

## EAGA93 Public Minutes

### MINUTES OF THE 93rd MEETING OF THE EXPERT ADVISORY GROUP ON AIDS 27 February 2013

**Chair:** Professor Brian Gazzard

**Secretariat:** Dr Linda Lazarus (HPA)

**Members:**

Dr Chris Conlon  
Mr David Crundwell  
Dr Matthew Donati  
Ms Ceri Evans  
Dr John Green (am only)  
Ms Deborah Jack  
Prof Anne Johnson (pm only)  
Ms Ruth Lowbury  
Dr Helen McIlveen  
Ms Beatrice Osoro  
Dr Keith Radcliffe  
Miss Susan Sellers  
Mr Paul Ward

**Observers:**

Jane Allberry (DH)  
Mrs Moji Ajeneye (MHRA) (until 2pm)  
Dr Su Brailsford (NHS BT/HPA)  
Dr Valerie Delpuch (HPA)  
Dr Naresh Chada (DHSSPS Northern Ireland)  
Professor Noel Gill (HPA)  
Lt Col Peter Hennessy (MoD)  
Mrs Julie Nugent (DH)  
Ms Kay Orton (DH)  
Dr Andrew Riley (WAG)  
Dr Nicola Steedman (Scottish Government)

**Apologies:**

Prof Jackie Cassell

Prof Deenan Pillay

Dr Anton Pozniak  
Dr Ewen Stewart

Dr Alison Brown (HPA)

**Invited for item 1:**

Prof Jane Anderson (BHIVA)  
Dr Simon Barton (HIV CRG)  
Dr Christine Bowman (South Yorkshire HIV Network)  
Ms Anita Corrigan (Cheshire & Merseyside Cancer Network)  
Ms Claire Foreman (LSCG)  
Mr Neil Jenkinson (Greater Manchester Sexual Health Network)  
Dr Frances Keane (Royal Cornwall Hospital)  
Dr Rashmi Shukla (DH) (until 12.30)  
Dr Ian Williams (UCL)

**Agenda item 1**

*Agenda item 1.1*

**Special session “The future of HIV care”**

*Introductions, Chatham House rule and purpose/aims of the session*

*Paper EAGA(93)1*

1. The Chair welcomed everyone and explained that the morning part of the meeting was a new departure for EAGA. EAGA’s remit is to provide scientific advice on matters relating to HIV, with an emphasis on the public health perspective, based on available evidence. On this occasion, however, the boundaries of EAGA’s remit had been extended to look at the broader issue of how to provide patient-centred care most efficiently, while maintaining the established high standards, and also to preserve training and education for future generations of HIV specialists.
2. The question the meeting was asked to consider was: “What is the optimum size for HIV treatment centres providing specialist inpatient services for patients with complex needs?” The success of antiretroviral therapy meant the number of very sick HIV patients had significantly diminished and previously common conditions (e.g. cryptococcal meningitis) now presented rarely. The reduction in caseload, and thus exposure to complications of advanced HIV disease, posed difficulties for junior staff seeking to acquire professional

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competencies to treat complex cases. The aim of the meeting was to reach a consensus on the best way to deliver HIV inpatient care now and for the future.

3. A number of relevant documents had been circulated for background in advance of the meeting, in the expectation that participants would have familiarised themselves with the content. It was not proposed to discuss these in detail, but they would be referred to as appropriate.
4. For the benefit of the invited participants, it was explained that the process of selection of members to EAGA was by open competition. Individuals were interviewed and selected for their personal expertise rather than as representatives of professional bodies or their employing organisations. EAGA's composition as a multi-disciplinary group, with members drawn from a broad range of clinical specialties together with scientific, HIV voluntary sector and lay members, gave it the legitimacy to reach an objective view based on input from invited experts.
5. The Chair encouraged all participants to speak candidly in the interests of patients and the health service and reassured them that any points raised would not be attributed in the published minutes.

### *Agenda item 1.2 Centre size and HIV patient outcomes – the evidence base*

6. A series of presentations was followed by a wide-ranging discussion. The Health Protection Agency had some data on patient outcomes according to clinic size, but this was based on outpatient attendance. There were few data in the scientific literature to guide decision makers. Evidence from a 2010 audit by Schwenk *et al.* of HIV inpatients in London, South East and East of England was referenced. This study found a 5-fold higher mortality in the district general hospital setting (5%) versus HIV specialist centres (1%).

