

15<sup>th</sup> Annual Conference of the  
National HIV Nurses Association (NHIVNA)



National HIV Nurses Association

# Chris Sandford

Mortimer Market Centre, London

*27-28 June 2013- The International Convention Centre, Birmingham*

# **Health literacy - peer support and patient engagement**

**Chris Sandford  
Patient Representative  
Mortimer Market Centre**

# BHIVA – Standard 9

*People living with HIV should be enabled to maximise self management of their physical and mental health, their social and economic well-being, and to optimise peer support opportunities*

**Why ?**

# Peer support and patient engagement can lead to ...

- a reduction in anxiety and fear
- increased confidence, self awareness and self esteem
- a greater understanding of the importance of psychological well-being
- empowerment through information and a sense of being in control
- better self management skills
  
- better adherence
- better quality of life

**How ?**

# Mortimer Market Centre

- Central London sexual health clinic
- 79, 000 appointments per year
- 4200 HIV+ patients
- 30 doctors, 18 nurses, 17 health advisers, 7 psychologists
- 3 salaried patient representatives
- GOSH > TEAM
- Teaching and research – UCL Medical School
- Ward in University College London Hospital



# **97 % of our patients on medication are undetectable**

- Health literacy programme – nurses, health advisers, doctors, psychologists and all staff.
- A holistic approach
- Patient representatives offering peer support – an integral part of the team.



*If a patient only sees a  
clinician they only get half  
the story*

Dr Simon Edwards – Co Chair BHIVA Standards

# **So....what do the patient representatives offer?**

- Five day a week drop in and appointment service - peer support, advice, advocacy and self management
- Early intervention – at diagnosis
- Peer led motivational workshops
- Educational forums
- Newly diagnosed courses

# Why is peer support effective?

- We break the feeling of isolation
- We can empathise and are role models
- We are living positively with the virus
- We take medication every day with no visible side effects
- We have experience of the psychological issues - the crisis of diagnosis, disclosure, fears of rejection, stigma and discrimination.

# One to one sessions cover ...

- Social isolation and exclusion
- Fears around disclosure and confidentiality issues
- Fears of stigma and discrimination
- Social and psychological support
- Diagnosis and life expectancy
- Starting treatment and adherence

- Physical health and well-being
- Dental care and GPs
- Pregnancy, childcare, adoption, fostering & surrogacy
- Referrals for legal advice, immigration, employment, benefits, housing and homelessness
- Referrals to our own health advisors and psychology department ... or external counselling
- Emergency fund - groceries, utility bills, school uniforms, travel, formula milk, child care and household items

# 914

patients received peer support from the  
patient representatives last year



# Top ten concerns

- Social isolation 33.4%
- Fears around disclosure 27.3%
- Fears of discrimination 27.3%
- Medication issues 21.8%
- Counselling 17.6%
- Housing 15.9%
- Physical health 14.3%
- Sexual health 12.1%
- Benefits 10.6%
- Employment 10.1%



# Case study 1

- Woman diagnosed in ante-natal clinic. Considered termination and suicide. Dropped out of college and stopped working.
- Post natal depression and isolation – fear of gossip because not breast feeding. Did not leave her flat. Benefits stopped.
- Food parcels. Powdered milk. Benefits sorted. Attended the Newly Diagnosed Course - with subsidised child care.
- She is back in college, working part time, volunteering and her son is now three.

# Case study 2

- Young man struggling with diagnosis, cut himself off from family and friends. Severe paranoia
- Fled the country to study. Isolated and became depressed. His CD4 fell sharply
- Would not engage with clinical or psychological services
- 9 meetings outside clinic. Re-engagement and started medication. No side effects and now VL < 50
- New job, new home and new partner

# Case study 3

- Refugee couple – no money, no clothes, no food
- Arranged food parcels, charity funding for furniture
- Co-ordinated care package including GP, dentist, optician
- English classes and the refugee council accredited their qualifications
- Husband now working as a university lecturer, wife studying accountancy and starting a family

# Bloomsbury Patients Network

Membership and mailing list of over 700

- *Motivational workshops*
- *Educational forums*
- *Social events*
- *Newly Diagnosed Courses*
- *Hep C co-infection courses*

# Workshops – helping people help themselves

- *Positive thinking*
- *Nutrition and the immune system*
- *Love , sex, relationships and transmission*
- *Disclosure – who to tell? How to tell? Do I have to tell?*

*Subjects outside the medical model but of great importance to patients  
5 workshops a year - average of 30 participants  
All facilitators are living with HIV – including Angelina & Silvia*



