Instead this document seeks to build upon the initial work and to concentrate on the issues raised by the responses to the most recent consultation.

Consultation Response

1.6. During the consultation period from 23 May 2012 to 31 August 2012, we received 46 responses that raised health inequalities or equalities issues. While many groups were broadly supportive of the policy objective, their concerns focussed on whether specific groups of service users, who may already find it difficult to navigate the NHS, may find

http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_134221

² http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353

http://www.dh.gov.uk/en/Consultations/Closedconsultations/DH_119651

it more difficult as a result of the proposals to give patients and service users more say in the decisions.

- 1.7. The main barrier to equal access to services that was identified was that disadvantaged groups may not have the information necessary to make the choices. They were also concerned that it requires more resources for the NHS to communicate successfully with these groups, e.g. providing information in different formats, and that these resources may not be forthcoming. A related issue is that of health literacy. Respondents raised the issue that many subsets of users who have poorer health literacy would be disadvantaged by the proposals as they would not be able to navigate the system as well as those with more developed skills.
- 1.8. A second issue raised was that of the attitude and behaviours of both NHS staff and patients. This went beyond the attitude issues raised in general to shared decision-making and choice policy. The concern was that service users from the most vulnerable groups are those that the NHS has the most difficulty accommodating. This may be from a belief that the member of staff thinks they know best or from time constraints that prevent the health professional from fully involving the person in decisions about their care.

2. Key issues raised by respondents

- 2.1. Out of the 172 valid responses that the Department of Health received during the consultation period, 46 raised equity issues or were concerned about health inequalities. Many of these responses were from organisations that represent specific patient groups. Others were from NHS organisations. The overriding theme of their concerns was that the proposals to allow more choice and involvement in decisions about care had the potential to exacerbate health inequalities. They felt that without sufficient support vulnerable service users would be further disadvantaged compared to other groups that are more articulate and who were better able to navigate the system.
- 2.2. The biggest barriers that might prevent vulnerable groups from being able to participate in the opportunities set out in the consultation were information and culture. The concerns went beyond those usually raised in relation to shared decision-making and choice, and respondents argued that more consideration of these issues is required when applying the principles to vulnerable groups. More details are given below.

Information and communication

- 2.3. At every stage of the consultation process, respondents have raised the importance of information if shared decision-making and choice are to be effective at driving quality improvement across the NHS. The responses to this consultation were no different.
- 2.4. The Deafness Support Network pointed out that simply providing information would not be sufficient to overcome barriers. People with hearing impairments would also need the information in a format suitable for them. These sentiments were echoed by Royal National Institute for the Blind they pointed out that the amount of information currently available in braille was disappointingly small.

The Deafness Support Network said:

"Only when deaf people have equality of access to information in a language they can effective communicate in, will this process begin its very long journey towards equity."

Royal National Institute for the Blind commented:

"At present, accessible information for blind and partially sighted people is rarely found."

2.5. Other organisations also raised the issue of how information is communicated to users. To them, this was as important as the need for information itself. For example, people with hearing difficulties can have difficulty making appointments to see a GP where a practice runs a predominantly telephone based appointments booking service. Further

problems can arise in communication between the healthcare professional and the patient. Sign Health, for example, pointed out that if staff fail to communicate with the patient then shared decision-making becomes meaningless. The point was made that if greater involvement in decisions is to become a reality, then more thought will be needed to overcome these problems of communication.

2.6. Darlington Health Partnership Scrutiny Committee were concerned that the main channel for communication of information appeared to be via digital means whether via NHS Choices or through Choose and Book to book appointments. Some might find websites difficult to use while others might not wish to. The response pointed out that this had the potential to create a barrier to accessing the information for some users groups.

Darlington Health Partnership Scrutiny Committee said: "Members view here was that the proposal relies heavily on access to digital information with no indication of research being conducted as to whether patients would want this or if patients had access."