### *Agenda item 1.3 Cancer services modernisation – lessons for HIV specialist care*

7. There were many potential lessons to be learned from the reconfiguration of cancer services. Some of the key points included:
  - Critical role played by the clinical network – engaging with clinicians and service users
  - National cancer plan as a driver
  - Mandatory Improving Outcomes Guidance (evidence-based where possible, otherwise experience-based)
  - Principle – the more you do, the better you get at what you are doing (plus efficiencies of scale)
  - Peer review integral to strategy – results published on web to empower patients
  - Patient pathway co-ordinated by clinical nurse specialist
  - Expect a lengthy process with service configurations evolving over time, responding to technological advances both in diagnostics/treatments as well as in IT that change delivery models
  - Transition arrangements can be beneficial for allaying concerns about destabilising local teams and recruitment
8. The meeting discussed both the successes of the cancer services experience and what could have been done better. It also considered several differences between cancer treatment and HIV care. For example:

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- engagement of service users in service redesign (perceived as easier for cancer care than HIV care due to stigma associated with the latter);
  - whether differences in treatment duration could impact on attitudes to travelling distance – in the case of cancer care, patients put best outcomes before distance to travel in choosing where to receive care.
  - HIV patients develop long-term relationships with services and may be resistant to change, necessitating a formal change management approach;
  - 60-70% of inpatient admissions for HIV care come via Accident & Emergency - this suggests location of HIV specialist inpatient care should match areas of higher prevalence of undiagnosed infection and late HIV diagnosis as these drive both mortality and admissions.
9. Lessons learned from the National Review of GUM Services, a series of peer review visits to 85% of English GUM services conducted by MedFASH in partnership with BASHH in 2004-7 were discussed. Key points: resource-intensive exercise; close working with Strategic Health Authority (SHA) sexual health leads was a key part of the methodology; multidisciplinary review team; focus on patient pathway and all aspects of the service; national policy priority an important driver - introduction of a 48-hour access target and its inclusion in top six priorities of NHS operating plan made a big difference to high-level engagement (i.e. by Trust Chief Executives); services, PCT commissioners and SHAs valued the review team's feedback. The main differences from the cancer peer review process were that patient involvement was limited, there were no STI service standards at the time and the review reports were not made public.

### *Agenda item 1.4 Experience from Cornwall on caring for HIV patients with complex needs*

10. Different considerations applied for complex HIV care in areas where specialist services are geographically dispersed, such as in Cornwall. These included:
- Poor access to psychological support;
  - Lack of good volunteer counsellors (peer support services limited to urban centres);
  - If HIV specialists are concentrated in a smaller number of centres, danger that HIV will become 'invisible' (loss of local champions), leading to more late diagnosis;
  - Not all category 2 patients need specialist care e.g. pregnancy;
  - Informal networks of care have developed but these need to be formalised and commissioned/funded;
  - Use of technology to bring care closer to home e.g. near-patient tests for CD4 count;
  - Patient-held records might offer a solution to confidentiality concerns;
  - Choice of provider is not a reality in rural areas.

### *Agenda item 1.5 Implications of the "BHIVA Standards of Care for People Living with HIV 2013" for service redesign*

11. The BHIVA standards were produced to benchmark the quality of HIV care and ensure the existing excellent treatment outcomes in the UK were sustained through the major structural reforms to the health economy. The standards were endorsed by a wide group of stakeholders as minimum standards of care, although some currently remained aspirational. Many aspects of the standards were dependent on critical mass to operate safely and efficiently, from professional training to information provision.

