



Transparency in outcomes: a framework for adult social care

Consultation response

NAT (National AIDS Trust)

1. Introduction

1.1 NAT (National AIDS Trust) is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expert advice and practical resources. We campaign for change.

1.2 As this is such a wide ranging consultation we have focused our response on the specific issues which have implications for people living with HIV. The response is structured using the chapter headings from the consultation document, and selected questions from these chapters are answered.

1.3 The premise of the Government's proposals is that as many decisions as possible concerning social care must be made at the local level without central government interference, performance management or bureaucratic burden. NAT considers the Government's position wholly neglects the interests of minorities who are few in number, socially marginalised and stigmatised. Equalities concerns are not properly addressed in the consultation document and key data sources will not capture the particular experiences of groups with quite specific needs, such as people with HIV. The assumption that local engagement will secure necessary provision does not take account of the weak voice of groups few in number, with limited voluntary sector capacity or who may be deterred from involvement by concerns around stigma and privacy. NAT strongly urges the Government to include proactively HIV organisations in the next stages of determining an appropriate outcome framework for social care.

The importance of transparent HIV outcomes in social care

1.4 In line with the Government's emphasis on local decision-making, the Comprehensive Spending Review in October 2010 ended the ring-fencing of most local authority grants, all funds being rolled into the Formula Grant. In the case of the AIDS Support Grant (ASG), however, whilst the ring-fence was lost it was decided that a separate allocation would continue to be made within the Formula Grant to local authorities based on local HIV prevalence. Furthermore this distinct allocation for 'HIV/AIDS Support' to local authorities will increase from £25.5 million in 2010/11 to £36.2 million in 2014/15. The allocation for each individual local authority in England has more recently been published for 2011/12 and 2012/13.

1.5 The decision to maintain and increase a distinct allocation to local authorities for HIV social care reflects the continuing importance placed by central Government on meeting these needs. Given the stigma and discrimination people with HIV still experience, and the fact that in any specific local authority the numbers with HIV will be low compared with the overall population, there is a risk that the significant social

care needs of this group will be ignored without some central encouragement to action.

1.6 Of course without the ring-fence local authorities have freedom to determine their local needs and priorities, but the HIV allocation is a marker of possible need, the need to assess such need and consider carefully how to respond and meet it.

1.7 It is essential over the duration of the next four years covered by the CSR that we are able to assess transparently how funds allocated to HIV social care have led to improved outcomes for people with HIV at the local level. This is an important aspect of accountability for government funds and taxpayers' money. The new Outcomes Framework for social care should take explicit account of the one condition which has a distinct allocation within the Formula Grant. **NAT recommends that as the submissions to this consultation are considered and an Outcomes Framework for social care finalised, that further discussions are held with HIV support organisations to ensure outcomes for HIV social care are effectively and consistently measured and that there is transparency in outcomes arising from the 'HIV/AIDS support' allocation.**

2. Build the evidence base

Question 2: How can we categorise Quality Standards in adult social care, and what should be the topics for the first Quality Standards?

2.1 The consultation document warns against a medical model in developing Quality Standards which focuses on clinical conditions. It points out, for example, that many service users have more than one condition. There is truth in this – it would not be possible or useful to have a different Quality Standard for every condition. In any event, some needs – for example relating to mobility or feeding oneself - may mean a set of standards common to people with range of conditions.

2.2 It will, however, probably be the case in any event that many social care users will have a number of Quality Standards which apply to their care. And there will be some conditions which raise specific issues which have to be distinctly and separately dealt with.

2.3 NAT recommends that there is flexibility in determining categories of Quality Standards for adult social care, on the basis of what is needed to address quality effectively, drive up standards and meet needs. There should be consideration of Quality Standards for those conditions which bring significant condition-specific issues.

2.4 We consider that an HIV-specific Quality Standard should be one of the first to be drawn up, because of the challenges which relate to stigma and discrimination for those with this condition, problems of social isolation and non-disclosure of status, the known high prevalence of mental ill-health and poverty amongst those with HIV, the number of different provider and commissioning bodies who may be involved in aspects of the individual's care, the risk that poor social care will result in treatment failure, increased infectiousness and further HIV transmission, and the need for close integration between social and NHS care for someone with this long-term condition.