2.7. The government recognises the importance of information in making shared decision-making the norm right across the NHS. The consultation for shared decision-making and choice was run alongside the consultation on the information strategy. The Information Strategy⁴ recognises the importance of appropriate, timely and accessible information to enable people to make informed decisions about their care.

Culture

2.8. A number of respondents raised the issue of culture within the NHS. Organisations like Homeless Link, Positive UK, Lesbian and Gay Foundation and Gender Identity Research and Education Society pointed out that attitudes towards vulnerable groups means that it is difficult for them to access services. They believe that the introduction of a greater range of opportunities to be involved in decisions will not raise quality of services for vulnerable groups unless attitudes to participation change.

Homeless Link agreed. They commented that:

"9% clients in a Homeless Link Health Audit said they had been refused access to a GP or dentist."

2.9. The Charter Society of Physiotherapists also suggested that the attitudes towards the commissioning process will need to change in order for the proposals to be a success. They believe that a large challenge exists for both providers and commissioners alike to understand which services and which patient pathways will benefit from integrated

⁴ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_134181

service design and those which are suitable for a plural provider base. They also believe more work is required to involve patients in the commissioning process itself.

Health inequalities

- 2.10. Many of the respondents were broadly supportive of the aims of the proposals. However, many felt that unless support for participation and involvement were integral to the delivery of services then not only would the policy be unsuccessful but that it had the potential to exacerbate health inequalities. This view was not confined to groups with special interests but was raised by organisations more widely.
- 2.11. The Association of the British Pharmaceutical Industry raised concerns about the potential to widen inequalities. They said: "Different patient subgroups could have different expectations. We would support ensuring that this does not exacerbate health inequalities."

This opinion was shared by Boehinger-Ingelheim, who commented:

"Should the recommendations be implemented, some patients will inevitably want more involvement and choice and take all the opportunities they are given.

Consequently, therefore, inequity of access to services and treatments is likely. To mitigate this risk, levels of health literacy and individual patient motivation will all need to be addressed."

- 2.12. The Government recognises the legitimate concerns raised by these respondents. The Equality Analysis published in May 2012 highlighted that one of the main aims of involving patients more in their care was to deliver greater equity within the NHS. The King's Fund Report (2010) points out that more affluent people have historically been better at navigating their way around the NHS or have the choice of opting out of the NHS altogether. Dixon and LeGrand (2006) discuss whether greater choice and equity are consistent. They conclude that, by giving choice to individuals or groups of individuals who previously had none, equity can be increased. In other words, inequalities can be reduced because those who were compelled to put up with poor local services or providers because they had no choice, can receive better care by having greater say over their care through for example, choosing an alternative hospital.
- 2.13. A review of the available literature finds no evidence to suggest that giving patients more say in decisions about their care and treatment has created any specific inequalities. A paper by Cookson and Laudicella looking at the impact of the choice of provider policy suggests that inequalities have stayed the same or reduced slightly since the introduction of this entitlement to make choices at referral.

Health Literacy

- 2.14. As discussed above, concerns were raised about information and communication and the dangers of widening health inequalities. The link between these two areas is the ability of service users to understand and make use of the information about different services and treatments. If some population groups are more health literate than others then they may be better placed to take advantage of the opportunities from these proposals. 23 respondents to the consultation raised this issue.
- 2.15. The Community Health & Learning Foundation expressed their concerns as follows:
 - "..., it is very disappointed at the lack of any reference at all within the document to health literacy and in particular any acknowledgement that limited health literacy, educational attainment and the consequent lack of functional skills might have on people's ability to make shared decisions in any or all aspects of the health care arena. We believe that unless this is rectified before the proposals in this document are implemented there is a real possibility that the health literate section of the population who have good educational outcomes will be able engage with this agenda while the significant numbers of vulnerable people, referred to above, who lack health literacy and educational attainment and who generally have the worst health outcomes will not. This in turn runs the risk of heightening health inequalities."
- 2.16. Commissioners of health and care services should recognise the benefits of ensuring appropriate information and communication support is made available for those who need it. This may include the use of a translator service for those where English is not their first language, or considering alternative forms of information for those with lower levels of health literacy, who may not feel confident in processing information within the allotted time of the consultation.