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12. The ambulatory HIV care service is the linchpin, integrating the care pathway and holding together primary care, peer support & social care and inpatient care. Unlike in other areas of healthcare, GPs cannot currently fulfil this role. Primary care is the appropriate setting for delivery of non-HIV care (e.g. flu vaccination, cervical screening) to HIV patients but currently lack the caseload, and hence confidence, to undertake routine HIV monitoring and prescribing.
13. From the commissioners' perspective, planning services in partnership was the way forward. This had been emphasised in the recent [FAQ document on sexual health commissioning](#) in relation to HIV testing services, which recommended a collaborative approach between local authorities, Clinical Commissioning Groups and the NHS Commissioning Board to agree the most appropriate testing strategy for a local area.
14. Good quality data will be of paramount importance to commissioners and expectations for it to be published will be high, resulting in increased scrutiny. The commissioning agenda was dominated by clinical outcomes, but there was a lack of information on inpatient outcomes. Interpretation of episodes of inpatient HIV care requires linkage to other important biomarkers (e.g. CD4 count/viral load collected through SOPHID). Linkage via the NHS number is not currently possible as it is not collected in SOPHID. Outpatient outcomes data were being collected in Scotland but no inpatient data at present. It would be challenging to collect objective data on patient needs. BHIVA had secured a grant from the MAC AIDS Fund to develop Patient Reported Outcome Measures (PROMs).
15. MEDFASH has been working with BASHH and BHIVA to develop a new topic proposal for a national audit programme on STIs and HIV, to be procured by the Healthcare Quality Improvement Partnership (HQIP). It will include long-term management of HIV and will use existing data sources as far as possible (i.e. HARS). Assuming procurement goes ahead and the audit programme is established (as part of the National Clinical Audit and Patient Outcomes Programme [NCAPOP]), audit data are likely to be published at service level. This is relevant for discussion of the relative performance of HIV treatment centres.
16. MEDFASH produced recommended standards for HIV services 10 years ago. As now, there were differing views about how prescriptive they should be (for example, who is allowed to manage what, what are minimum service requirements). A non-prescriptive approach was taken, setting out the standards of care that should be achieved. A number of current challenges may threaten the quality of care and lead to local variation - funding cuts, fragmented commissioning - and the same question arises. Prescriptive or not (e.g. regarding the minimum caseload for inpatient care), it will be important to ensure decisions are made based on evidence where it exists, consensus of expert opinion and the patient voice.
17. A point was made about future-proofing. The cancer model had demonstrated that service reconfiguration is a dynamic process, taking many years, and responsive to changing needs.
18. The problems of an ageing population are generic, cutting across many specialties, and need addressing at the national level. Rather than HIV specialists becoming experts in care of the elderly, they should provide appropriate training to the gerontologists. There was some optimism that the average cost of HIV treatment will decline (owing to generic prescribing), therefore allowing more patients to be treated within existing resources.

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19. The Chair thanked everyone for their contributions to the morning's discussion. He summed up the session with the following observations/advice, for the NHS Commissioning Board and others, on how HIV treatment services might be commissioned and provided in the future to optimise outcomes for patients and, potentially, offer QUIPP savings for the NHS:
- 1) Clinical networks are essential. The NHS Commissioning Board needs to fund both the network infrastructure (e.g. co-ordinators) and the specialist input.
  - 2) Rural areas may require special networking arrangements and adjusted critical mass numbers (see 4 below).
  - 3) Inpatient care will need to be focussed in fewer specialist centres to sustain medical education and provide the best patient care for the relatively small numbers of patients.
  - 4) The London HIV Clinical Working Group's draft proposals for HIV inpatient services – addressing the definition of what constitutes specialist HIV inpatient care and the associated services and expertise – were endorsed as a good basis for making a preliminary decision on critical mass. It was recognised that the critical mass numbers were, to some extent arbitrary, and in areas where case numbers were low, might need some adjustment (e.g. from number of admissions to population served) to enable the largest unit in the area to continue providing inpatient services.
  - 5) A Trust that is commissioned as a provider of specialist HIV inpatient care has to recognise that it is providing a national service and have sufficient designated HIV inpatient beds.
  - 6) Good referral pathways are key for outpatient services, especially linkage to care.
  - 7) A future area of specialism that needs to be commissioned is specialised care for poorly adherent patients.

### **Agenda item 2            Minutes of the last meeting (17 October 2012)**

20. Before proceeding with the afternoon's business, the Chair expressed his satisfaction with the morning's proceedings and felt that it had been worthwhile and informative. The published minutes would serve as the formal outcome. For the benefit of newly appointed members attending their first meeting, he reminded everyone that EAGA is not a forum for advocacy or lobbying.
21. The minutes were agreed as an accurate record without amendment.

