



**North West  
Perinatal and Paediatric HIV  
Network Workshop**

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**Thursday 17 September 2009**

*Haydock Park Racecourse, Haydock*

*Sponsored by:  
Bristol Myers Squibb*

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## **1. INTRODUCTION**

The fifth North West Perinatal and Paediatric HIV Network Workshop was held at Haydock Park Racecourse in Haydock on Thursday 17<sup>th</sup> September 2009. The event was generously sponsored by Bristol Myers Squibb, and facilitated by the *North West Perinatal and Paediatric HIV Network*. (For network contact details please refer to Appendix A).

Dr Andrew Riordan, Consultant in Paediatric Infectious Diseases and Immunology from Alder Hey Children's Foundation Trust chaired the morning session, Dr Toni Tan, Consultant Paediatrician at North Manchester General Hospital chaired the mid-morning session and Dr Paddy McMaster, Consultant Paediatrician from University Hospital of North Staffordshire NHS Trust, chaired the afternoon session. (Please refer to Appendix B for the programme).

The workshop was well represented with 60 delegates registering to attend in total. Attending were representatives from a number of health professions with clinical, nursing and commissioning backgrounds as well as pleasingly high representation from the voluntary sector (Please refer to list of delegates attached in Appendix C).

## **2. AIM OF THE WORKSHOP**

Key aims of the annual work shop were to:

- Deliver an overview of perinatal and paediatric HIV services and statistics in the North West
- Inform delegates of National and Local guidelines and useful resources
- Encourage partnership working and engagement with the Voluntary Sector
- Inform delegates of difficult legal cases and how to manage them

## **3. PRESENTATIONS**

Please refer to copies of the speaker's profiles in *Appendix D*. The speaker presentations are available electronically. All presentations were circulated to all delegates after the event.

## **4. WORKSHOP DISCUSSIONS**

Dr Paddy McMaster provided an introduction to the draft CHIVA Standards. Delegates were divided into groups in order to discuss various sections of the draft standards. Each group then fed back key issues and recommendations that they had discussed. All suggestions were recorded centrally and Paddy McMaster informed the groups that recommendations would be considered and shared with CHIVA.

## **5. SEMINAR EVALUATION**

Sixty delegates registered to attend the event. Of those attending, 34 completed and returned the evaluation form. Feedback received regarding the presentations was overall excellent/good (please refer to Appendix E).

## 6. FUTURE MEETINGS

It is hoped that these educational workshops will continue to take place on a yearly basis. Delegates were asked if they had any other topic suggestions for future events. Comments provided are as follows:

### Suggested topics for next event

- Prematurity in babies born to HIV positive mothers
- Common pitfalls in looking after a child with indeterminate or determinate status
- More counselling and persuasion of parents to test their children
- Child protection / safeguarding lead to talk about children who are vulnerable and our responsibility i.e. Kay Walsh, Consultant Nurse Safeguarding, Manchester
- A DVD made by local young people about what it's like to be HIV +ve, or how to talk with doctors etc
- Breast feeding and HIV
- Why infants need ART urgently
- Latest Drugs
- More again on transition to adult services

## 7. GENERAL FEEDBACK

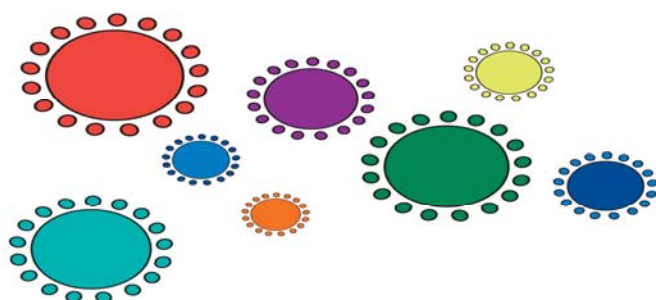
The majority of delegates described the whole day as inspiring, friendly, worthwhile, educational, stimulating, interesting, good for networking and a learning experience. All presenters received positive feedback. Generally delegates were pleased with the venue and the lunch provided (*please refer to Appendix E*). Overall, the day was extremely well received. Recommendations and lessons learned were noted and will be considered for future workshops.

## Appendix A

### CONTACT LIST FOR NORTH WEST PERINATAL AND PAEDIATRIC HIV NETWORK

| Name  | Designation  | Organisation                                     | E-mail Address   |
|---|--|--|--|
| <b>Tertiary Centre Representation</b>           |  |  |  |
| Andrew Riordan                                  | Consultant in Paediatric Infectious Diseases and Immunology      | Alder Hey Children's Hospital                    | <a href="mailto:andrew.riordan@alderhey.nhs.uk">andrew.riordan@alderhey.nhs.uk</a>                   |
| Cath Benson                                     | Immunology and infectious disease associate                      | Alder Hey Children's Hospital                    | <a href="mailto:cathryn.benson@alderhey.nhs.uk">cathryn.benson@alderhey.nhs.uk</a>                   |
| Dr Paddy McMaster                               | Consultant Paediatrician   | North Staffs Hospitals                           | <a href="mailto:Paddy.McMaster@uhns.nhs.uk">Paddy.McMaster@uhns.nhs.uk</a>                           |
| Dr Toni Tan                                     | Consultant Paediatrician   | Pennine Acute Trust                              | <a href="mailto:anton.tan@pat.nhs.uk">anton.tan@pat.nhs.uk</a>                                       |
| <b>District General Hospital Representation</b> |  |  |  |
| Ignatius Losa                                   | Consultant Paediatrician   | Macclesfield Hospital                            | <a href="mailto:Ignatius.losa@echeshire-tr.nwest.nhs.uk">Ignatius.losa@echeshire-tr.nwest.nhs.uk</a> |
| Dr Ruth O'Connor                                | Consultant Paediatrician   | Lancs Teaching Hospitals                         | <a href="mailto:Ruth.o'conner@lthtr.nhs.uk">Ruth.o'conner@lthtr.nhs.uk</a>                           |
| <b>PCT Zonal Commissioner Representation</b>    |  |  |  |
| Neil Jenkinson                                  | Commissioner for Sexual Health Services                          | North Manchester PCT                             | <a href="mailto:neil.jenkinson@manchester.nhs.uk">neil.jenkinson@manchester.nhs.uk</a>               |
| <b>Specialised Commissioner</b>                 |  |  |  |
| Roz Jones                                       | Specialised Commissioning Manager                                | NWSCT  | <a href="mailto:roz.jones@nwsct.nhs.uk">roz.jones@nwsct.nhs.uk</a>                                   |
| <b>Voluntary Sector Representation</b>          |  |  |  |
| Jill Hellings                                   | Team Leader  | Barnardos  | <a href="mailto:Jill.Hellings@barnardos.org.uk">Jill Hellings<br/>jill.hellings@barnardos.org.uk</a> |
| Emma Hawley                                     | Children's Services Manager                                      | Barnardos  | <a href="mailto:Emma.hawley@barnardos.org.uk">Emma.hawley@barnardos.org.uk</a>                       |
| <b>Council Representation</b>                   |  |  |  |
| Emma Massey                                     | Social Worker  | Bolton Social Services                           | <a href="mailto:emma.massey@bolton.gov.uk">emma.massey@bolton.gov.uk</a>                             |
| <b>Zonal Sexual health Leads</b>                |  |  |  |
| Simon Henning                                   | Cheshire & Merseyside Sexual Health Network Lead                 | Cheshire & Merseyside Sexual Health Network Lead | <a href="mailto:simon.henning@nhs.net">simon.henning@nhs.net</a>                                     |
| Sarah Stephenson                                | Greater Manchester Sexual Health Project Manager - Commissioning | Greater Manchester Sexual Health Network         | <a href="mailto:Sarah.Stephenson@manchester.nhs.uk">Sarah.Stephenson@manchester.nhs.uk</a>           |
| Stephen Woods                                   | Cumbria and Lancashire Sexual Health Network Coordinator         | Central Lancashire PCT                           | <a href="mailto:stephen.woods@centrallancashire.nhs.uk">stephen.woods@centrallancashire.nhs.uk</a>   |
| <b>Network Manager &amp; Support</b>            |  |  |  |
| Andrea Hughes                                   | NW Tertiary Children's Programme Manager                         | NWSCT  | <a href="mailto:Andrea.Hughes@nwsct.nhs.uk">Andrea.Hughes@nwsct.nhs.uk</a>                           |
| Louise Little                                   | NW Tertiary Children's Project Support                           | NWSCT  | <a href="mailto:Louise.little@nwsct.nhs.uk">Louise.little@nwsct.nhs.uk</a>                           |