3. Protected characteristics

3.1. As mentioned in the introduction, this equality analysis builds upon earlier analysis including analysis that accompanied the first consultation in October 2010, the subsequent guidance on any qualified provider in July 2011 and named consultant-led team in October 2011, and the further consultation in May 2012. Those documents provided detailed analysis of the evidence on the protected characteristics. The discussion below draws on the summary published in May while concentrating on new evidence and the responses we received to the consultation.

Age

- 3.2. The National Children's Bureau (NCB) and Council for Disabled Children submitted a response to the consultation that pointed out that an analysis of the impacts on children was missing in previous publications. This comment was echoed by a number of organizations including Participation Works Partnership, Shared Decision Making in Child and Adolescent Mental Health project team and The Children's Heart Federation.
- 3.3. They provided evidence that young patients wanted a say in decisions about their health⁵ ⁶,. Children and young people also wanted better information, explanations and communication and valued being involved.
- 3.4. The response also made clear the importance of supporting children and that careful consideration about decisions and choice will be needed "...not least due to children and young people's legal capacity to consent and their relationship with their parents.⁷"
- 3.5. They also provided evidence that studies of children and young people have found "involvement in management of care is associated with positive outcomes, like avoiding diagnostic delay and negative psychological effects⁸, and preparation for making informed decisions about their treatment and other health choices in adulthood.⁹"
- 3.6. NCB also point out;

"they need to be respected, informed and supported in a way appropriate to individual needs."

⁵ See www.ncb.org.uk/ourhealth; series of dedicated events

⁶ Robinson, S. (2010). "Children and young people's views of health professionals in England." Journal of Child Health Care **14**(4): 310-326, cited from *Listening to children's views on health provision*⁷ ncb response, page 4

⁸ Gibson, F., S. Pearce, et al. (2009). Cancer in young people: a narrative study to explore their experience from first symptoms to the diagnosis of cancer, CLIC Sargent, cited from *Listening to children's views on health provision*

⁹ Gibson, F., S. Aldiss, et al. (2010). "Children and young people's experiences of cancer care: A qualitative research study using participatory methods." International Journal of Nursing Studies 47(11): 1397-1407, cited from *Listening to children's views on health provision*

- 3.7. Royal College of Paediatrics and Child Health highlights the need for adequate training for healthcare professionals. In their response, they stated:
 - "We agree with the statement in 3.1 that 'The GP practice is the front door to the NHS', but would underline that this is especially true for children and young people. The RCPCH supports the extension of training for GPs from 3 to 4 years with an emphasis on paediatric training, but it is also vital, as identified by the recent Children and Young People's Health Outcomes Forum that all staff in a general practice "should be adequately trained to deal with children and young people."
- 3.8. The Government recognizes these concerns. The You're Welcome quality guidelines set out how services should adapt to accommodate young people. RCPCH acknowledged this in their response, saying "The You're Welcome quality criteria produced by the DH provides an excellent set of guidelines in making all health settings accessible and appropriate for children and young people."
- 3.9. In response to the consultation in October 2012, Age UK provided some qualified support for our proposals. For example, they expressed the opinion that the any qualified provider model could be expanded relatively easily in areas of importance to older patients where decision-making is less complex, such as audiology, podiatry and ophthalmology, which should allow some older people to benefit.
- 3.10. However, the British Geriatric Society expressed some concern relating to potential fragmentation of services as a result of giving patients more choice of provider. For example, they said:
 - "Emergency care for older people is often related to one or more long-term conditions and requires an integrated response across Primary Care, urgent hospital care, community-based services and support. Communication and integration are key to good results. Introduction of multiple providers would fragment the service and deliver lower quality, less joined-up care."
- 3.11. There are certain services for which continuity is extremely important, such as integrated care for older people with complex care needs. In these cases, commissioners can make reasonable amendments to service specifications to set expected levels of service quality or to set other specific requirements to meet the needs of local patients and determine the nature of local services, referral pathways and thresholds. These local flexibilities will enable commissioners to ensure patient choice is offered whilst also delivering integrated packages of care for people with complex needs so that healthcare professionals, in partnership with patients and their carers, can continue to consider how to ensure care is delivered in an integrated way.

