## Standard 4a

| **Organisation name** (if you are responding as an individual, please leave blank) | British Infection Association | | |
|---|---|---|---|
| **Name of commentator** | Andrew Ustianowski (author) and Anna Goodman (Guidelines secretary and submitting) | | |
| **Role of commentator** | As above | | |
| 7 | 4a | 50 | It is generally viewed as optimal for an in-patient to be under a consultant-led specialist MDT experienced in managing HIV. Such care would be an optimal model, but *when not feasible* an acute medical team supported by HIV expertise would be acceptable if required? This would also aid the aim of 'equitable access to best quality care' mentioned elsewhere in the Standards, and also the 'nursing team with specialist nursing skills' mentioned on page 52 would presumably not be possible via an acute medical team? |
| 8 | 4a | 52 | Not all sites will have 'on-site negative pressure units' - would a robust pathway to such facilities elsewhere be deemed adequate? |

| **Organisation name** (if you are responding as an individual, please leave blank) | | | |
|---|---|---|---|
| **Name of commentator** | Ben Cromarty | | |
| **Role of commentator** | | | |
| 11 | 4a | 51 | Nosocomial…I had to look this up! Is there a way of saying this that might be easier to understand? |

<table>
<tr><td colspan="3">Organisation name (if you are responding as an individual, please leave blank)</td><td></td></tr>
<tr><td colspan="3">Name of commentator</td><td>Hilary Curtis</td></tr>
<tr><td colspan="3">Role of commentator</td><td>BHIVA Clinical Audit Co-ordinator</td></tr>
<tr><td>29</td><td>4a</td><td>52</td><td>“Proportion of all patients admitted to specialist HIV inpatient care within 24 hours of time of request for transfer (target 90%).”<br><br>This is needed for clarity.</td></tr>
<tr><td>30</td><td>4a</td><td>52</td><td>“Proportion of all patients admitted with AIDS-defining opportunistic infection/cancer still alive 30 days and 6 months after diagnosis.”<br><br>Although this is measurable and interesting, I am mildly alarmed at the possibility that commissioners/policy makers might perceive it as an indicator of quality of care. It is likely to be very heavily determined by case-mix in terms of which OIs/cancers people present with, plus co-morbidities and whether previously diagnosed or not.</td></tr>
<tr><td>31</td><td>4a</td><td>52</td><td>“Proportion of all inpatients presenting with an AIDS-defining condition or serious bacterial infection and CD4 count <350 cells/mm3 started on, or maintained on, antiretroviral therapy within 12 weeks (target 95% of those surviving).”<br><br>This is a longer timeline than for individuals with uncomplicated HIV. I understand that there are clinical reasons but this should be acknowledged in the preceding rationale/quality statement. I’d suggest adding “Antiretroviral therapy should be initiated as soon as management of the presenting condition permits and the individual is ready” at the end of the first quality statement headed “Treatment”.</td></tr>
<tr><td>32</td><td>4a</td><td>53</td><td>“Proportion of all patients discharged from an HIV specialist inpatient unit (with an HIVrelated problem) seen in HIV outpatient services within 1 month (target 95%).”<br><br>Is 95% a realistic target? What proportion of patients discharged from specialist IP unit require step-down care in eg a residential nursing facility, and for how long?</td></tr>
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| **Organisation name** (if you are responding as an individual, please leave blank) | | | Scottish Drugs Forum |
|---|---|---|---|
| **Name of commentator** | | | Austin Smith |
| **Role of commentator** | | | Policy and Practice Officer |
| 30 | 4a | 52 | **Measurable and auditable outcomes for in-patient care** should include separate reporting for people who have been infected through injecting drug use and/or are injecting drug users so that issues in this particular group are not missed in overall statistics. |

| **Organisation name** (if you are responding as an individual, please leave blank) | | | Sophia Forum |
|---|---|---|---|
| **Name of commentator** | | | Sophie Strachan |
| **Role of commentator** | | | Co Chair |
| 13 | 4/4a | 50 | A welcomed thorough section /statements |

| **Organisation name** (if you are responding as an individual, please leave blank) | | | Scottish HIV Clinical Leads group |
|---|---|---|---|
| **Name of commentator** | | | Dr Nick Kennedy |
| **Role of commentator** | | | Consultant Physician. Former Clinical Advisor on HIV to Healthcare Improvement Scotland (HIS); former Co-chair of HIV Clinical Leads group |
| 19 | 4a | 51 | Care pathways: *'People who need admission or transfer... or require access to specialist HIV inpatient expertise...should be able to access this within 24 hours of referral'* . Again, an important Quality Statement at a time when many clinicians are |