## Appendix B



# North West Perinatal and Paediatric HIV Network Workshop

## Programme

17<sup>th</sup> September 2009

Horseshoe Suite, Haydock Park Race Course, Haydock, Newton-Le-Willows, WA12 0HQ

|               |  |
|---------------|--|
| 8:30          | <b>Registration</b>  |
| 9:00          | <b>Welcome and Introductions</b><br><i>Dr Andrew Riordan, Consultant Paediatrician, Alder Hey Children's Hospital</i>  |
| <b>Chair:</b> | <b>Dr Andrew Riordan, Alder Hey Children's NHS Foundation Trust</b>  |
| 9:15          | <b>Don't Forget the Children</b><br><i>Katie Rowson, Clinical Nurse Specialist, Alder Hey Children's Hospital</i>  |
| 9:40          | <b>Setting the Scene, the Local Picture</b><br><i>Dr Andrew Riordan, Consultant Paediatrician, Alder Hey Children's Hospital</i>   |
| 10:00         | <b>Antiretroviral (ARV) Drugs in Pregnancy</b><br><i>Andrew Moss, Bristol Myers Squibb</i>   |
| 10:30         | <b>Break</b>   |
| <b>Chair</b>  | <b>Dr Toni Tan, North Manchester General Hospital: Pennine Acute Hospital Trust</b>  |
| 10:45         | <b>Partnership Work and Engaging with the Voluntary Sector</b><br><i>Maria Phelan, Coordinator - Children and Young People's HIV Network, National Children's Bureau</i> |
| 11:25         | <b>Resources to Explain HIV to Children</b><br><i>Alice O'Sullivan &amp; Jill Hellings, Barnardo's</i>   |

- 12:10      **Difficult Legal Cases**  
*Dr Hermione Lyall, Consultant Paediatrician (Infectious Diseases), Imperial College Healthcare NHS Trust*
- 13:10      **Lunch (1 Hour)**
- Chair:**    **Dr Paddy McMaster, University Hospital of North Staffordshire**
- 14:10      **Introduction to CHIVA Standards**  
*Dr Paddy McMaster (Consultant Paediatrician, University Hospital of North Staffordshire and chair of CHIVA)*
- 14:30      **Workshops: CHIVA Standards Consultation**
- 15:15      **Break**
- 15:30      **Feedback from Groups**
- 16:00      **Closure** (*Dr Andrew Riordan*)

## Appendix C

### DELEGATE LIST

*For internal use only*



## Appendix D

### SPEAKER PROFILES

#### **Dr Andrew Riordan (Morning Chair)**

Dr Andrew Riordan is a Consultant in Paediatric Infectious Diseases and Immunology at the Alder Hey Children's Foundation Trust in Liverpool and is the Lead Clinician for the North West Perinatal and Paediatric HIV Network. He worked in Birmingham for 10 years and developed the Paediatric HIV service there, before moving to Liverpool. He is a founder member of the CHIVA executive committee. His hobbies include rock climbing and ironing.

#### **Dr Toni Tan (Mid-Morning Chair)**

Dr Toni Tan is the Lead Paediatrician in Greater Manchester in Paediatric HIV and has been for the past 7 years. He is a founder member of the North West Perinatal and Paediatric HIV Network and was its Clinical Lead until 2008. He has now been elected a member of the CHIVA Executive Committee.

#### **Dr Paddy McMaster (Afternoon Chair)**

Dr Paddy McMaster was appointed Chair of Children's HIV Association of UK & Ireland (CHIVA) last year. He is based at University Hospital of North Staffordshire in Stoke on Trent and would very much like to hear from anyone with suggestions about how CHIVA should be supporting the care of children infected and affected by HIV nationally. CHIVA will be developing their website ([www.chiva.org.uk](http://www.chiva.org.uk)), establishing and working to implement standards in each of the CHIVA Networks round the country and holding national CHIVA meetings.

#### **Katie Rowson**

Katie Rowson is the Associate Nurse Specialist in Paediatric Infectious Diseases and Immunology at Alder Hey Children's Foundation Trust in Liverpool.

#### **Andrew Moss**

Andrew Moss is a member of the field based medical team for BMS Virology, a non-promotional role. He worked clinically as a nurse for many years including work in HIV. Andrew has also worked in the HIV charitable sector, writing and editing treatment information. He was one of the people responsible for establishing HIV-ibase, a treatment information and advocacy organisation.

#### **Maria Phelan**

Maria Phelan is the coordinator of the Children and Young People's HIV Network, which is based at the National Children's Bureau. The Network is a national organisation that works to be an effective voice for children and young people living with and affected by HIV, to challenge the stigma and discrimination associated with HIV, and to build child-centred and effective, policy and practice. Previous to her role at NCB Maria worked for the Terrence Higgins Trust, coordinating sexual health outreach for vulnerable young people in the London Borough of Camden, supported young people with chronic long-term health problems in schools in North London and ran youth clubs in West and North London.

#### **Alice O'Sullivan**

Alice is a social worker at Barnardo's Gregory's Place as part of the specialist HIV service. This service provides HIV specific emotional, social and practical support to children and families living with and affected by HIV. Alice co-facilitates the Children's Peer Support Group (ChiPS) & a group for Affected Young People (A Team).

### **Jill Hellings**

Jill has worked at Barnardo's Gregory's Place since January 2006. She is part of the specialist HIV service which provides HIV specific emotional, social & practical support to children & families who are living with or affected by HIV. Children, young people & parents can access services via one-to-one support & within groups. Jill is also the lead worker for the Teenage Peer Support Group (PSG) & co-facilitates the Parent Group.

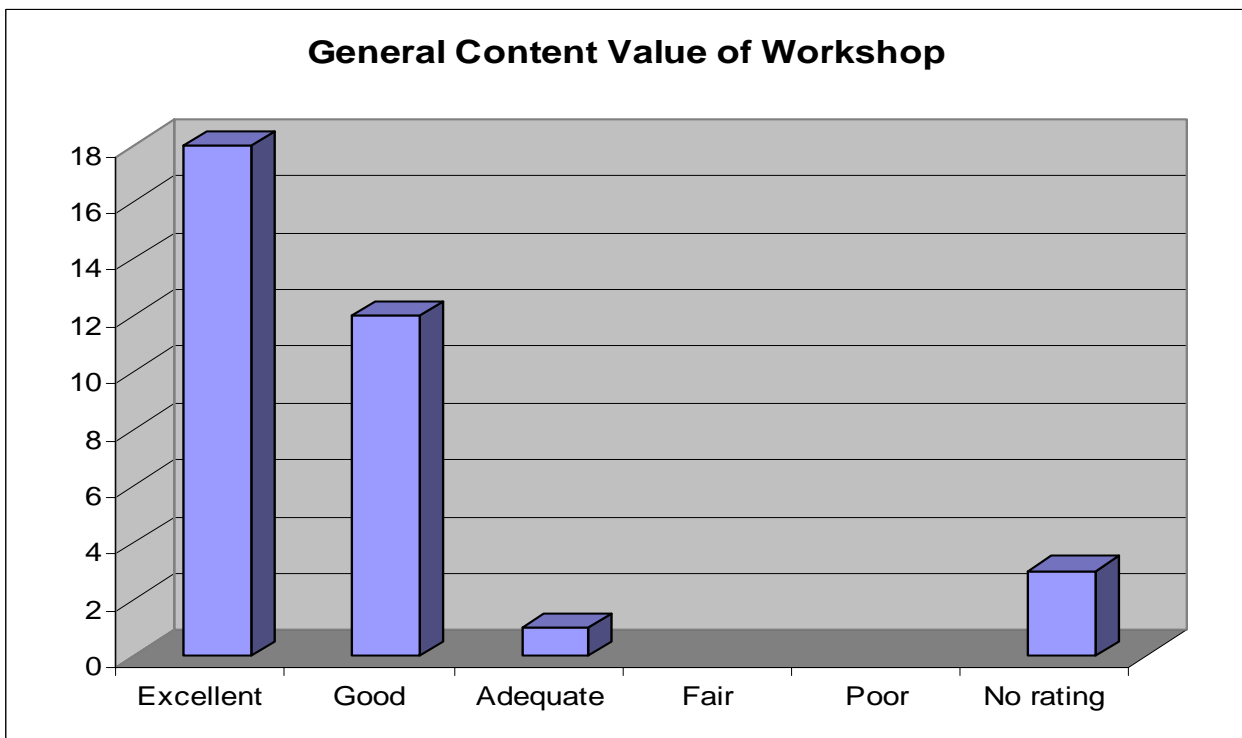
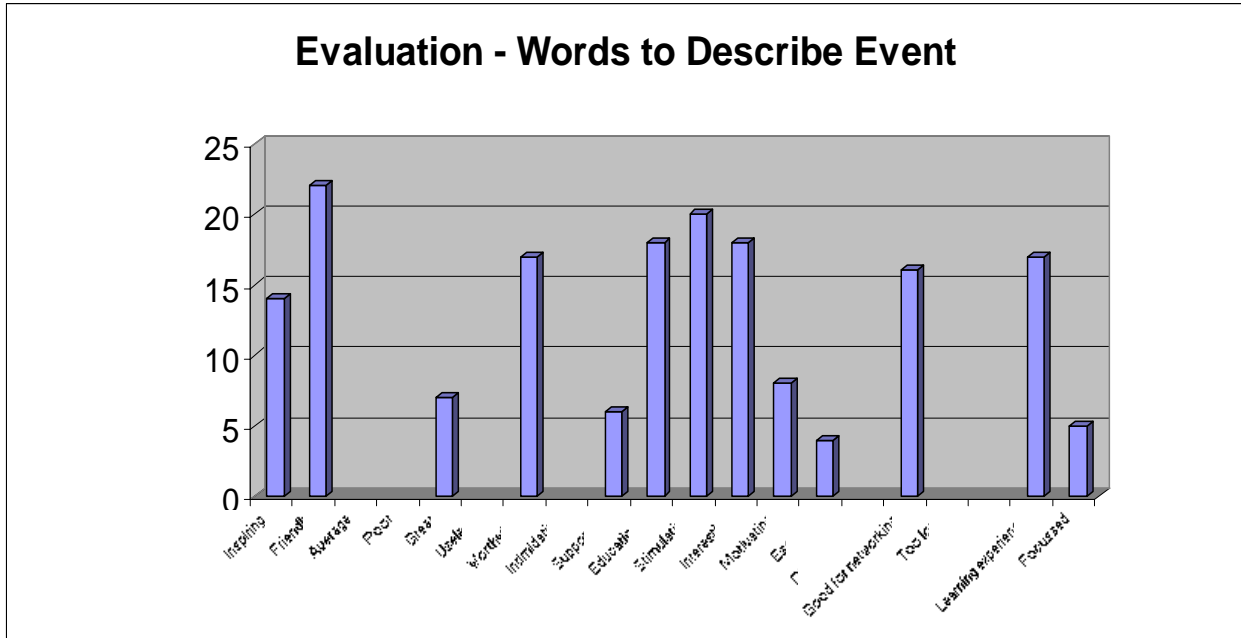
### **Dr Hermione Lyall**