# Forums – empowerment through information

- ***A medical update*** – latest research and developments
- ***Growing older with HIV*** – clinical and social support
- ***The new NHS & our standards of care***
- ***Benefits & back to work – the new reality.***

*6 Forums a year – average attendance 75*

*Speakers include: Professor Jane Anderson (BHIVA), Dr Ian Williams (BHIVA), Claire Foreman (Public Health England), Yusef Azad (NAT), Ruth Lowbury (MEDFASH) and representatives from the Commons and Lords, RCGPs, BMA*

# Newly Diagnosed Course

6 courses a year – maximum 15 participants

6 sessions over three Saturdays

- *The impact of diagnosis*
- *Disclosure*
- *Medical aspects and therapy*
- *Love, sex, relationships and transmission*
- *Keeping your immune system in good shape*
- *Emotional, social and practical support*

*All facilitators are living with HIV*

*The course is inclusive and welcomes all patients*

*Lunch in a restaurant is an integral part of the day.*



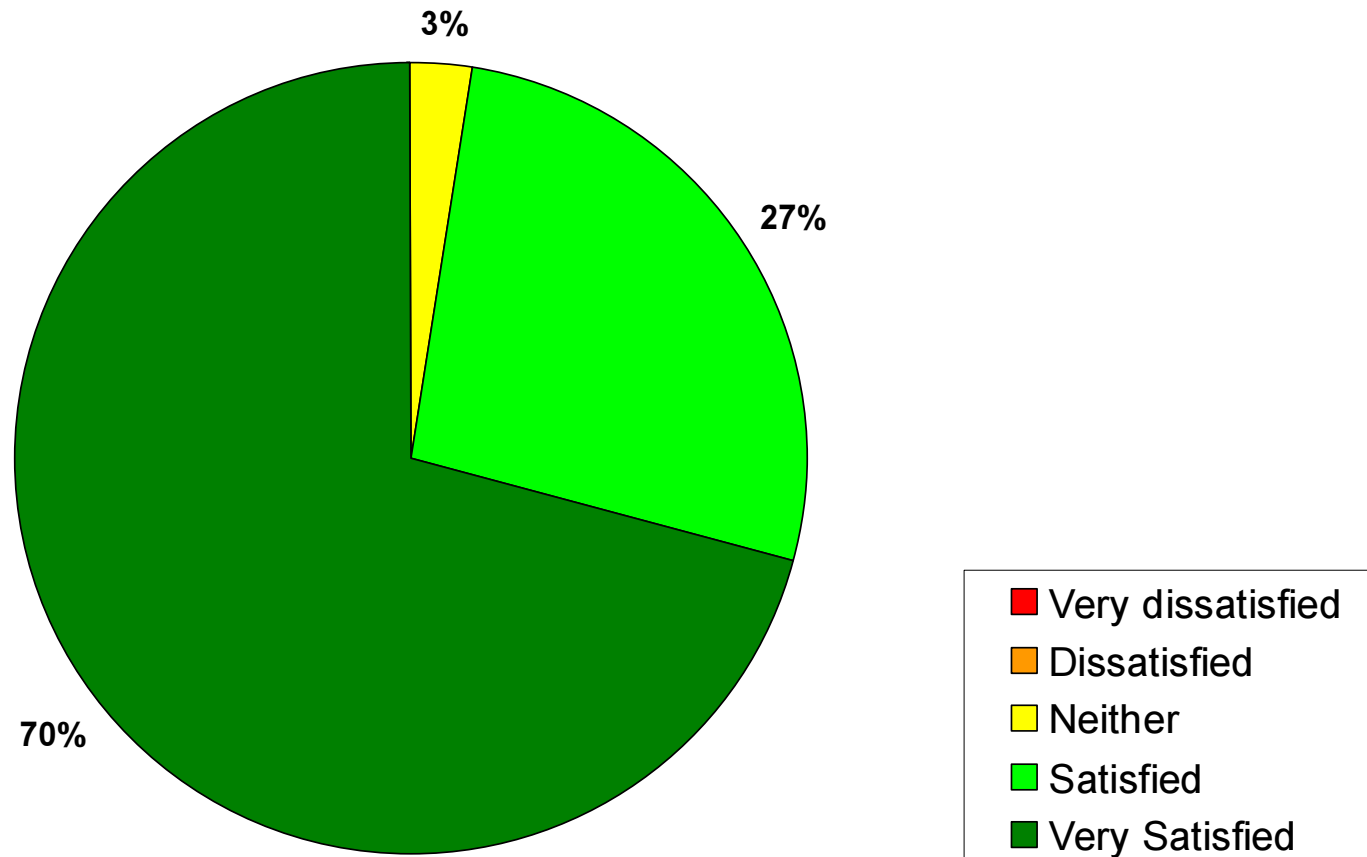
# The NDC offers...