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| | | | struggling to maintain control of their specialist beds in the face of high volumes of Acute/ General Medical admissions to hospitals |
| 20 | 4a | 52 | Wording issue: Direct co-location with HDU/ITU is surely not necessary – but an HIV inpatient ward should be at a hospital site that also provides HDU/ITU care. |

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| **Organisation name** (if you are responding as an individual, please leave blank) | |
| **Name of commentator** | Laura Waters |
| **Role of commentator** | Consultant Physician |

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| 30 | 4a | | Are there any references related to outcomes for HIV-related admissions by cohort size/expertise etc? If so suggest inclusion to add weight to some of the suggested outcome measures. II think some of the outomces (e.g. “🎬vidence of recording of clinical incidents, complaints and their investigation.”) are ingrained within broader NHS governance procedures so do not need to be covered here |

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| **Organisation name** (if you are responding as an individual, please leave blank) | NAT |
| **Name of commentator** | Yusef Azad |
| **Role of commentator** | Director of Strategy |

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| | | | We appreciate the need for appropriate isolation facilities for people living with HIV with advanced immune deficiency. We have, however, recently been informed of a couple of cases where people with HIV have been placed in isolation when their immune system was not deficient. This is stigmatising and discriminatory treatment and it could possibly be worth stating clearly that isolation should not be routine for every person with HIV in inpatient care. |

## Standard 4b

| **Organisation name** (if you are responding as an individual, please leave blank) | | | British Infection Association |
|---|---|---|---|
| **Name of commentator** | | | Andrew Ustianowski (author) and Anna Goodman (Guidelines secretary and submitting) |
| **Role of commentator** | | | As above |
| 9 | 4b | 57 | Not all malignancies necessarily need specialist oncology services - e.g. localised cutaneous KS etc |

| **Organisation name** (if you are responding as an individual, please leave blank) | |
|---|---|
| **Name of commentator** | Ben Cromarty |
| **Role of commentator** | |

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| 12 | 4b | 52 | If you have co-morbidities, it may not be clear who is 'in charge' of your care. And due to confidentiality protections and bureaucratic issues, information may not always be shared as much as you'd like between the medical teams who are treating you.<br><br>These problems are not unique to HIV. They affect large numbers of people with multiple health conditions in the general population, particularly older people.<br><br>The National Institute for Health and Care Excellence (NICE) has issued guidance on this. NICE says that anyone taking a lot of different medications or who is finding it hard to cope with multiple health problems can ask to have their healthcare reviewed, so that it is better co-ordinated. You could ask any of your doctors to initiate this review.<br><br>The review should take full account of what is most important to you and include a review of all the medications you are taking. You and your doctor should agree a plan for how future healthcare will be provided. This could include naming a clinician who will co-ordinate your care across different healthcare services and deal with any conflicting advice.<br><br>NICE doesn't say who should provide this co-ordinating role, but you could ask your HIV doctor if your clinic can offer any support. There may be a community nurse or clinical nurse specialist who could help co-ordinate your care.<br><br>Nonetheless, your HIV clinic may suggest that it is done by someone with a broader medical background. This could be your GP or someone else working at the GP practice, such as a community matron or senior nurse. Another option could be a doctor or nurse who specialises in the care of older people (geriatric medicine) – they have particular experience of managing the care of people with multiple health conditions.<br><br>(…this is from AIDSmap Factsheet…)<br><br>This document needs to say something along these lines… |

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| **Organisation name** (if you are responding as an individual, please leave blank) | |
| **Name of commentator** | Hilary Curtis |

| Role of commentator | | | BHIVA Clinical Audit Co-ordinator |
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| 33 | 4b | 56-57 | “People with HIV from high and medium risk countries screened for latent TB (>90%).<br>People with HIV diagnosed with active TB managed according to BHIVA guidelines (>95%).”<br>The TB guidelines do not set targets but recommend screening for latent TB “with particular attention to those with newly diagnosed HIV or who have recently been exposed to TB”. I think it would be logistically very difficult to audit everyone so suggest amending first outcome to:<br>“Newly diagnosed individuals who have previously lived in high and medium risk countries screened for latent TB (>90%).”<br>Also suggest omitting % target from the second outcome – the guidelines are complex and address many different clinical scenarios that can arise in active TB, so there isn’t an obvious composite outcome to measure.<br><br>Similarly omit % target from: “People with HIV co-infected with either hepatitis B or hepatitis C managed according to national guidelines (>95%).” It’s trying to measure too many things at once.<br><br>In line with other outcomes where underlying aim is 100%, I’d suggest the target for linking to specialist oncology services should be 97%. |

| Organisation name | | | |
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| Name of commentator | | | Dr Anthony France |
| Role of commentator | | | Retired consultant physician – HIV & Respiratory Medicine<br>I set up the HIV/AIDS service in Dundee in 1989 and ran it until I retired from HIV work in 2012. I do not see HIV patients now. I have no conflict of interest. |
| 4 | 3a | 37 | The document fails to grasp the vital role of Primary Care. Some loosely worded ambitions and a weak standard on annual communication with GPs for patients with stable HIV is all you have to offer. Why are HIV services so reluctant to |

