



Notes from the Roundtable Discussion on the Late Diagnosis of HIV 10th November 2008

Present: Hong Tan, David Borrow MP, Michael Bell, Deborah Jack, Titise Kode, Baroness Sue Masham, Neil Gerrard MP, Christine Owen, Dr Simon Tanner, Dr Cathy Read, Eamonn Kelly, Dr Robert Sherriff, Steven Nicholson, Paul Ward, Kevin Smith, Professor George Kinghorn, Dr Mayur Chauhan, Veronica Oakeshott, Tim Chadborn

Apologies: Derek Boddell, Evan Harris MP, Dr Chris Kenny, Ruth Carnall

Introduction:

Presentation on NHS London's adoption of a target on the late diagnosis of HIV

In 2007-08 NHS London set itself the target of halving the incidence of late diagnosis of HIV - defined as people with HIV having a CD4 count of less than 200 - by 2010/11. Achieving the target would take rates of late diagnosis down from thirty percent to fifteen percent. Late diagnosis was chosen as a measurable proxy for rates of undiagnosed HIV (nationally around 30%) and early diagnosis is a means of prolonging individual's life-expectancy as well as reducing the onwards transmission of HIV. London's Sexual Health Programme Director, Hong Tan, gave a presentation which showed that the adoption of the indicator had already driven new innovative approaches to increasing access to HIV testing and focussed minds on the improved integration of HIV with other sexual health services. The presentation was able to show some very early results, with rates of late diagnosis going down in some PCTS although Hong Tan warned it was too early to draw definite conclusions. A copy of this presentation in full is provided with these notes.

Key Messages from roundtable discussion:

Main points are in red for easy reference

1. HIV is not just a London issue

Although Hong Tan's presentation concerned London, the meeting strongly reflected the fact that HIV is not just a London issue. George Kinghorn and Kevin Smith noted that **rates of infections and of expenditure on HIV were growing faster in some regional PCTs than in London**. Kevin reported 500 new cases a year in his area alone (Yorks and Humber), which has a population of 5 million.

Hong Tan also noted that there was considerable disparity within London in terms of HIV prevalence and that many outer London areas had similar rates to other regions.

Whilst big cities (and not only London) may have the highest prevalence of HIV, David Borrow commented on the mobility of people and the way in which HIV rates in cities are likely to affect rural areas nearby. Given that all SHAs have disparities in HIV rates within their regions, their leadership is needed to encourage rural PCTs that HIV is an important issue for them too.

2. SHAs have a key role to play in driving progress

There was a consensus that **PCTs could not, and often would not be inclined to, improve rates of late diagnosis without SHA help and encouragement**.

Simon Tanner noted that SHAs were primarily concerned with policy whilst PCTs were primarily concerned with delivery and combining the two strengths was important. He felt that **having the Chief Executive of a PCT chair the Sexual Health Group at SHA level, helped drive the late diagnosis agenda forward** by ensuring that practical delivery issues were taken into account in developing policy and that at least one PCT could lead by example.

Michael Bell noted that **SHA level 'benchmarking'/ data collection of late diagnosis was a good driver of performance**. Late diagnosis in some London PCTs was far worse than others and sometimes those

performing relatively badly can be embarrassed into action. One East London PCT was singled out for having a late diagnosis rate of 42% and a 200% increase in HIV rates since 2002.

Kevin Smith felt that **specialised SHA level commissioning of HIV services** was very important, given the level of understanding needed to do it well, although not all SHAs do this. He feared that trends towards devolution of responsibility would threaten specialised commissioning.

Simon Tanner noted that **consultation on priorities for SHA level targets (in which HIV came out high)** also helped develop PCT level ownership of the target. However it was agreed that some PCTs were unlikely to lobby for targets on HIV. There was consensus that GUM targets had transformed GUM services and that this change had in fact come from above rather than being a grass-roots PCT development. This suggests that leadership is needed in addition to consensus. Whilst it is unlikely that the Government would bring in national targets on HIV, SHAs can play that leadership role.

3. It's a two way process – PCTs need to put in the money and staff training is key

Mayur Chauhan noted that whilst SHA leadership was important, many of the constraints were at a PCT level, such as funding, time and training for staff.

Developing Mayur's point, both Robert Sheriff and Christine Owen noted that **staff needed training** around improving take up of testing. Opt-out testing would not necessarily be effective if the offer was worded wrongly and patients need to be reassured about the implications of the test. Christine Owen reported on poor rates of testing despite an opt-out policy in ante-natal care in one of her hospitals because of this. Tim Chadborn noted that 30% of GUM clinic attendees were still leaving the clinic without having had a test. George Kinghorn said a change of culture amongst doctors is needed so that HIV testing becomes normalised and the rule rather than the exception. BHIVA has done some recent work on this.¹

4. Key levers for action on late diagnosis:

- **Inequalities performance targets.** Michael Bell made the point that late diagnosis goes to the heart of this agenda, as it predominantly affects BME groups and MSM
- **Life expectancy performance targets.** Late diagnosis has a strong impact on life-expectancy.
- **World Class Commissioning** and the new focus on prevention. Eamonn Kelly noted that from a commissioner's perspective the case for tackling late diagnosis was 'totally compelling'. Hong Tan also noted that as we migrate to Payment By Results prevention will be better rewarded. THT has done some economic modelling on the cost/benefit of increased testing and is happy to share the information with attendees to the meeting.
- **Cost considerations.** The estimated cost of a person with HIV to the NHS in drugs alone is £0.5million. Christine Owen noted that in addition to this there are not only costs of care and support but also of co-morbidities. Prevention costs are tiny in comparison.
- **Vital Signs.** Simon Tanner noted that tier three vital signs targets are an important driver in London.
- **The moral argument.** There are very few other diseases where anyone would consider *not* identifying someone's illness because of the cost of treatment. To do so with HIV is unacceptable.

Non clinical issues

Community involvement is key – **PCTs can't deliver through traditional health service mechanisms alone** as key groups are often missed out. Paul Ward noted that the community based services THT was piloting in high-risk communities were getting rates of around 4% positivity. The people accessing these services were not typically accessing other sexual health services.

¹ The new Guide 'HIV for non-HIV specialists: Diagnosing the undiagnosed' recently published by MEDFASH is an excellent resource to increase general understanding of HIV amongst medical professionals.

Paul Ward also said that a change in 'testing culture' was needed. Titise Kode also mentioned the role of stigma in preventing African communities from accessing sexual health services.

Neil Gerrard noted the potential of Local Authority level scrutiny committees and developing the interest of individual councillors in the issue, who can take a leadership role in the Council and put external pressure on PCTs to drive up performance. George Kinghorn noted that this system was working well in Sheffield.

It was noted by Neil Gerrard, Deborah Jack and Christine Owen that immigration policy has an impact on our ability to reduce late diagnosis. Neil noted that failed asylum seekers are not included in National Asylum Support Service and are therefore essentially under the radar when they move into new areas. Both Deborah Jack and Christine Owen noted that limits on eligibility for treatment are preventing people from coming forward for treatment.