- Early Intervention
- Empathy, education and empowerment
- A safe environment to explore fears and feelings
- A way to meet others, overcome feelings of isolation - including social interaction
- Support in developing acceptance of diagnosis
- Support in developing self management skills, coping mechanisms and inner resources
- Continuity of care

# 6 courses = 90 participants

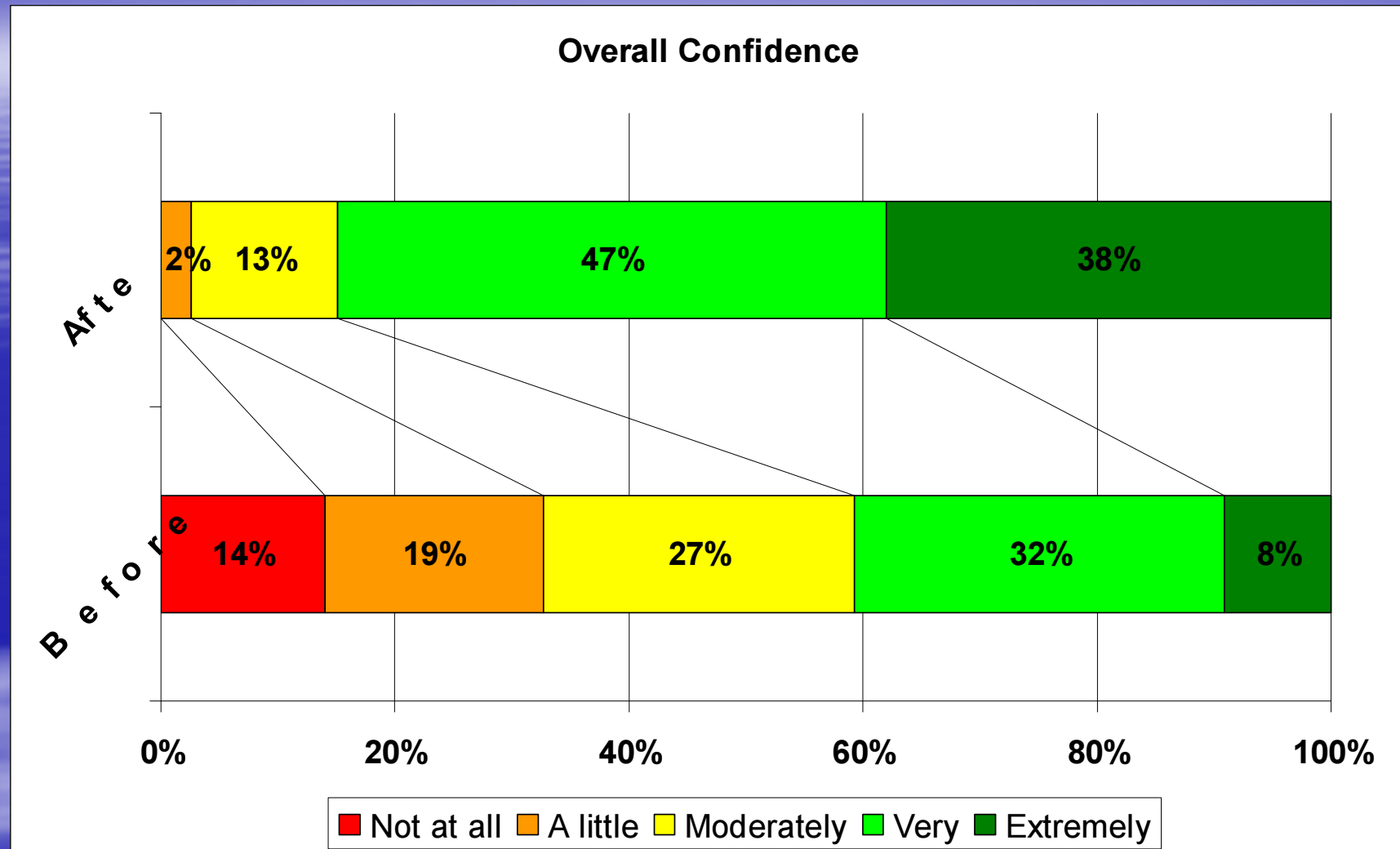
- 97% satisfaction rate with course
- 95% completed the course
- 89.5% attendance rate
- 84% were male
- 75% MSM
- Age range 21- 73 yrs old
- Length of time diagnosed: 3 days – 13 years