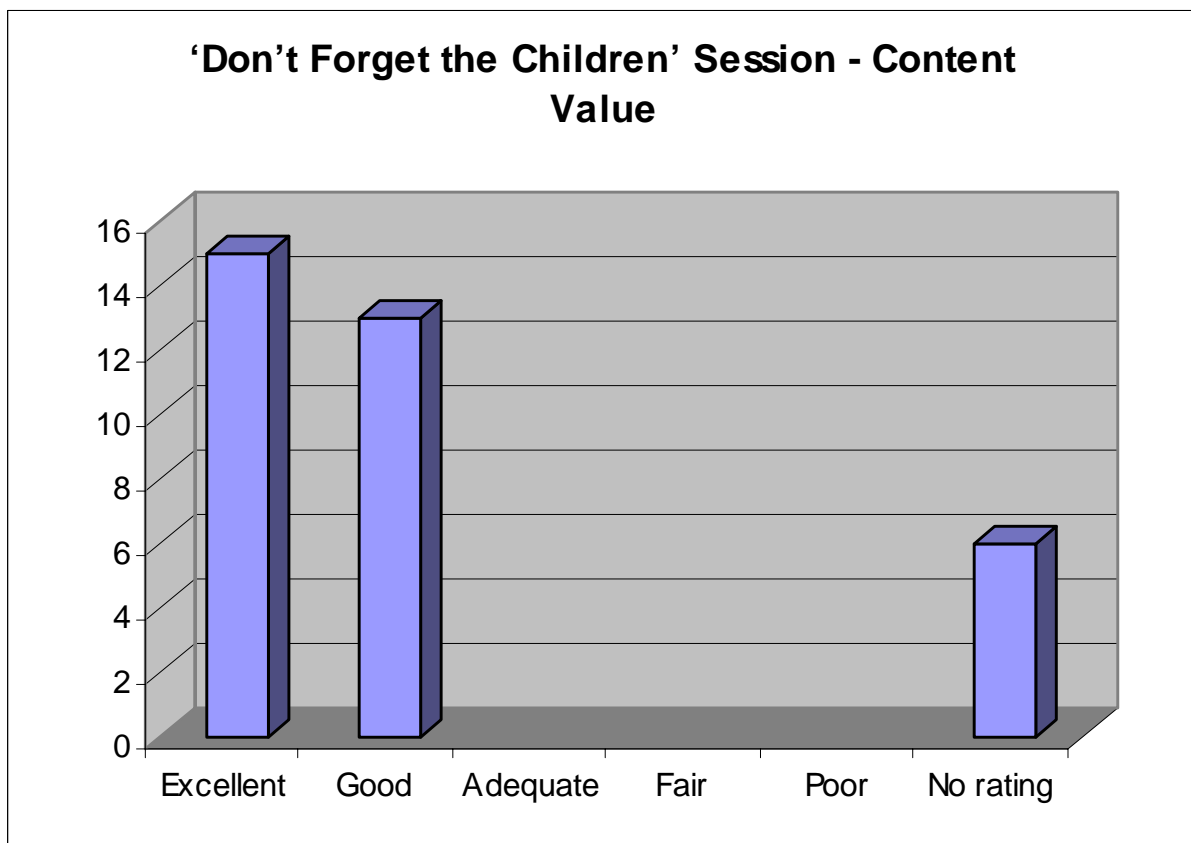
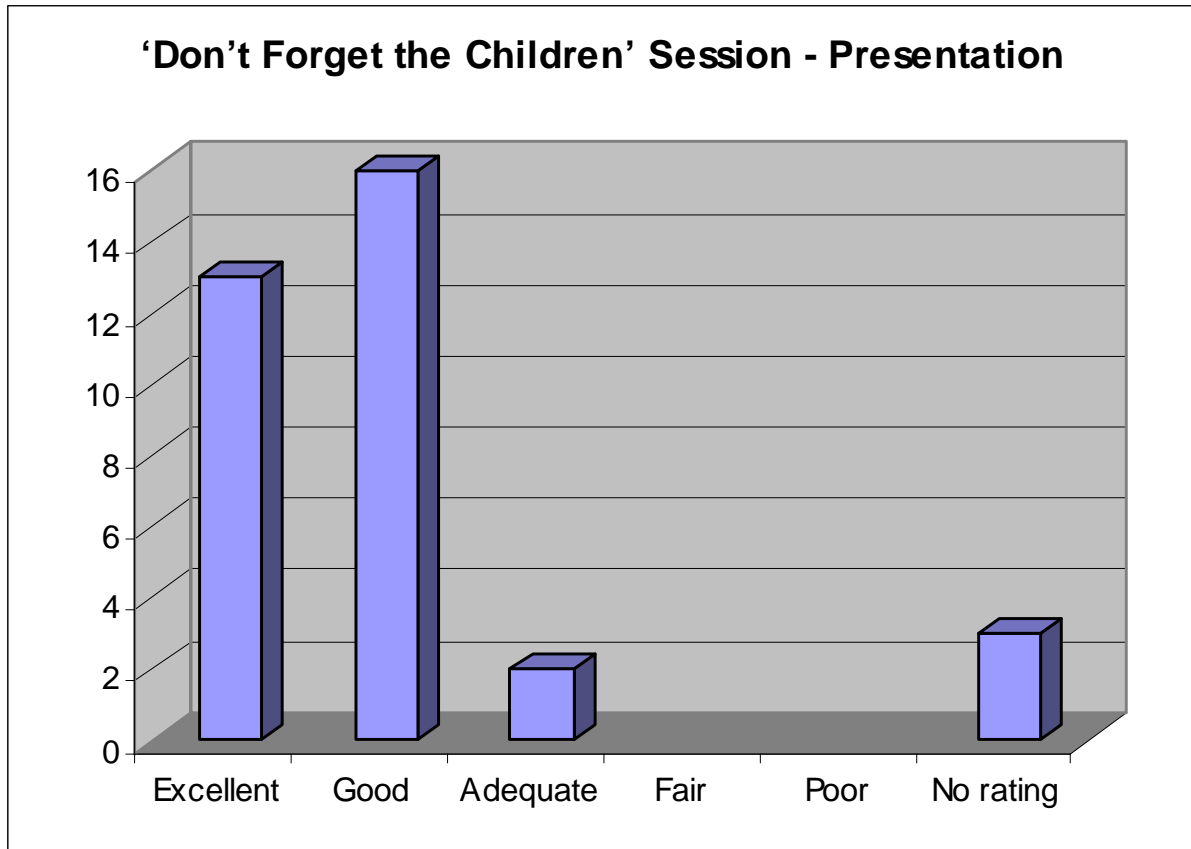
"As an infectious diseases paediatrician, my main areas of interest are the prevention of transmission of HIV from mother to infant, and the management of HIV infected children and young people. I am a member of the multi-disciplinary family clinic HIV team at St Mary's, Paddington, London.