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| | 3b<br>3b<br>4b<br>8c | 41<br>44<br>54<br>106 - 107 | communicate with GPs ? As a bare minimum, each appointment with a doctor in an HIV clinic should be followed by a letter to the GP within two working days. When I ran the HIV service in Dundee every patient had a letter after each appointment. Most letters were sent electronically to the GP's inbox before the patient got home after the clinic. It can be done.<br>You are slowly coming round to sharing information but still allow patients to conceal information from their GP. This is an area where failure to allow sharing should be seen as an adverse event and lead to a critical analysis of "Why not ?" I see no standard about %age of patients who refuse to share info with GPs. This is where you need a look back exercise.<br>Eventually it comes down to the epidemiologists and public health departments to crack this issue. Using CHI or NHS numbers is the obvious way forward. Why no standard ? It would help to avoid duplicate dispensing and other misdemeanours. |

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| **Organisation name** (if you are responding as an individual, please leave blank) | Gilead Sciences UK |
| **Name of commentator** | Chris Robinson |
| **Role of commentator** | HIV Medical Affairs |

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| 2 | 4b | 55 | Suggest state which CV risk calculator be used QRISK3 and that HIV adjustment factor be considered |
| 3 | 4b | 55 | Suggest trusts have access to all eGFR values rather than just >60ml/min to be able to correctly assess renal function |
| 4 | 4b | 55 | Suggest state that the FRAX calculator be used for bone fracture risk assessment |

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| **Organisation name** (if you are responding as an individual, please leave blank) | |
| **Name of commentator** | Roy Trevelion |

| Role of commentator | | | UK-CAB BHIVA Rep, i-Base staff |
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| 6 | 4b | 54 | The summary, “People with HIV should be able to access a comprehensive range of specialist services to manage co-morbidities, co-infections and cancers as required.”<br>Comment: Could be expanded to include this point from the rationale, “Establishment of clear protocols and pathways for care between primary and secondary care are essential for safe delivery of service.” Creating pathways of care is especially important in complex care when coping with serious multi-morbidity in conditions not usually associated with HIV. |

| **Organisation name** (if you are responding as an individual, please leave blank) | | | Scottish Drugs Forum |
|---|---|---|---|
| **Name of commentator** | | | Austin Smith |
| **Role of commentator** | | | Policy and Practice Officer |
| 31 | 4b | 55 | **Measurable and auditable outcomes on co-morbidities** should include separate reporting for people who have been infected through injecting drug use and/or are injecting drug users so that issues in this particular group are not missed in overall statistics. |
| 32 | 4b | 56 | **Measurable and auditable outcomes on co-infections** should include separate reporting for people who have been infected through injecting drug use and/or are injecting drug users so that issues in this particular group are not missed in overall statistics. |
| 33 | 4b | 57 | **Measurable and auditable outcomes on cancers** should include separate reporting for people who have been infected through injecting drug use and/or are injecting drug users so that issues in this particular group are not missed in overall statistics. |

| Organisation name (if you are responding as an individual, please leave blank) | | | Sophia Forum |
|---|---|---|---|
| **Name of commentator** | | | Sophie Strachan |
| **Role of commentator** | | | Co Chair |
| 14 | 4b | 61 | This speaks to people living with HIV rather than  those who may be at risk and should be getting targeted messages as delivered through sexual health services around prevention methods for all, as stated at the start of this document in reaching those who are not HIV positive but at perceived risk or don't know they are at risk |

| Organisation name (if you are responding as an individual, please leave blank) | | | African Health Policy Network |
|---|---|---|---|
| **Name of commentator** | | | Deryck Browne |
| **Role of commentator** | | | Chief Exec |
| 3 | | 54 | Risk factors include immuno-suppression associated with advanced HIV in the case of TB, as well as shared routes of transmission between HIV and hepatitis B and C viruses, and higher prevalence of these infections in parts of the world where HIV is endemic, especially **sub-Saharan Africa**. It is essential, therefore, that people with HIV infection are screened for these co-infections both at initial HIV diagnosis and during follow-up, according to national guidelines. |