### Overall Satisfaction with Course



**Average ratings over 5 satisfaction questions covering:**

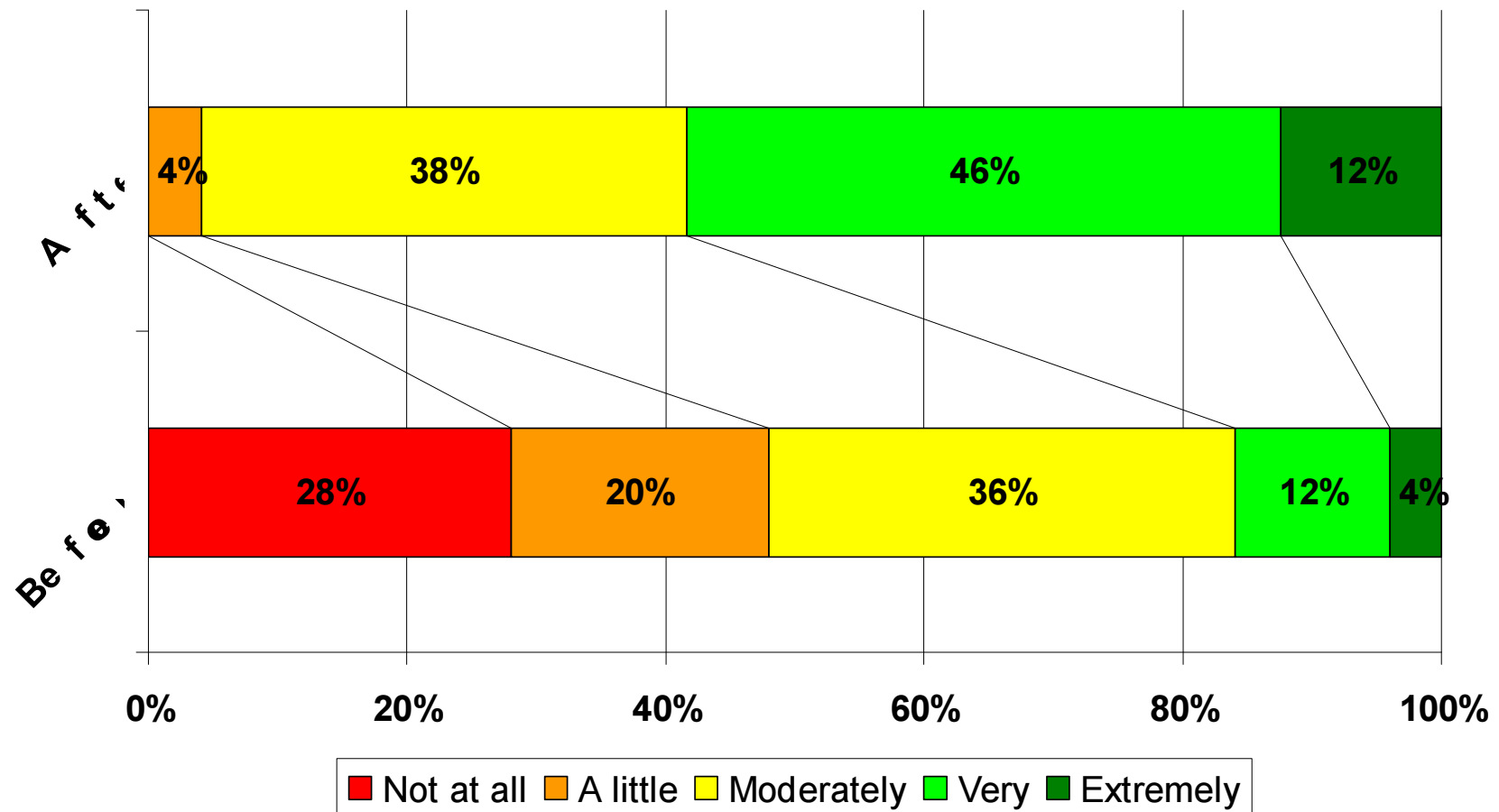
Time available for Q&As, length of sessions, material covered, facilitators, overall usefulness of course