### **Agenda item 3            Matters arising**

*Agenda item 3.1*

*Report from the Secretariat*

*Paper EAGA(93)2*

22. Membership matters: Mr David Crundwell was elected as EAGA's new Vice Chair via a vote by the members, with effect from November 2012. Three of the four newly appointed members of EAGA had been able to attend at least part of the meeting: Deborah Jack and Paul Ward had been appointed as HIV voluntary sector members; Professor Anne Johnson was appointed as an academic epidemiologist and Professor Jackie Cassell (who sent apologies) as a public health specialist. The vacancy for an occupational physician was not filled and a vacancy would arise shortly for a perinatal HIV specialist as Miss Sellers had indicated her intention to resign from EAGA in the summer.
23. The principle had been established with the Department of Health that EAGA could co-opt members to the committee as an interim measure, to ensure access to appropriate expertise, until such time as another formal recruitment exercise was run. Accordingly, the Chair had

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invited Professor Andrew Phillips to become a co-opted member of EAGA, in order that the committee could benefit from the insights that mathematical modelling could bring to many of the issues addressed by EAGA.

### *Agenda item 3.2 CMO Seminar on HIV: feedback*

24. In December 2012, Dame Sally Davies had convened a meeting of HIV experts, including a number of EAGA members and observers, to share views on research in the HIV field. It had also provided an opportunity to brief the CMO on the fragmentation of HIV service commissioning. An action arising from the meeting was that CMO would highlight commissioning of HIV testing (as one of a range of public health topics) in a communication to Local Authorities after 1 April 2013.

### **Agenda item 4 HIV partner notification: review of the evidence base**

25. Starting from the definition of partner notification (PN) and the different methods and measurements of effectiveness, an overview of the published outcomes of conducting PN for HIV was presented. UK studies consistently found a contact ratio of around 0.5 partners/index case and one new positive case for every 10 index cases. Some of the key factors associated with effective PN were: provider referral versus patient referral (50% of partners notified versus 7%); current partners versus past partners (72% tested versus 32%); and early initiation of PN (within 2 weeks of new diagnosis) versus later (12.7% versus 4.8%). One possible drawback to provider referral is the index case wanting to know the outcome, but this has to remain confidential.
26. Logically, recent partners were both more likely to be tested and to be positive. The benefits of earlier diagnosis for notified partners were three-fold: increased life expectancy/decreased morbidity; reduction in onward transmission; and reduction in unsafe sexual behaviour (among all those notified, whether or not they tested positive). The potential harms of PN include relationship breakdown and intimate partner violence. There were also implications for criminalisation.
27. One of the dilemmas for HIV PN is knowing how far to 'look back' when contacting partners. This would be guided by timing of a previous negative test, sexual history, RITA result and history of seroconversion illness. Consideration may need to be given to repeating PN during a person's care, unless they abstain from sex, only have protected sex or have stably undetectable viral load. The ongoing need for PN can only be established by regular sexual health assessment (recommended at 6-monthly intervals in BHIVA monitoring guidelines).
28. The recently published [BHIVA Standards of Care for People Living with HIV](#) do not recommend a specific number of partners be contacted per index case (evidence base lacking). By comparison, the recommended standard for chlamydia is 0.6 partners notified/index case (patient-reported) and 0.4 partners notified/index case (healthcare worker-verified) within 4 weeks. To reduce the fraction of undiagnosed HIV cases, it makes sense to focus on where the most positive cases will be found, i.e. among partners of the newly diagnosed. Optimising PN performance for male partners of HIV-positive pregnant women was an obvious target.
29. PN has the potential to be highly cost-effective and should be promoted. Partner testing in the community is a public health imperative that needs to be well resourced. PN is known

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to be less effective among MSM because of higher numbers of anonymous partners, but methods need to adapt to new the technologies used for finding partners (e.g. internet dating). The new HARS dataset will enable collection of information on the number of contacts in the past year, the number contactable and the number who tested for HIV.