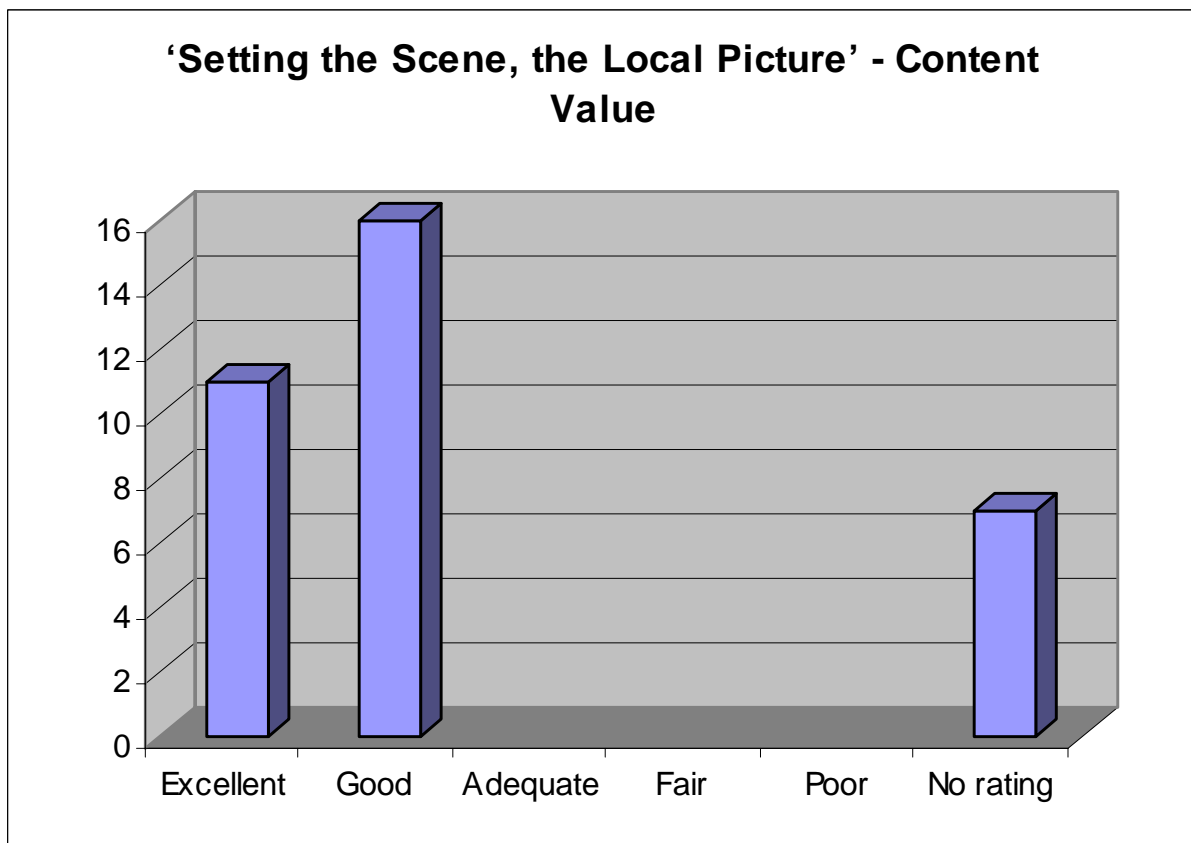
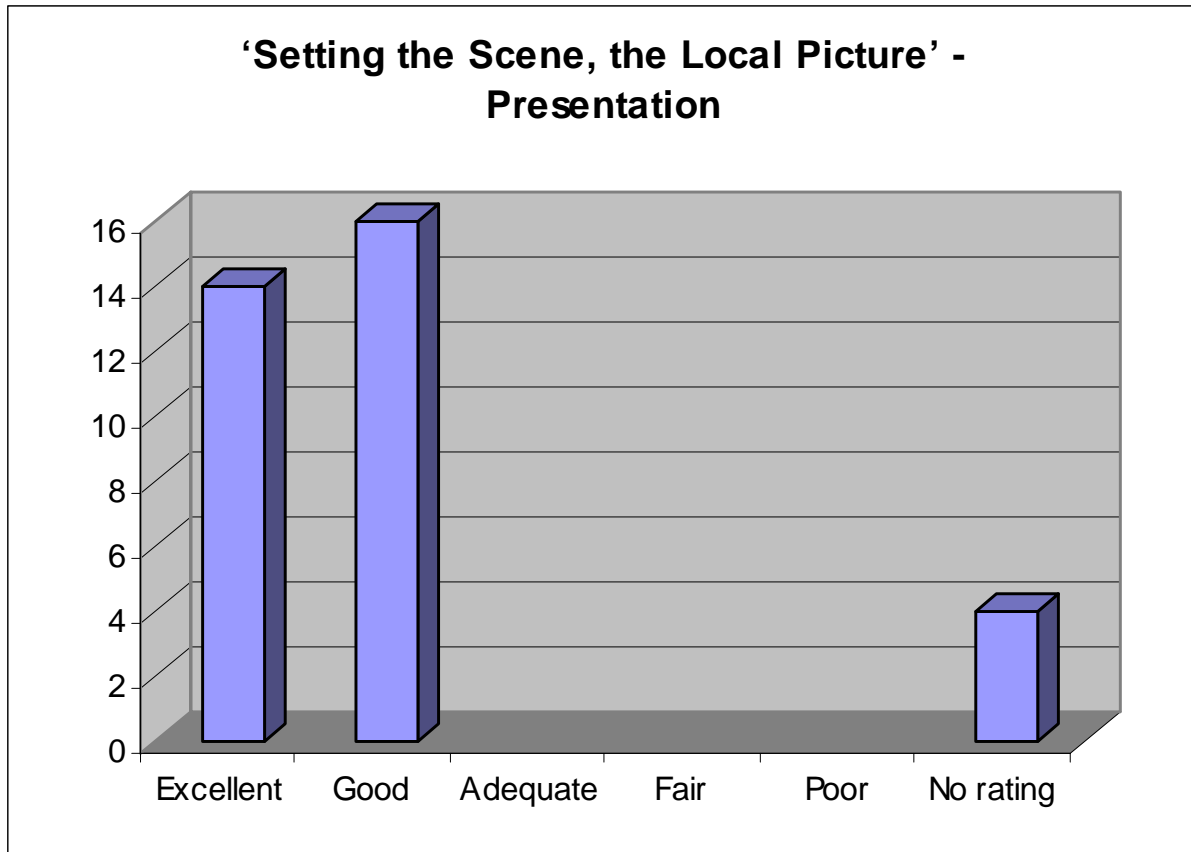
I am a member of the steering committee of the National Study of HIV in Pregnancy and Childhood ([www.nshpc.ucl.ac.uk](http://www.nshpc.ucl.ac.uk)). I have written the infant section of the BHIVA guidelines for the prevention of transmission of HIV from mother to child 2008 ([www.bhiva.org](http://www.bhiva.org)). I am a member of CHIVA; this organisation supports health professionals in the UK working with children with HIV, with the aim of improving the care for families and children with HIV ([www.chiva.org](http://www.chiva.org)). I have led the writing group for the CHIVA Standards of care for children with HIV, currently out for review. I wrote the paediatric section of the BHIVA Guidelines on HIV Testing 2008 ([www.bhiva.org](http://www.bhiva.org)). I am a member of the steering committee of PENTA (Paediatric European Network for the Treatment of AIDS) and participate in international treatment trials for HIV infected children ([www.ctu.mrc.ac.uk/penta](http://www.ctu.mrc.ac.uk/penta)). I am the chair of training for PENTA, training clinicians who care for children with HIV in Europe and Africa (<http://trainforpedhiv.conted.ox.ac.uk>).” ([hermione.lyall@imperial.nhs.uk](mailto:hermione.lyall@imperial.nhs.uk))