Disability

3.12. A potential risk of negative impact on equality, that was raised in responses to the consultation, is as a result of availability or otherwise of transport. Some disabled patients may not have the capacity to travel to an alternative non-local provider, due to mobility problems or restricted access to necessary information – information on travel timetables and routes is often inaccessible - which is particularly challenging for blind or partially sighted individuals. Issues raised around the availability of, or access to, transport mainly relate to concerns about access to services, but some also relate to choice - as a patient's choice of provider may be effectively restricted by where a patient is able to travel to.

For example, The Foundation Trust Governors' Association made the following commented:

"The effect of transport on decision-making also needs to be looked at in more detail. There was a general feeling that decisions that should be based on clinical quality were more likely to be swung by whether a patient to get to the hospital. Therefore, a policy about choice and decision making that does not take account of transport falls when practically implemented. There's no point of telling a person they can go to the best surgeon in the world if they can't physically get to the consultation."

And The British Lung Foundation said:

"For reasons of convenience, ease of mobility and financial constraint, many patients will feel unable to choose anywhere other than their nearest centre to receive diagnostic testing."

- 3.13. The Patient Transport Service is a service provided by the NHS for non-emergency patients to transport them from and to a premises providing NHS healthcare and between NHS healthcare providers. Commissioners are responsible for commissioning these services and decide who is eligible to receive patient transport services in their area.
- 3.14. In addition, commissioners and local authorities should be working together to ensure that new services are accessible by public transport. Existing facilities should ensure that people are able to access healthcare facilities at a reasonable cost, in reasonable time, and with reasonable ease.

People with learning disabilities

- 3.15. People with learning disabilities have poorer health status, a shorter life expectancy and increased risk of early death compared to the general population¹⁰. A report on health inequalities by the Learning Disabilities Observatory identifies access to and quality of healthcare as two determinants of the health inequalities faced by people with learning disabilities. Given the evidence of greater health need, it would be expected that people with learning disabilities would be accessing primary care more frequently than the general population; however, people with learning disabilities visit their GP with similar frequency to the general population. The report also finds that people with learning disabilities have an increased uptake of medical and dental hospital services but a reduced uptake of surgical specialities compared to the general population.
- 3.16. There is some evidence to suggest that, with respect to healthcare, other people make choices for people with learning disabilities¹¹. People with learning disabilities, where possible, should be given support to make their own choices, however it may be necessary to engage with their carer or person with legal authority to make decisions on their behalf to ensure that their needs and preferences are met. Turning Point made the point:

"One area that does not receive enough attention is the support required by those with a learning disability. Turning Point knows from our experience of providing learning disability services for over 20 years, that choice and shared decision making can and should be better enabled for people with a learning disability, often involving their families, friends and carers"

Ethnicity

- 3.17. The UK is increasingly ethnically diverse. The 2001 Census showed that approximately 12.7% of the population of England and Wales was from a black or minority ethnic (BME) background. Population projections indicate that this percentage would have increased to 15.7% by 2007 and will increase further to 21.3% by 2016. As outlined earlier, our initial equality analysis document discussed issues relating to ethnicity using the available literature.
- 3.18. That analysis will not be repeated here other than to recognise a message heard from engagement events that many minority groups including Romany Gypsies and Irish Travellers have poorer access to NHS services. Therefore implementation of proposals to give patients more say in decisions about their care will need to be done at a local level taking account of the needs of the whole of the population, which the

 $^{^{\}rm 10}$ Health Inequalities & People with Learning Disabilities in the UK: 2010

Ferguson, M., Jarrett, D., Terras, M. (2011) "Inclusion and healthcare choices: the experiences of adults with learning disabilities" British Journal of Learning Disabilities, 39 (1) pp 73-83.

commissioner has responsibility for. Provisions for reflecting these local considerations are proposed in the Health and Social care Bill 2010.