2.5 The early development of an HIV social care Quality Standard will provide much needed information as to how effectively local authorities are spending their 'HIV/AIDS Support' allocation and the outcomes being achieved.

Question 3: How can Quality Standards be developed to support service users as commissioners, and local people in their role to hold councils to account?

2.6 It is essential, both in the process of determining which Quality Standards to develop and then their content, that service users are closely and meaningfully involved. This is the best way to ensure the output is useful at the local level both to individuals and community groups when considering their care. It is worth stressing that people with HIV have tended to access and be represented by HIV-specific services. Reliance on generic or even disability patient groups will not reflect the views of people with HIV.

2.7 There needs to be much greater clarity on how Quality Standards, as they develop, will be integrated into existing reporting frameworks in such a way as to provide meaningful information on the quality of services locally. The consultation document is keen to ensure Quality Standards are not 'prescriptive or directive', however as entirely non-mandatory guidelines with no reporting requirements they are unable to provide the information required to enable local people to determine whether the services provided are of a good quality or not, and unable to provide data for commissioners on where services need to be commissioned differently or purchased from a different provider. **Councils should be required to provide regular information, if not reported nationally at least available to local people, on how services meet Quality Standards and where they do not, details of plans and progress towards meeting them.**

3. Demonstrate progress

Question 7: Do you have any further views on how adult social care outcomes should align with other sectors to support integrated working? How might this be put into practice?

3.1 It is also important that councils are made aware of the close link between public health and social care in terms of the role that social care plays in preventing HIV transmission. Research has shown that people living with HIV often experience social care needs around depression and social isolation, and that without adequate social care support are less likely to adhere to their HIV treatment. Most HIV treatment requires at least 95% adherence to ensure it is effective. The increase in the amount of virus in someone's body as a result of failure to adhere to treatment causes them to be more infectious. The impact of this is compounded as research shows that the distress caused by psychological symptoms is also associated with higher risk sexual behaviour, resulting in a higher risk of onward transmission. **It is important for people living with HIV that social care and public health work in an integrated manner within councils, alongside housing, employment and other relevant local services.**

3.2 In particular it is important that there is integrated working with the NHS and Public Health England, and their respective outcomes frameworks. The consultation document does not refer enough to planned outcome measures in these other frameworks, which seem to be more ambitious in terms of capturing the experiences of people with long-term conditions and disabilities, and more concerned to develop

data collection where information gaps currently exist. **Consistency and integration of measures will be very important for people with HIV who are living with a long-term serious medical condition.**

4. Support Transparency

Question 10: What is your view on the balance between requiring standard elements in reports, and allowing freedom to fit to local circumstances?

4.1 NAT does not agree with the consultation document's position that the content of local accounts should be left wholly to local authorities themselves to determine. As the consultation acknowledges, this is a recipe for inconsistency both in content and quality, which will poorly serve many vulnerable people. It is untrue to state that specifying some minimal content will be a 'burden' – it simply explains what is required of a local account in a way which both local authorities and their residents should find helpful.

4.2 In particular, NAT recommends:

- **that the local account does not limit itself to local authority priorities but also reports local performance across all outcome measures, since there may be causes for concern in non-prioritised areas**
- **that local accounts contain a section which outlines how performance against outcome measures and progress against local objectives are meeting the local authority's public sector equality duty.**

Question 12: Would you support an assurance role for the local Health Watch in the production of accounts?

4.3 NAT supports the idea of involvement of Health Watch in the production of the Local Account. It may be simpler and more appropriate to Health Watch's independence for Health Watch to be consulted in the production of the account and for their commentary on the final text to be published alongside the account itself. This will strengthen transparency both for the local authority and for Health Watch itself.

4.4 We do, however, have some concerns about the format and regulation of Health Watch generally which we have expressed in previous consultation responses. HIV is a stigmatised condition. As a result of this people with HIV are often reluctant to disclose their status. This may prevent their participation in involvement schemes such as Health Watch. Given the sample limitations of the Adult Social Care Survey and NHS GP Patient Survey, it is essential that there are consistent contractual requirements for Health Watch to involve an appropriate range of people from marginalised groups, with effective confidentiality protocols.