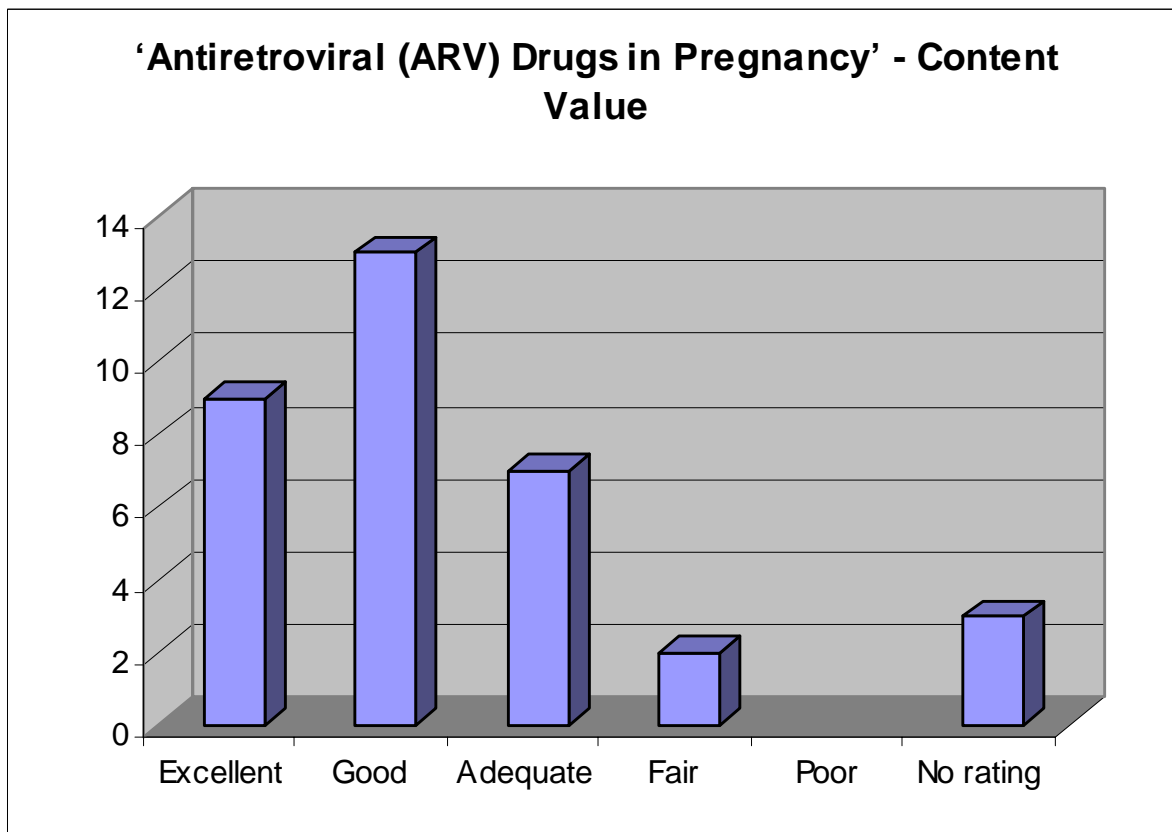
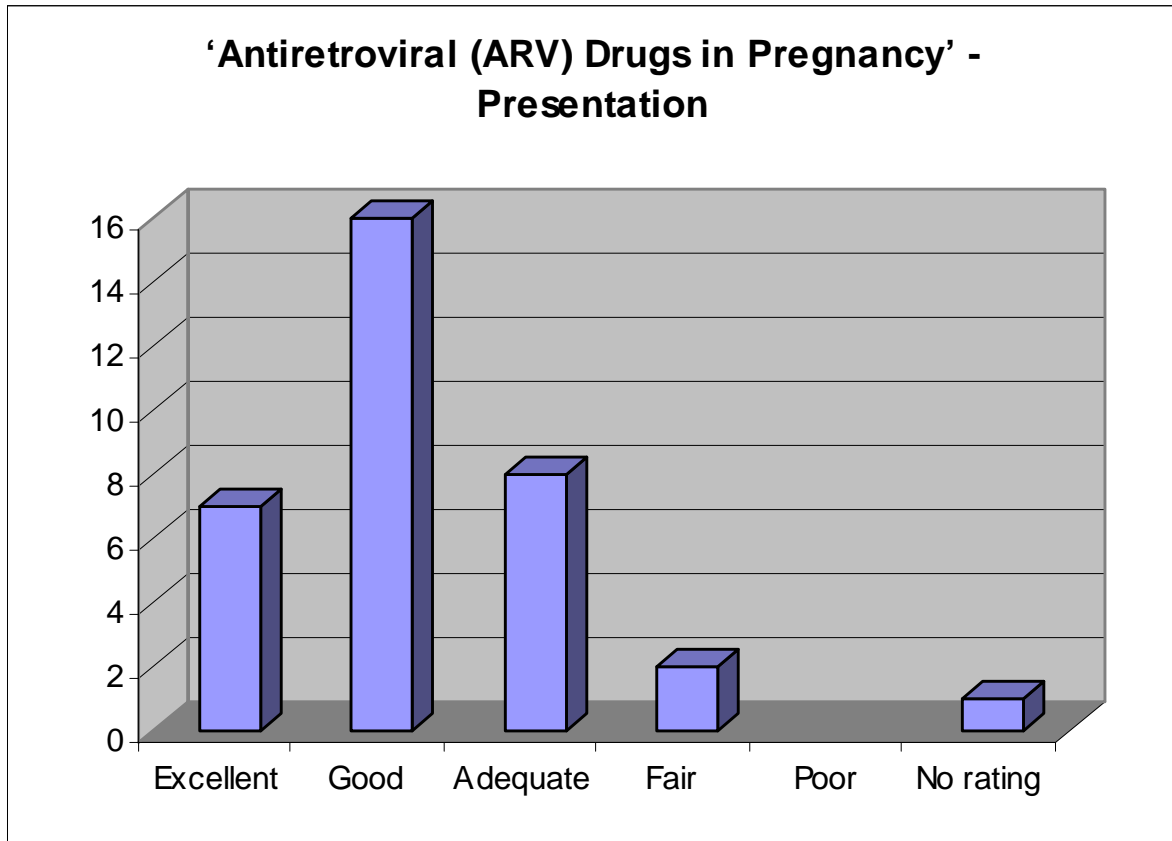
## Appendix E

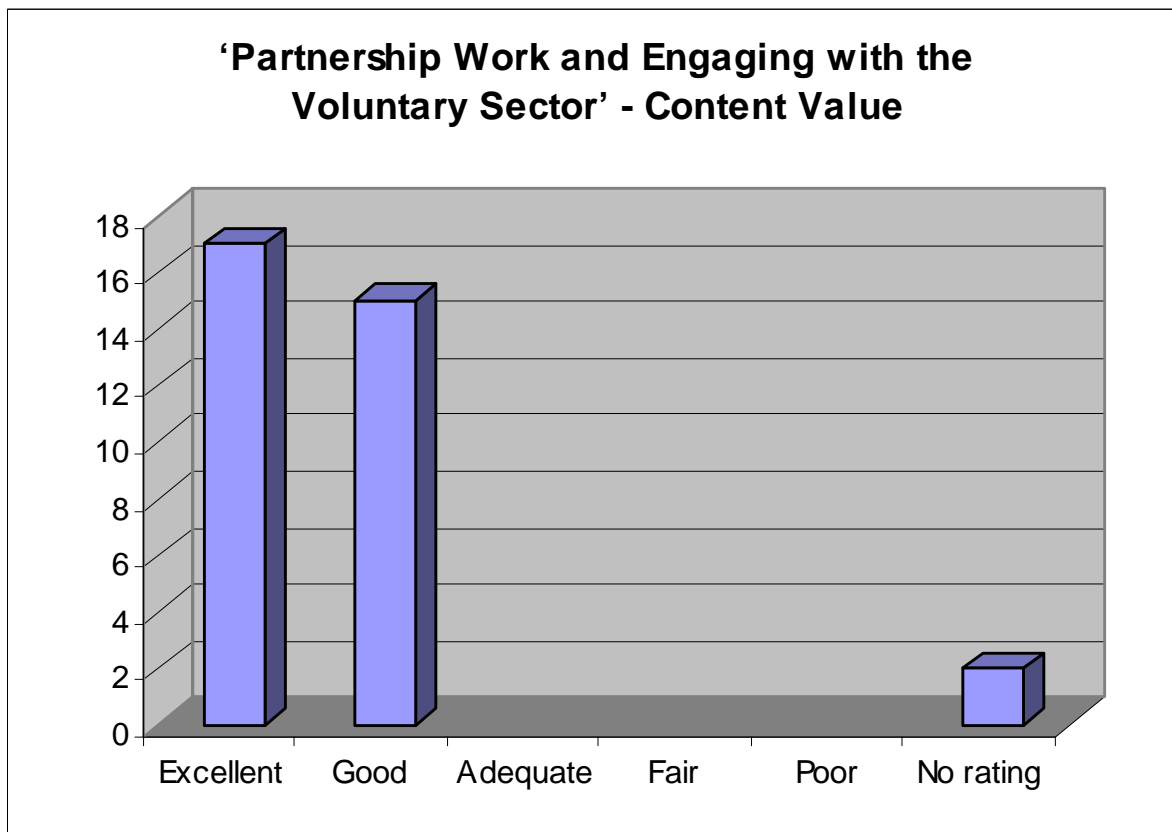
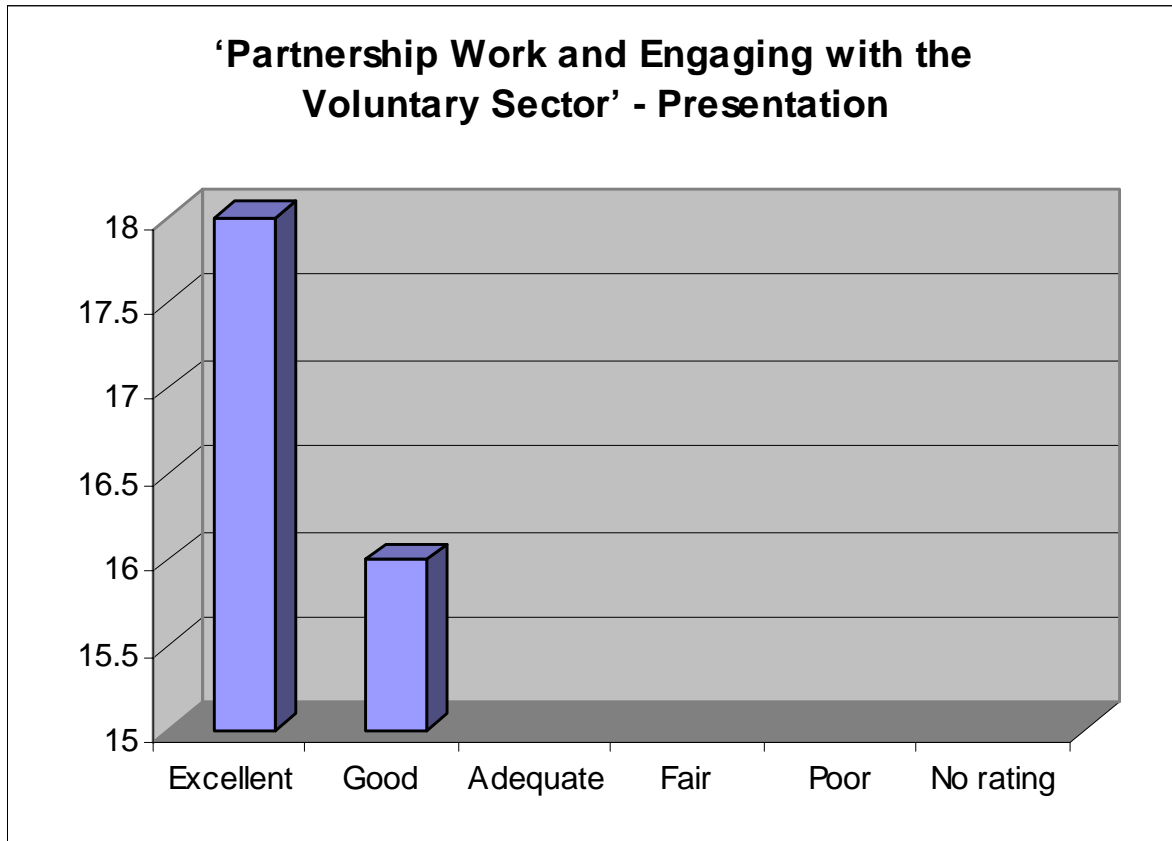
### EVALUATION RESPONSES

