

16th Annual Conference of the
National HIV Nurses Association (NHVNA)



National HIV Nurses Association

Mark Platt

UK Community Advisory Board (UK-CAB)

26-27 June 2014- City Hall, Cardiff

NHIVNA 2014

**Developing PROMs & PREMs
for HIV Care**

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**'Beyond Undetectable:
what matters to people living with HIV
in the age of effective treatment'**

**Mark Platt
UKCAB**

Background

- Project inspired by Prof. Jane Anderson
- Funded by MAC AIDS Fund
- Managed by BHIVA
 - Project Administrator Dr Hilary Curtis
- 'Connected' to BHIVA treatment guidelines
- Comprised: community, clinicians, researchers

What are we trying to achieve?

- Create structures to enable measurement
- Map BHIVA standards of care to experience
- Ensure clinical priorities mapped
 - Reference existing PROMs tools, e.g. EQ5D
- Develop patient experience priorities
 - PREMs
- Enable regular monitoring, improvement

What have we done?

- Created on-line survey for groups & individuals
- Facilitated community engagement events
 - Explained conceptual background
 - Allowed for free discussion
 - 3 Mixed groups – London & South East
 - 8 African groups – London & England
 - Positively UK conference 2013
- Presentation at BHIVA Autumn Conf 2013

What have we learnt?

- All groups support the concepts
- Appetite for engaging with the work
- Key concerns:
 - Clinic care and arrangements
 - Emotional and psychosocial issues
 - Care from non-HIV services, e.g. GPs, social care
- Specific community issues
 - Stigma, legal and immigration matters
 - Discrimination in treatment

What did we hear?

- “Nurses treat you differently; they say they can't deal with it”
- “There is no confidentiality in hospitals as they share your medical details with other staff...”
- “I went to hospital for surgery and as soon as they learnt about my HIV they postponed it...”
- “Some of the nurses have showed a degree of ignorance “I'm surprised you look so well” being an example

What next?

- More detailed engagement
 - Clinicians, including nurses
 - Commissioners
 - Provider organisations, including 3rd sector
- Production of report with proposal for continuation
- Development of second research proposal
 - Submission to MRC
 - Community researchers
- NIHR research proposal 'post implementation'