### Agenda item 5      DH policy update

30. [HIV testing kits and services regulations 1992](#): A draft document supporting the repeal of these regulations had been prepared for consultation. It detailed the existing or planned safeguards that would be put in place to ensure there were no undesirable consequences of the change to legislation. The MHRA had provided input on the regulatory framework for self-testing kits. An impact assessment would need to be published alongside. There were no cost implications to the public purse; indeed, lifting the current ban could create commercial opportunities.
31. [Sexual health policy document](#): Anna Soubry, the Minister for Public Health, in responding to a parliamentary question in the House of Commons on 26 February 2013, stated that she anticipated publication of the sexual health policy document in March. The document was being finalised after incorporating feedback from EAGA, the Sexual Health Forum and the Minister. It was currently under embargo and could not be shared.<sup>1</sup>
32. [NHS \(Venereal Diseases\) Regulations 1974 and the NHS Trusts and PCTs \(Sexually Transmitted Diseases\) Directions 2000](#): Once the Health and Social Care Act 2012 comes into force, these Regulations will fall (i.e. cease to apply). DH had convened a meeting with key stakeholders in February 2013. There was an opportunity to strengthen the current safeguards through a statutory code of practice around confidentiality and patient information and for it to apply to new commissioning bodies (NCB, LAs etc). This would permit, with patients' consent, to the sharing of information with other care providers. This point had been argued by BHIVA as being necessary for the long-term safety of HIV patients.
33. It was noted that the Regulations have been useful for making Trusts aware of the importance of confidentiality in the context of STIs. However, implementation has been variable and the Regulations only apply to GUM clinics and not to other providers of sexual health services, such as community services or primary care. The Regulations also do not apply in Scotland, but this had not impacted on the ability to maintain confidentiality in Scotland.
34. The voluntary sector could have a role in encouraging patients to permit the sharing of their information (acknowledging the differences between one-off attendance for STI treatment, the confidentiality concerns of under-16s versus lifelong HIV care). However, there was a balance to be struck between raising anxiety (where none previously existed due to being unaware of the provisions under the Regulations) and raising awareness. NAT and BHIVA were currently collaborating on work around confidentiality.
35. One of the consequences of the imminent legislative changes was the need to ensure a legal basis for sexual health information to continue to flow to Public Health England. A new statutory Code of Practice on sharing patient identifiable information was due to follow publication of the latest Caldicott review of information governance, together with new

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<sup>1</sup> [A Framework for Sexual Health Improvement in England](#) was published on 15 March 2013.

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guidance. The latter presented an opportunity to address the confidentiality requirements for sexual health services.

### **Agenda item 6      Review of 2012/13 workplan, topics for 2013/14 workplan and proposed agenda for June meeting of EAGA and Felicity Harvey's attendance** **Paper EAGA(93)3**

36. Discussion about the future workplan started with consideration of possible agenda items for the next EAGA meeting when Felicity Harvey, Director General for Public Health at the Department of Health, would be attending. The following items were suggested:
- Review of the discussion around service reconfiguration for specialist HIV inpatient care
  - EAGA's remit
  - Medical indications for HIV testing/expansion of HIV testing/HIV in Europe
  - State of the market for point-of care HIV tests that might be suitable for home testing – update on performance characteristics
  - Update on the HARS dataset – strategic issue of retaining clinical care quality monitoring in PHE because of important synergies with surveillance/barriers to maintaining good surveillance
37. Possible 2013-14 workplan topics included:
- HIV testing intervals – how often should MSM be tested? What can modelling tell us?
  - Window period –clarify what the window period should be under different circumstances e.g. point-of-care tests, routine sexual health screen, PEP, according to the latest evidence
  - Current public health issues relating to HIV
  - 'Greying' of the HIV epidemic – how quickly will this occur?
  - Costs implications of starting treatment immediately on diagnosis (i.e. following the recommendations in the latest [US HIV treatment guidelines](#))
  - Syndemic<sup>2</sup> of HIV and other STIs

### **Agenda item 7      Any other business**

38. One way to increase HIV testing in medical services was to make HIV testing more visible on electronic test ordering systems. Using technology to prompt clinicians to consider an HIV test when they order other tests for indicator conditions or for illnesses that present with clinical features similar to HIV infection, e.g. infectious mononucleosis, lymphopenia, could increase appropriate targeted test offer and uptake. This would only be effective if consent arrangements were no different than for any other blood test.
39. HIV testing is already routine in antenatal clinics and *in vitro* fertilisation assessment, for example. Electronic HIV testing would be an interesting topic for EAGA to explore and would tie in well with the HIV in Europe initiative, from which some data on positivity rates in different indicator conditions were now available.

### **Agenda item 8      Date of the next meeting**

40. The next meeting will be held on **19 June 2013**. Timings to be advised nearer the date.

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<sup>2</sup>The aggregation of two or more diseases in a population in which there is some level of positive biological interaction that exacerbates the negative health effects of any or all of the diseases.