Sex

- 3.19. Although the available literature shows no evidence that there is gender inequality in who is offered choice, the Woman's Health and Equality Consortium, in response to the consultation, highlighted some barriers to making informed choices which may be faced by some women:
 - "Women face particular barriers to exercising choice. These barriers include inequality in power and resources; poverty; gender-based violence; caring responsibilities; confidence and voice; knowledge of rights and a lack of access to appropriate maternity services."
- 3.20. We acknowledge this potential barrier. This barrier could be tackled by ensuring that women are given a voice in local structures, through for example the proposed Healthwatch system.

Religion or belief

- 3.21. People from different religious groups and communities have specific concerns when choosing a healthcare provider. Healthlink's report (Taking Soundings, 2004), found that Muslim patients and their visitors wanted to be assured that they would have prayer space within the grounds of the hospital, and that members of certain faiths would not use mixed wards under any circumstances. The policy on Delivering Same Sex Accommodation should have helped to address some of these concerns ¹².
- 3.22. No further substantive issues on religion or belief were raised during the consultation exercise itself. By giving patients more say in decisions about their care and treatment, it is envisaged that all patients will have more flexibility to use services in a way that is more convenient for them and fitting in with their personal preferences.

Sexual orientation

3.23. We have very little evidence about whether or not lesbian, gay or bi-sexual (LGB) people face discrimination in being offered choices over their healthcare, or in exercising those choices. However, the literature suggests that they do face specific issues with respect to accessing healthcare. This was discussed in the initial equality analysis document for the choice consultation in October 2010 overall and for the

¹² The 2010/11 Operating Framework advocates the elimination of mixed sex accommodation http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH 110107

- response to the proposals on extending choice of provider (Any Qualified Provider) in July 2011.
- 3.24. In response to the consultation on Liberating the NHS: Greater Choice and Control, the Lesbian and Gay Foundation voiced the opinion that sexual orientation monitoring, along the lines of monitoring for other protected characteristics, would help LGB people make more informed choices.

They said this again in this consultation:

"There is growing recognition that more outcome indicators need to be disaggregated by the protected characteristics including sexual orientation, and The Lesbian & Gay Foundation welcomes DH's commitment in the Government's LGB&T Action Plan to 'support NHS providers to appropriately collect data on sexual orientation'. Unfortunately, little progress on these points has been made".

"LGB people need to have access to information which shows how highly LGB people have rated a service, compared to heterosexual people. This data cannot be collected or shared unless sexual orientation of service users and service provider staff is collected and shared."

3.25. Consultation responses also suggest that in order for LGB people to have more involvement in decisions about their healthcare, they would need access to a range of providers where they feel able to discuss their health issues in relation to their sexuality. Respondents believe that this choice can be increased through provision of specialist providers, especially in areas where LGB people represent a significant proportion of the population, as well as ensuring that generic services are more inclusive.

Gender reassignment

- 3.26. Feedback to the White Paper consultation suggested that trans people report that GPs do not include or engage them by offering choice or in decision-making. The independent scrutiny role that local Healthwatch will have, has the potential to contribute to closing the gap in current inequalities for this group.
- 3.27. For individuals seeking gender re-assignment therapy the first step in the process is a referral from their GP to a consultant psychiatrist. The proposals for choice in mental health services will allow service users to choose a named consultant-led team or a team led by another healthcare professional with which they are most comfortable.

Marriage and Civil Partnership

3.28. We do not envisage that this policy will have any disproportionate effect on those who are married or in a civil partnership.