| Organisation name (if you are responding as an individual, please leave blank) | Terrence Higgins Trust |
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| **Name of commentator** | Alex Sparrowhawk |
| **Role of commentator** | Membership and Involvement Officer |

| 8 | 4b. | p54 | Second paragraph 'Primary care has an important role…' could be stronger. We think that there needs to be more detail about what primary care involvement could or should look like, how communication between primary care and specialist HIV services can be maximised and how we can most efficiently manage those areas where there is considerable overlap and potential duplication between the work of GPs and HIV clinicians e.g. the monitoring and management of cardiovascular risk factors. An emphasis on the responsibility to engage with primary care should be recorded in the quality statements and measurable and auditable outcomes. |
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| **Organisation name** (if you are responding as an individual, please leave blank) | |
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| **Name of commentator** | Laura Waters |
| **Role of commentator** | Consultant Physician |

| 31 | 4b | 55 | "People with HIV should have access to services to manage co-morbidities safely and effectively either within the HIV service or in collaboration with appropriate non-HIV specialist teams." Considering for that many of the population it is primary care who appropriately manage co-morbidities, or triage the need for specialist referral, who are we to necessarily decide that PLWH should see non-HIV specialists? I think primary care should be included also. |
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| 32 | 4b | 55 | Suggest outcomes covered in the monitoring, TB, hepatitis etc guidelines are not also included here – signpost instead |

| **Organisation name** (if you are responding as an individual, please leave blank) | HIV & Diabetes Support |
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| **Name of commentator** | George Rodgers |
| **Role of commentator** | |

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| | | | I read through the BHIVA Standards online consultation and the issues around living with HIV and diabetes needs to be high lighted more. HIV consultants need to have a better understanding and not just putting it down to life style especially those of us that got it through anti-virals.<br><br>Last November I organised a workshop for HIV Nurses and Diabetic Nurses, I've attached a copy of the Evaluation Feedback from the workshop and a copy of my presentation. I've also attached a copy of What Do Healthcare Professionals Need To Mange HIV. |

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| **Organisation name** (if you are responding as an individual, please leave blank) | NAT |
| **Name of commentator** | Yusef Azad |
| **Role of commentator** | Director of Strategy |

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| | | | In the sub-section on co-morbidities etc, there could usefully be further information and possibly outcomes on communication between the HIV clinic and other specialties. For example, does the HIV clinic keep track at all of the patient's attendance at other specialties and relevant outcomes? |

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| **Organisation name** (if you are responding as an individual, please leave blank) | PHE |
| **Name of commentator** | Valerie Delpech |
| **Role of commentator** | Lead for national surveillance of HIV for the UK |

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| | | | Co-morbidities<br>• *Patients aged >40 years with 10-year cardiovascular disease (CVD) risk calculated within 1 year of first presentation (90%), and within the last 3 years if taking ART (90%). (pg 55)* |

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| | | | Information on CVD risk assessments is not available from HARS or PV; however PV does include data on CV conditions. PV collects data on being diagnosed with diabetes, high cholesterol, high blood pressure, heart attack, stroke, any other CV condition and whether medication is being taken for it (Medical conditions and treatment, C1). |
| | | | Co-infections<br>• *People with HIV from high and medium risk countries screened for latent TB (>90%). (pg 56)*<br><br>HARS collects information on country of birth, which can be used to identify countries of high and medium risk. Since the beginning of 2018, a new measure on screening for latent TB is included in HARS and can be used to assess this outcome. |
| | | | • *People with HIV diagnosed with active TB managed according to BHIVA guidelines (>95%). (pg 56)*<br><br>HARS collects information on AIDS defining illnesses including TB, which could be used to estimate the number of people co-infected with HIV and TB. Information on TB treatment is also collected and could be used to approximate the proportion of people with TB and HIV who are receiving TB treatment. |
| | | | • *Hepatitis A, B and C screening on diagnosis or first clinic appointment (>95%) (pg 56)*<br><br>HARS collects some information for hepatitis B and C, which can be used to determine the proportion of HIV diagnosed individuals diagnosed with the two diseases at the first appointment (HARS does not collect information on screening). |
| | | | Cancers<br>• *Proportion of people with HIV and malignancy linked to specialist oncology services (96%) (pg 57)*<br>Information on this outcome is not available from HARS; however PV does include data on cancer diagnoses (Medical conditions and treatment, C3). |