5. Reward and incentivise

Question 14: What role is there for 'payment by results' or other financial incentives on providers or commissioners at a national level to support the focus on quality and outcomes?

5.1 NAT believes there could usefully be consideration of an incentive similar to CQUINS being developed for social care. We do not think 'payment by

results' to be a suitable incentive process at present. Social care is provided to many isolated and vulnerable people. There is a significant danger of PbR driving down quality for the sake of cost savings with few robust safeguards in place to protect the interests of every individual in receipt of such care.

6. The Outcomes Framework

Annex A: Available outcome measures from 2011/12

Question 18: Are these the most appropriate criteria for assessing measures? Should other areas be considered?

Equalities

6.1 The consultation document states that it is 'desirable' for outcome measures to be broken down by equalities 'to support a focus on inequalities'. This is welcome. It is, however, the only reference to equalities in the document. This is inadequate - a much greater focus on equalities needs to be integrated into the vision for an outcomes framework for adult social care.

6.2 It is not clear in any instance whether the relevant measure can be broken down across all equalities strands or only some. For disabilities there is a further question as to whether people are simply known to have or not to have a disability, or whether there is more detailed information available on the nature of the disability. It is all too possible for a local authority to be performing well in relation to one disability (for example meeting the needs of those with mobility impairment) whilst neglecting another (for example providing opportunity for social contact for those who are isolated as a result of stigma relating to their condition).

6.3 Not only should outcome measures be capable of being broken down by equalities. The relevant data should always be presented both aggregated and disaggregated by equalities to facilitate analysis. All protected characteristics should ordinarily be covered. There should be careful consideration as to how the disability category should be further broken down (on nature of disability e.g HIV infection) to provide meaningful information.

6.4 As recommended above the local account should include consideration of the equalities implications of outcome measures and local authority performance.

Question 19 - Annex A: Throughout the outcomes domains, we would be grateful for your views on the particular measures proposed, in particular

- ***Their fit within the relevant domain and how they effect the balance of the set of measures as a whole;***
- ***How they support joint working with the NHS and other partners;***
- ***What interventions you think contributed towards the improvement in outcomes in this domain, and what evidence there may be locally on their cost-effectiveness***

Reach of surveys to people with HIV

6.5 We welcome increased attempts to learn about the outcomes of social care services from users and the current piloting of the new Adult Social Care Survey.

The current model of the survey involves surveying a sample of the population receiving adult social care funded by the local authority. Whilst we understand the rationale for sampling we have two concerns:

6.6 In many areas sampling of these key measures will not provide robust data on the particular experiences of minorities such as those living with HIV.

6.7 Much of the most effective HIV social care has been implemented at a community level, providing easily accessible, low threshold and confidential community services for anyone in an area with an HIV positive diagnosis. It will be important that local authorities identify ways to include such service users in their Survey samples.

6.8 While we do not claim to have the answers to these issues there are a number of solutions that could be considered:

- A larger sample size for the Adult Social Care Survey – this would enable a greater number of people with less common conditions, including those living with HIV to be captured.
- Ensuring a more representative sample – local authorities have data on the healthcare conditions of social care users, and therefore are able to ensure when selecting the sample, that there is a sufficient number of people living with HIV approached to ensure meaningful data on this group.
- Undertake a separate survey of people with HIV – local authorities could work with local HIV clinics to distribute surveys tailored to capture the social care experiences of people living with HIV.

6.9 There is additionally an issue for people with HIV in relying on the NHS GP Patient Survey. HIV treatment and care is mainly provided through GU services and is open access, not requiring referral from a GP. Whilst people with HIV are now encouraged to discuss their HIV with their GP, a significant minority do not do so. This need not preclude someone with HIV confidentially providing information via the NHS GP Patient Survey but there could be a greater emphasis than at present on the fact that the GP has no access to an individual's response. There are also some people with HIV who are not registered with a GP, either because historically they have been able to access primary care via their HIV clinic, and/or because there have been issues around ease of GP registration because of their migration status. Their experience will not be captured.