Carers

3.29. We do not have any specific evidence on how the proposals to give patients more say in decisions about their care might affect their carers. However, we recognise the important role carers play in the lives of the people they care for and their role in sharing in decisions about that person's care. It is also important to recognise the health of the carer themselves and the difficulties the carer might have in making choices about their own care when having the responsibility of looking after someone who is dependent on them.

Socio-economic status

3.30. Evidence from The King's Fund (2006) and RAND (2006) found that certain population sub-groups were less likely to exercise choice and digest information. However, Cookson and Laudicella (2010), in their analysis of healthcare reform between 2003 and 2008, found no substantial change in socio-economic equity as a result of expanding choice, and their findings may actually point to some slight improvement.

Community Health & Learning Foundation said:

"Health Literacy is strongly linked with health knowledge which is developed through educational intervention and is thus at its lowest among those people with the poorest educational outcomes, who often lack the functional (language, literacy and numeracy) skills needed to manage their own health, make informed choices and decisions and access health services for themselves and their families."

3.31. There are various reasons why people from certain socio-economic groups may find it difficult to exercise choice. The main barriers identified in previous equality analyses were transport difficulties and that people in lower socio-economic groups have lower education levels (King's Fund 2010) making it more difficult to navigate the system. As mentioned above, proposals to involve patients in decisions about their care are designed to allow all patients to benefit from making choices and not just the more articulate higher socio-economic groups. For further analysis see the previously published equality analysis documents.

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4. Summary of impacts

4.1 The table below summarises the potential equality impacts associated with choice of any qualified provider and the actions that can be taken to mitigate risks or promote positive impacts. The impacts and actions outlined below are not exclusive to choice of named consultant-led team, but are associated with the expansion of patient choice more generally.

Potential Risk or Opportunity Identified	Who will this affect?	Actions to mitigate/opportunity to promote
There is an opportunity to deliver more say and involvement in decisions to all healthcare patients and service users	All groups	The Department of Health will publish a choice framework to bring together, for the first time, the choices available to patients all along the care pathway. The Choice Framework will meet the recommendation of the NHS Future Forum to set out clear expectations for the NHS Commissioning Board and commissioners about the choices patients ought to be able to make, and to ensure that patients have clarity over what choices they can reasonably expect to have.
In order for choice of provider to work effectively, the information must be accessible to all patients and service users to enable them to make an informed choice. If information is not accessible to all, those with the best access to information will benefit most from choice policy, potentially exacerbating inequalities.	Older people, disabled people, ethnic minorities, socio-economically deprived groups, those with conditions affecting their mental capacity.	From April 2011, providers have been required to publish information about their services so that people can use this to make informed choices about their healthcare 13. Where possible, information should be available in a variety of formats so that all groups can access it, including those with learning disabilities, those with hearing or sight impairments and non-English speaking people.
Even where information is provided,	All groups	Voluntary and community organisations and Local Healthwatch

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¹³ The Operating Framework for the NHS in England, Department of Health, December 2010

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Potential Risk or Opportunity Identified	Who will this affect?	Actions to mitigate/opportunity to promote
some people may need further support to make choices.		would play a role in supporting patients to make choices. Healthcare providers and commissioners should engage with Local Healthwatch and voluntary sector groups to ensure that the needs of vulnerable and marginalised communities are being met.
Some patients may face barriers to travel and therefore have their choice restricted based on local availability.	Older people, disabled people, those from socio-economically deprived groups.	Commissioners will be responsible for mitigating the potential risk that particular groups receive an unequal quality of service. PCTs currently provide Patient Transport Services.
The policies require clinicians to engage with patients to encourage, and to respond to their greater involvement.	All groups	Education and training could help improve the communications skills of clinicians to ensure that every patient is as actively involved in making decisions about their health and healthcare as they wish to be.
People seeking gender reassignment must first be referred to a psychiatrist	Trans gender	The proposals on choice of named consultant-led team should make it easier for people seeking gender reassignment to be referred to a team that best meets their needs

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