## Standard 4c

| **Organisation name** (if you are responding as an individual, please leave blank) | | | |
|---|---|---|---|
| **Name of commentator** | Hilary Curtis | | |
| **Role of commentator** | BHIVA Clinical Audit Co-ordinator | | |
| 34 | 4c | 4 in separate doc | Suggest “agreed pathways” rather than “formal network arrangements”. The latter have proved difficult to maintain and can be problematic especially since HIV services may overlap different commissioners.<br>Suggest “screened for alcohol and drug use in past 15 months (target 95%)” – should ask about both, and 15 months is a standard audit outcome for things that are supposed to be done “annually”, so as to allow for minor variations in appointment dates, holiday periods etc.<br><br>Should it say “Evidence of referral pathways to drug and alcohol support services, including chemsex support”? This seems quite important since one of the issues is that many drugs services don’t really deal with chemsex. |

| **Organisation name** (if you are responding as an individual, please leave blank) | | | |
|---|---|---|---|
| **Name of commentator** | Sum Yee Chan | | |
| **Role of commentator** | I am a consultant in GUM and HIV in CNWL Surrey. Outside of this work I am also doing a PGCE in special education and music and am currently placed in a special needs school for blind and visually impaired children | | |
| | | | For the section about supporting people with higher levels of needs (general comments) |

| | | | Could you please consider adding sections for people with disabilities e.g. deaf people, blind or visually impaired people, people with learning disabilities, dyslexia and those with physical disabilities? As information about HIV and their medications etc. needs to be communicated to people with disabilities also. Also in terms of being able to examine patients who cannot climb onto couches, hoists and other equipment are important, otherwise people cannot be examined properly. Thank you. |
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| **Organisation name** (if you are responding as an individual, please leave blank) | | | |
|---|---|---|---|
| **Name of commentator** | | | Shaun watson |
| **Role of commentator** | | | Clinical Nurse Specialist (HIV Community) |
| | | 33 | General comment – I'd like some clarification about who is the care coordinator as this role is traditionally the remit of a specialist nurse (community or clinic) and rarely a clinician, I'd like this to be made explicit. |
| | 4c | | Same comment, this role is highlighted and as such needs clarification |

| **Organisation name** (if you are responding as an individual, please leave blank) | | | Scottish Drugs Forum |
|---|---|---|---|
| **Name of commentator** | | | Austin Smith |
| **Role of commentator** | | | Policy and Practice Officer |
| 34 | 4c | | **Care Planning and Management**<br>The group involved in the ongoing Glasgow outbreak is a group of people involved in or around public injecting of heroin and cocaine and a street scene with high levels of homelessness and insecure housing. Many have been failed by NHS and care services which are meant to ensure care planning and management repeatedly. Currently the majority are not involved in effective HIV treatment. Care and treatment planning and management are key recommendations mentioned |

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| | | | in these guidelines. While planning and management are key to successful engagement and treatment simply mentioning these is inadequate to ensure they are delivered.<br><br>The effectiveness of the HIV treatment system should be measured by the effectiveness of its testing and treatment regime for its most marginalised at risk group. In this way, we can ensure the no group is being left behind and that there is no residual threat to public health.<br><br>HIV testing and treatment systems should be audited with reference to the most marginalised group. The planning of services and service development should be based on services being accessible to the most marginalised group. Each component of patient engagement should be accessible and acceptable to this group.<br><br>Treatment planning and management for people who inject drugs will have to take account of the likelihood that they will have unplanned exits from drug treatment and that they have an elevated risk of imprisonment and hospitalisation. |
| 35 | 4c | | Measurable outcomes for supporting people with higher levels of need should include separate reporting for people who have been infected through injecting drug use and/or are injecting drug users so that issues in this particular group are not missed in overall statistics. |

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| **Organisation name** (if you are responding as an individual, please leave blank) | Sophia Forum |
| **Name of commentator** | Sophie Strachan |
| **Role of commentator** | Co Chair |

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| 7 | 4c | | Please refer to Inside Gender identity report- needs of transgender people in criminal justice system, - a rich report that feeds into what Is missing in this SOC document |

| **Organisation name** (if you are responding as an individual, please leave blank) | | | Positive East |
|---|---|---|---|
| **Name of commentator** | | | Mark Santos & Steve Worrall |
| **Role of commentator** | | | Director & Deputy Director |
| 19 | 4c | 3 | Add a measurable about referral to Voluntary Sector |

| **Organisation name** (if you are responding as an individual, please leave blank) | | | |
|---|---|---|---|
| **Name of commentator** | | | Eileen Nixon |
| **Role of commentator** | | | Consultant Nurse / Research Fellow |
| | 4c | p4 | Should the auditable outcomes include evidence if individualised care plan for people with increased needs? |