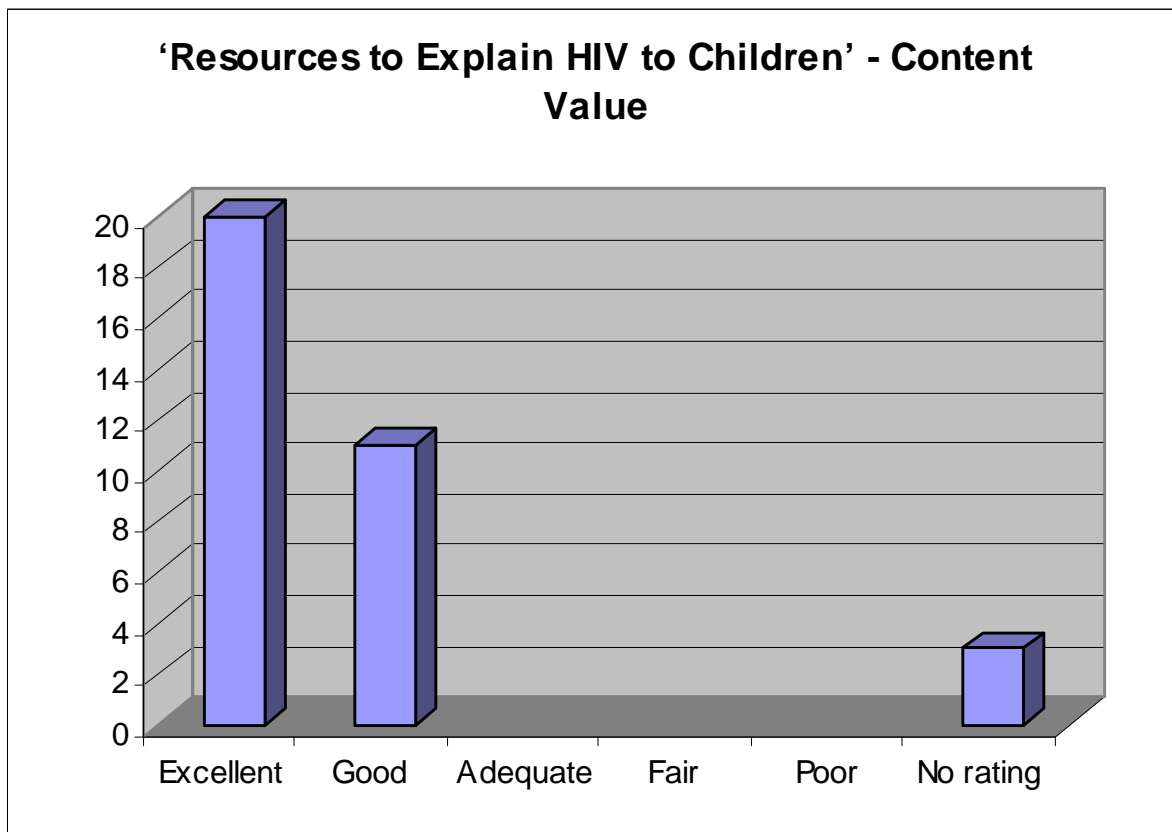
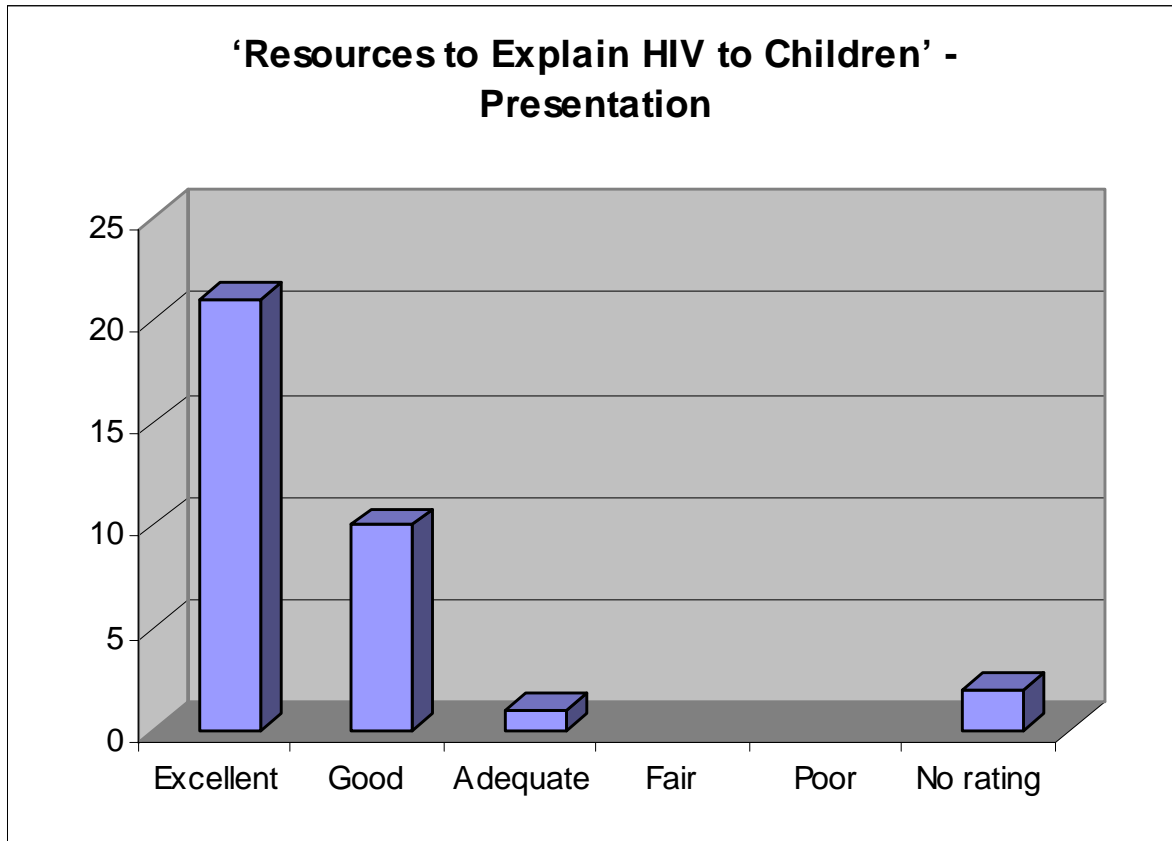