Domain 1 – Promoting personalisation and enhancing quality of life for people with care and support needs.

6.10 NAT considers this to be a valuable domain. There are useful measures for the proportion of those with learning disabilities or in contact with secondary mental health services who are in employment. People living with long term fluctuating conditions such as HIV often experience similar barriers to entering and staying in employment due to the limitations of their condition and the additional problem of periodic deteriorations in their health as their condition fluctuates which employers can struggle to accommodate. **There should be a specific outcome measure which relates to employment rates of those people living with long term conditions/disabilities.** In the DH consultation document on a Public Health Outcomes Framework Domain 2, there is a proposed indicator around proportion of people with mental illness and/or a disability in employment, with acknowledgment of further work necessary on the definition of disability and data sources. And in the

NHS Outcomes Framework 2011/12 there is an indicator around the employment of people with long term conditions.

6.11 One important outcome statement for people with HIV is “*people engage socially as much as they wish to do to avoid loneliness and isolation*”. This is very relevant to those who have a stigmatised condition, which can be extremely isolating and affect wider social care needs, including mental health and well-being. Local Authorities must be encouraged to provide support for people living with HIV experiencing stigma and discrimination. **The current outcome measures do not capture well issues of social isolation and more work should be done to identify a measure.**

6.12 Our main concern relates to the outcome measure on the proportion of people with long-term conditions feeling supported to be independent and manage their condition. **For the reasons outlined above we do not consider people with HIV will be effectively reached by the NHS GP Patient Survey in its current form, and information will not in any event be broken down by condition from this survey's results.**

Domain 2 – Preventing deterioration, delaying dependency and supporting recovery

6.13 This again is an important domain. NAT welcomes the emphasis that ‘Early diagnosis and intervention means that people are less dependent on intensive services’. But the outcome measures appear constrained by the data currently available and easily collected. This results in an emphasis on hospitalisation and residential care as outcome markers – in other words, institutionally-related definitions.

6.14 It is important that long term fluctuating conditions are explicitly taken into account within this outcome domain. People living with HIV, when they experience serious and/or rapid deteriorations in their health and medical crisis that do not result in hospitalisation, are excluded from consideration. Preventing deteriorations and crisis of this nature are important elements of ensuring that people living with HIV are able to live stable and normal lives. Helping people to recover quickly when they experience deterioration in health, and to manage their condition and avoid such problems, is an essential element of social care and contributes significantly to helping people cope. **The outcome measures for Domain 2 must therefore also take account of a wider range of deteriorations (such as treatment failure) and non-hospital medical crisis and include measures to meet the social care needs of those with long-term fluctuating conditions. We accept this may mean additional data collection from social care users.**

Domain 3 – Ensuring a positive experience of care and support

6.15 The final outcome statement in this domain states that ‘people, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual’. **It is particularly important that those making decisions and those delivering care have a good understanding of HIV (as an often hidden condition) its impact on the individual and the nature of the social care needs that may be experienced.** This should include an understanding of information on the wider elements that contribute to social care need for people living with HIV, such as experiences of

stigma and discrimination, social isolation and emotional distress. It is also important that the privacy and confidentiality of people living with HIV are respected and there is awareness of the pressure and stress many people experience when dealing with disclosure of their status.

6.16 One outcome measure for Domain 3 is 'the proportion of people using social care and carers who express difficulty in finding information and advice about local services'. The consultation document rightly states that such information is a 'core universal provision'. This does raise the question of whether there is a 'bias' in relying on the Adult Social Care Survey and Carers' Survey – surveys of people who have by definition already had some success in accessing local authority-funded social care. This outcome measure misses those people who are unable, or struggling to, access social care at all - this is likely to be a particular problem for people from hard-to-reach and minority groups. It is important that the ability of people from such groups is measured and captured within this system. **NAT recommends that the outcome measure for information and advice about local services be amended to capture the wider local population, and particularly those from vulnerable groups.**

NAT
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