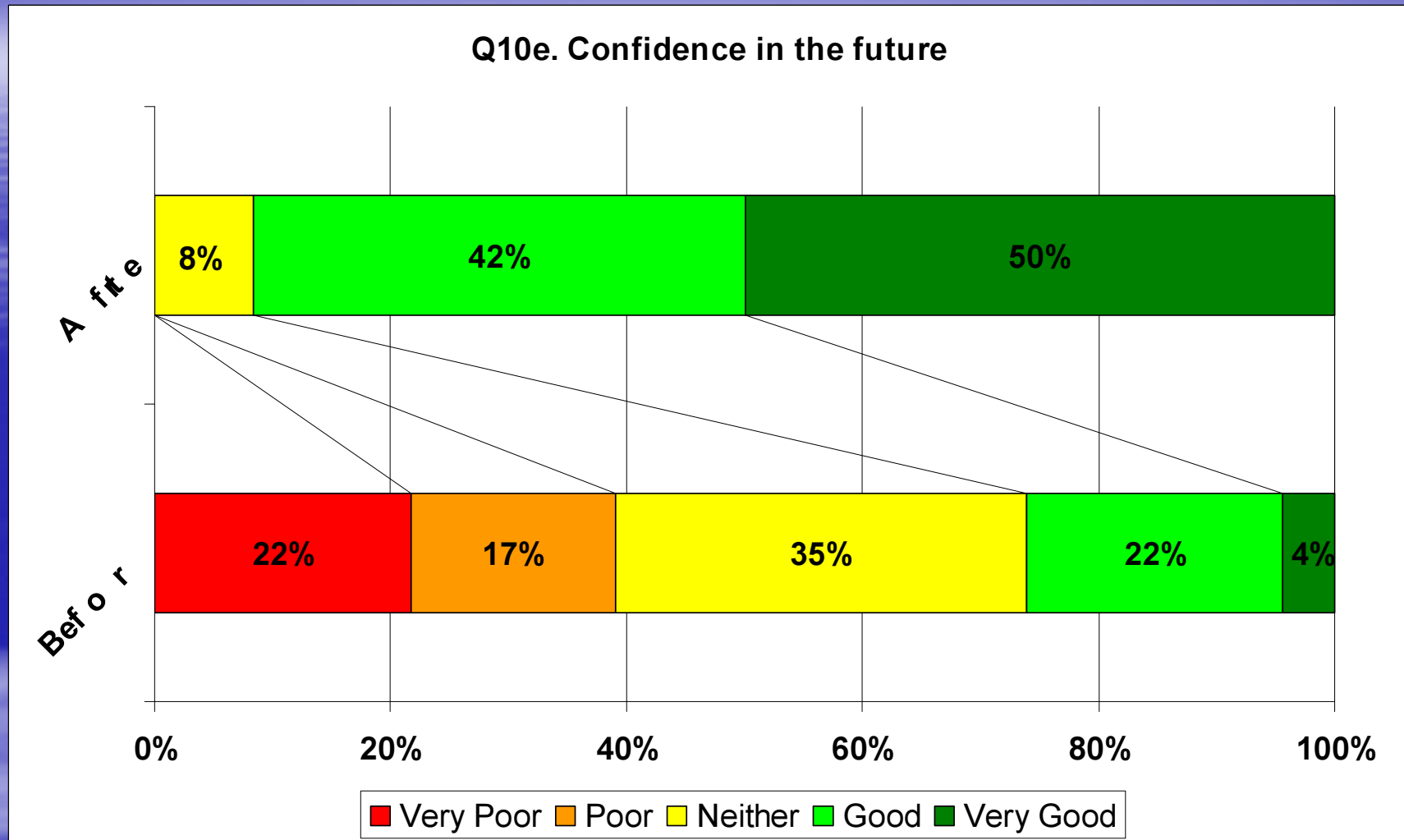
**Average ratings over 5 confidence questions covering:** Emotional state, dealing with status, telling others, dealing with sex & relationships, outlook for the future

- Average score: 2.46 pre-course, 3.93 post-course
- **59.6% improvement in average score**

### Q1. How comfortable do you feel about your HIV diagnosis



- Average score: 2.44 pre-course, 3.67 post-course
- 50.3% improvement in average score



- Average score: 2.70 pre-course, 4.42 post-course
- 63.8% improvement in average score

# 600

Patients engaged in workshops,  
forums and newly diagnosed  
courses



# To conclude...

Peer support and patient engagement can:

- address patients' concerns outside the medical model
- impact positively on the physical health and psychological well-being of the patient
- help acceptance to prevent distress and suffering from developing into something more severe
- provide empathy, education, empowerment and self management skills

**Thank you**

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# Breakdown of clients...

28.9% heterosexual female

21.6% heterosexual male

49.5% MSM

44.51% BME

Patients from over 60 countries including UK