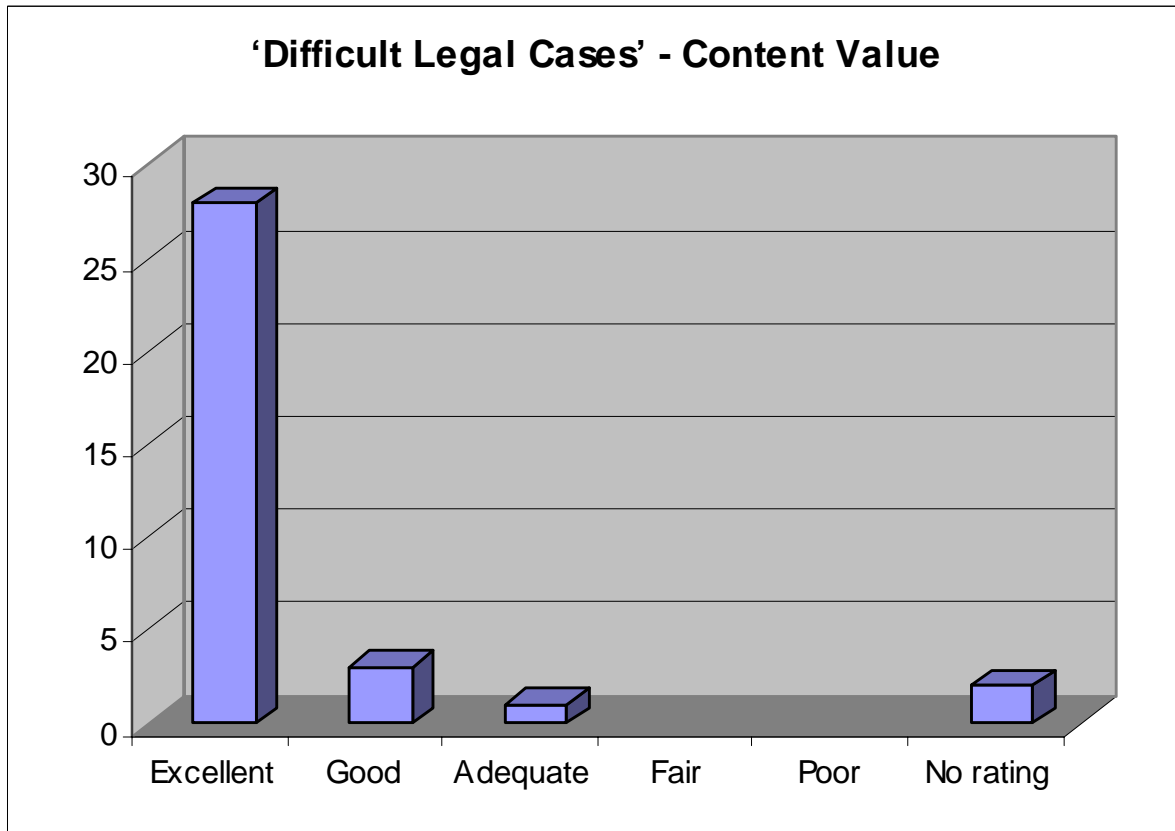
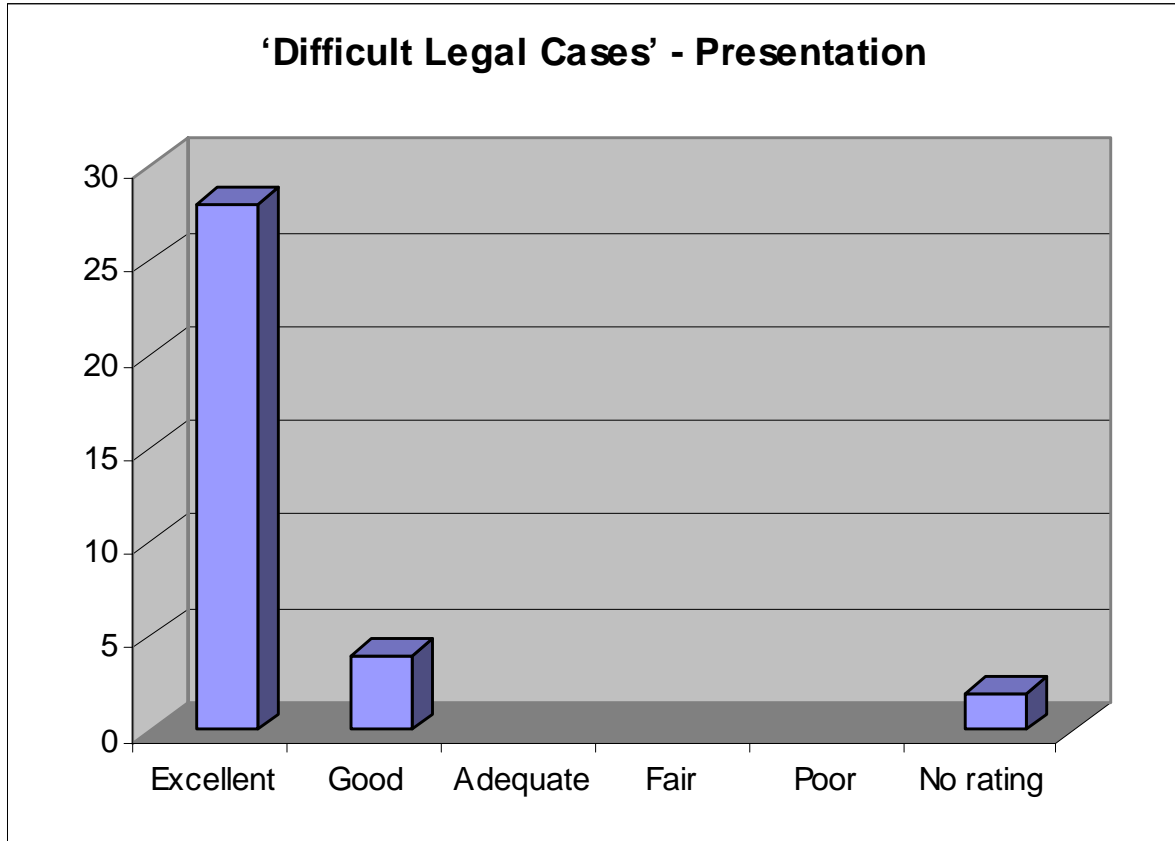


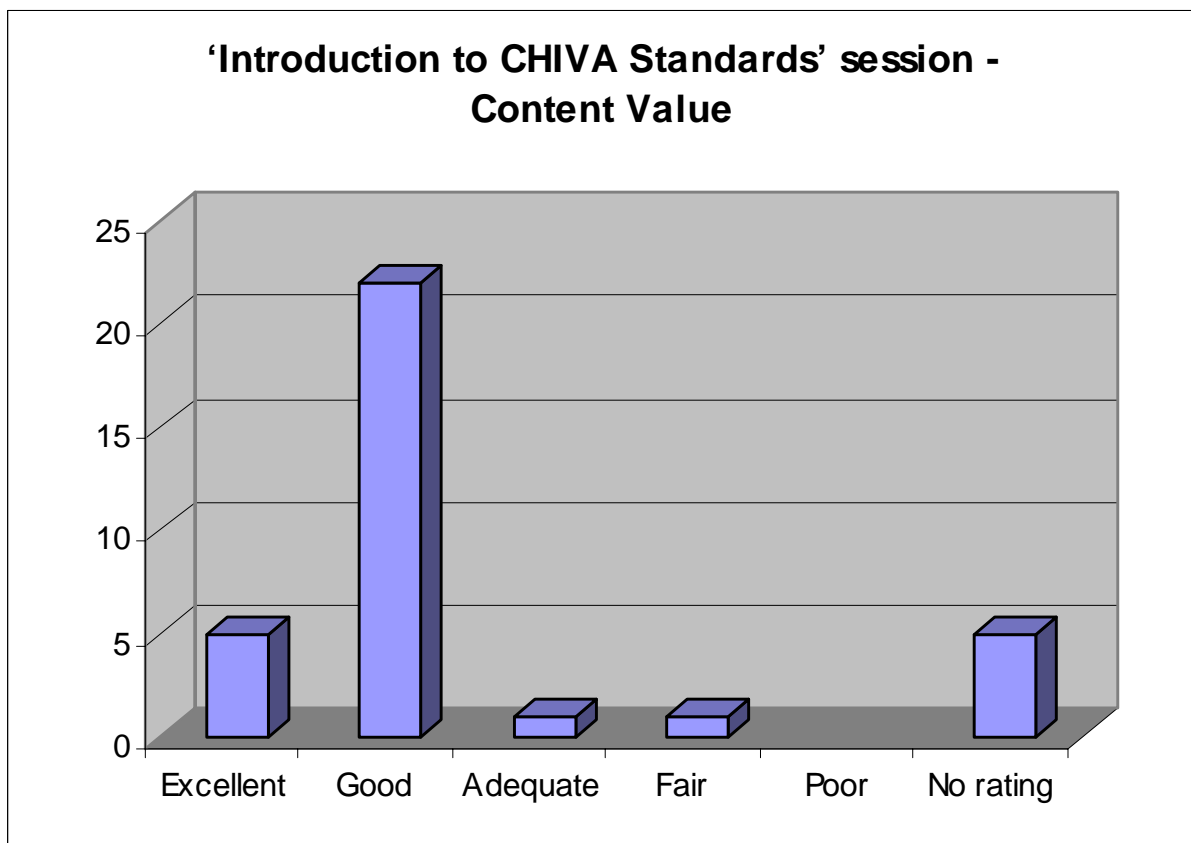
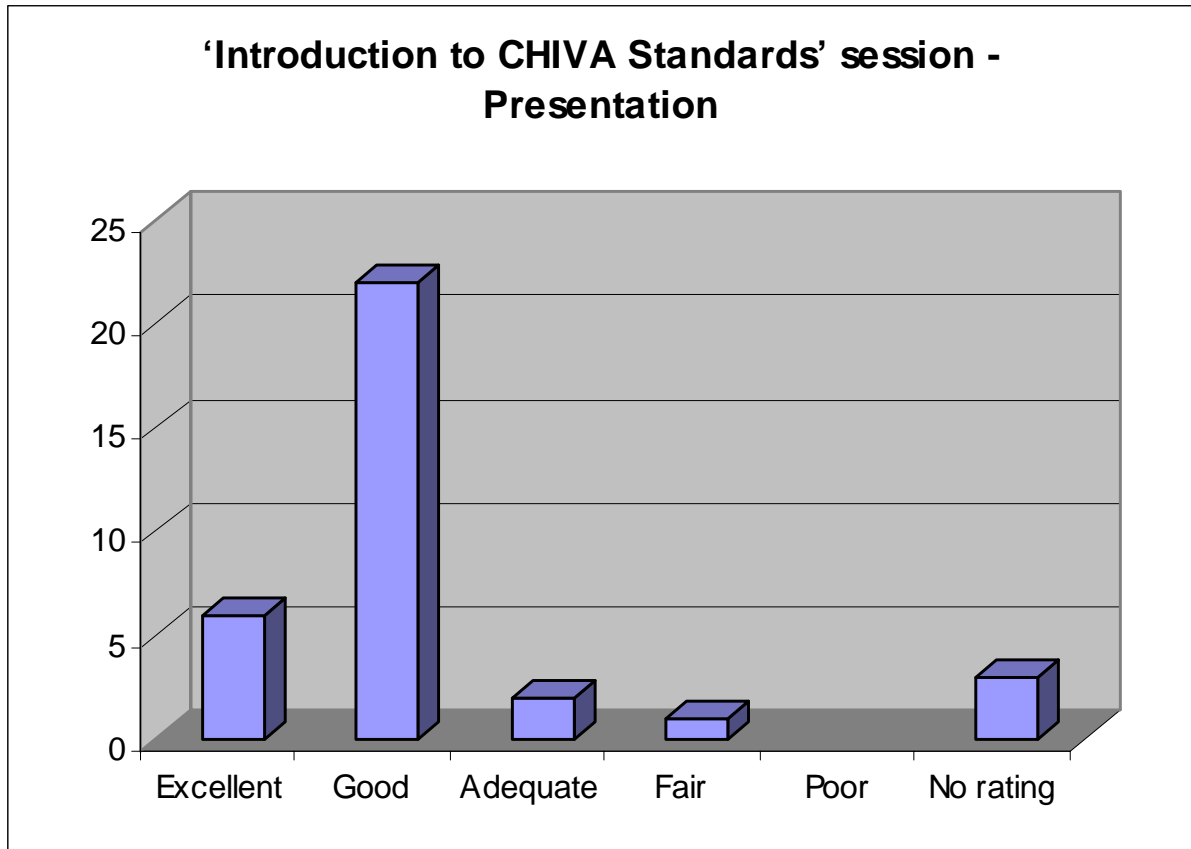


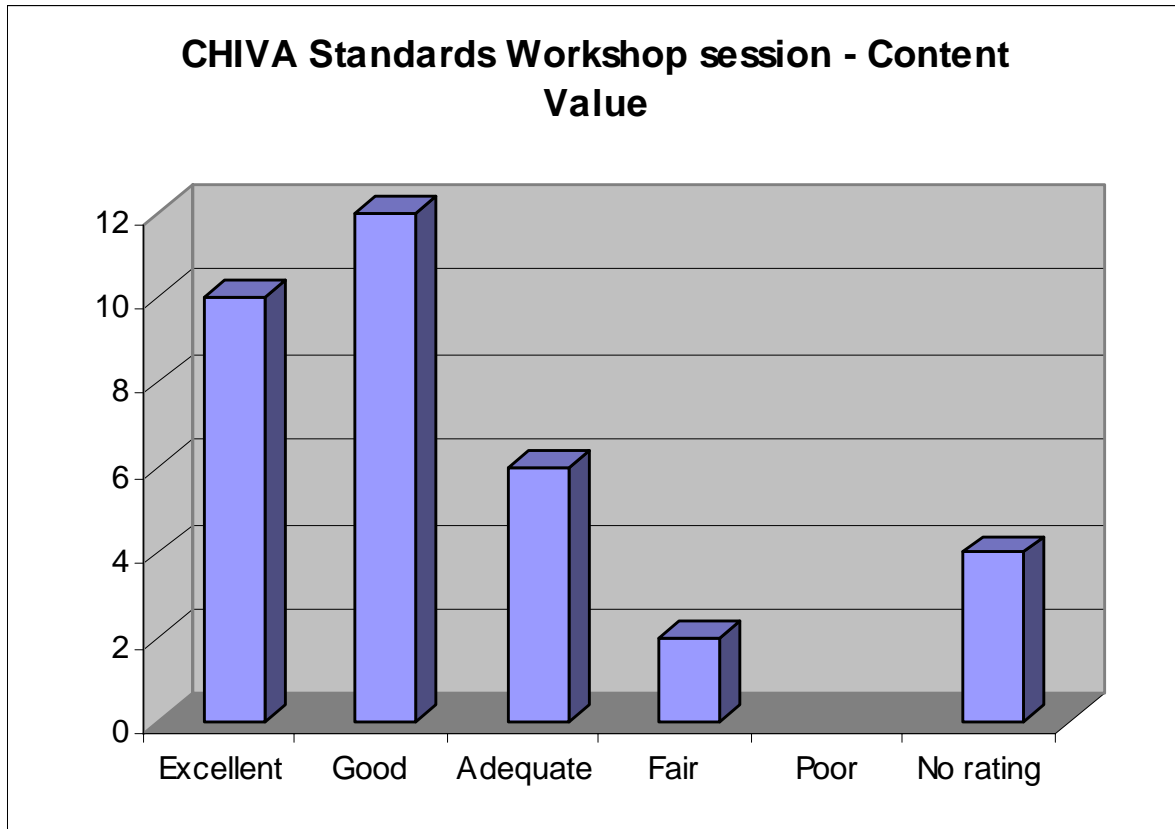












**'In your opinion, what was the most important 'top tip' that you will take away from this event?'**

Ask patients about testing their children and keep going till it's done.

Look closely at the set up for HIV provision in my clinical practice.

Important websites for guidelines. Seeking help from network.

How to breakdown HIV information to children and those aged 11-15.

Timescales for testing children of positive parents. Legal rights.

Antenatal discussions.

More reason to promote antenatal HIV screening.

Use positive language to describe HIV to children living with HIV.

PENTA Guidelines.

Re-testing high risk -ve women in 3rd trimester. Looking at women who decline testing.

Standardising re-offer of women who refuse antenatal testing. Consider re-testing high risk groups i.e. i/v drug users, asylum seekers.

Need to follow up children of HIV parents.

That all children of positive parents should be followed up and tested.

Keep pushing families to HIV test their children.

Multidisciplinary team networking.

Legal aspects. Resources to explain.

The urgency of a becoming sexually active teenager knowing if they have a HIV +ve diagnosis.

Pushing the boundaries

Testing all S/Ass for BBV at presentation for baseline bloods, even when patient says assault was 'first sexual intercourse'.

No reply: 15

**What have you learnt today that you will do tomorrow?**

Refer a patient to Gregory's Place for support.

Going back to the Obs & GUM colleagues regarding 'Don't Forget the Children'.

I have learnt how to communicate with the young. I would try to put that into practise.

Use positive language message and remove any negative materials we are using.

To find out HIV Lead Obstetrician and Midwife in my hospital.

Share with colleagues re: increase of uptake of antenatal testing.

Standardising re-offer of women who refuse antenatal testing. Consider re-testing high risk groups i.e. i/v drug users, asylum seekers - Implement immediately by expert (core) member of antenatal team, followed by re-offer at 20 week scan.

Discuss with MDT how we can follow up children of HIV parents.

Include the new standards into guidelines.

Ask GUM to 'look back'. Antenatal clinic to identify decliners re: testing.

Not to make assumptions about a case ever re: route of transmission. Good to know Hermione (St Marys) would support a teenager if up against a criminalisation allegation.

D/W GU Dr whether all HIV patients are asked about their children and testing of them.

No reply: 22

**How did you hear about this event**

|                    |    |
|--------------------|----|
| Emailed invitation | 23 |
| Manager            | 3  |
| Word of mouth      | 1  |
| Colleagues         | 2  |
| Other              | 3  |
| No reply           | 2  |

**Would you recommend this event?**

|          |    |
|----------|----|
| Yes      | 32 |
| No       |    |
| No reply | 2  |

**Comments:**

Aimed appropriately in the main.  
Enjoyable.

It is essential if we really care about the children and reducing the number of HIV cases.

Interesting and varied topics - thank you.

Excellent, informative day which keeps me updated. Thanks.

Very well organised. Great venue. Very interesting and lots of information given.

Informative.

Interesting, excellent mix of professionals / volunteers organisations

Excellent content.

Excellent for improving and updating knowledge, also for networking with other professionals.