



Patient Advocacy & Switching to Generics

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No Disclosures



Shared **Decision Making Project**

What's Shared Decision Making?

- Health professionals and patients working together
- Patients are placed at the centre of decisions about their own treatment and care.
- Clinicians bring their expertise and patients their experiences
- Care or treatment options are fully explored, along with risks, benefits
- Different choices available to the patient are discussed and a decision is reached together

(NICE, NHS Constitution, BHIVA)



HIV Switch Initiative

National Anti-Retroviral Therapy Commissioning for Value 2016-2018

- Switching patients to therapeutically equivalent generic anti-retroviral medication
- Potential savings of £21m over 2 years
- Enable switching in line with routine outpatient review
- Discussion with patient over most clinically appropriate, cost effective regimens (*NHS England*)



Patient **Experiences**

Concerns Highlighted

- Treatment changes made without adequate consultation
- Patients unaware of new treatment until delivered by homecare
- Feelings of being pressured by clinical staff to accept the change
- Insufficient information and no time to make an informed decision about the changes
- Ageing, poly pharmacy, adherence issues



Shared Decision Making Project

Organisations: AAF, CARA Trust, AAEGRO, Positive Voices, AHPN, NAM, OPAM

157 HIV Patients

Patient Survey

April 2017

57 Consultants

BHIVA

October 2017

June 2018

NHIVNA

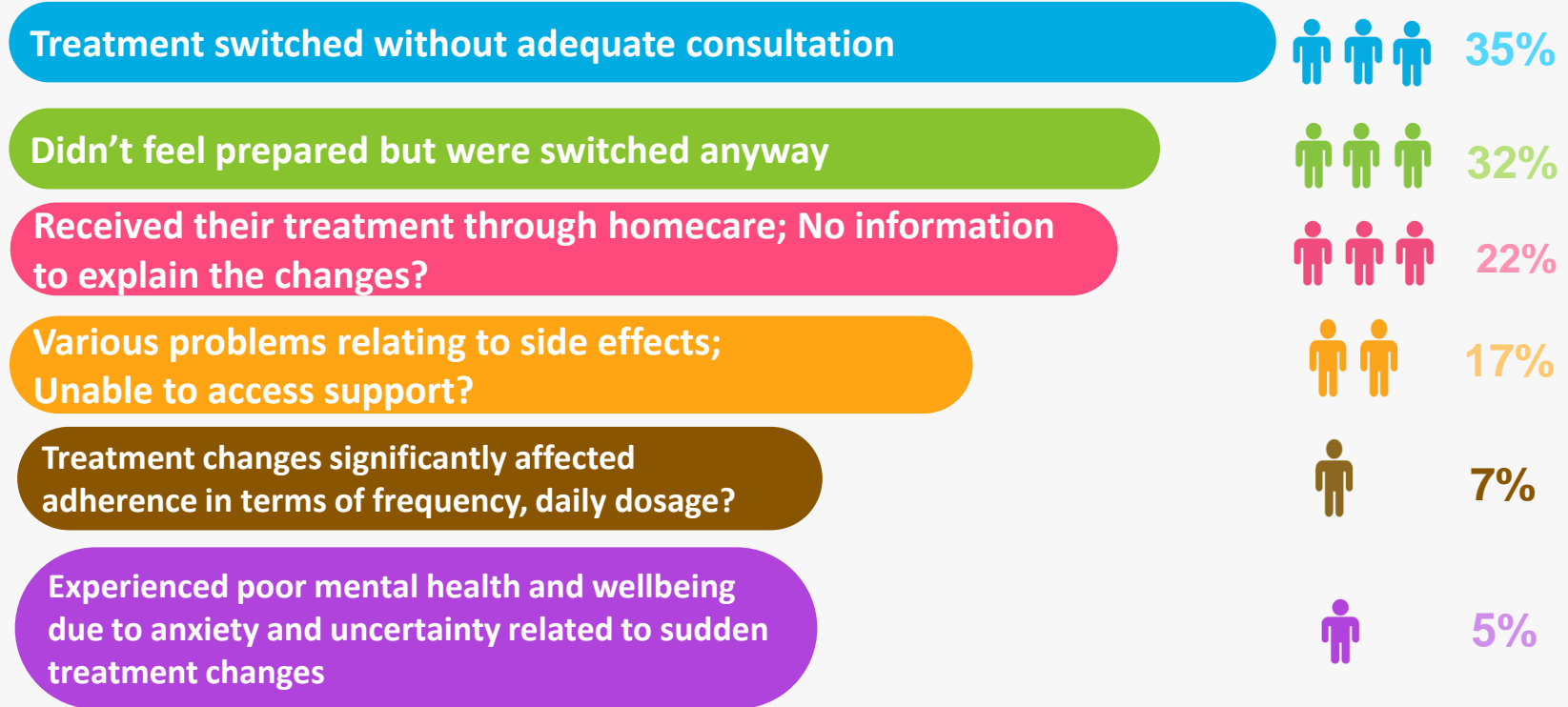
68 Nurses

Feb 2018

Focus Groups

4 Groups, 32 Patients

Patient Survey Results



N= 132;
 Nurses = 68
 Consultants = 57
 Registrars = 5
 Pharmacists = 2



NHIVNA & BHIVA Survey Results

NHIVNA Conference 2017 ; BHIVA Autumn Conference 2017



Case Study 1

Male 35 Years, Black African Diagnosed 2011 ; VL = 1300, CD4 = 490

- Not on treatment until 2015 when he was admitted with epileptic seizures
- Initiated on branded drug A and goes undetectable
- Dec 2016 - Switched to A1 generic version of treatment A
- March 2017- Goes back not happy with treatment i.e. headaches, dehydration, night sweats
- Switched to A2, but no change in symptoms. After 2 weeks, switched back to A



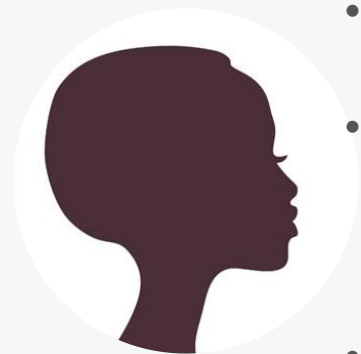
** 3 – 4 Additional Clinic Visits*



Case Study 2

Female 35 Years, Black African, Diagnosed 2010, CD=150, VL?

- Previously on branded drug B but switched to generic version B1; Feb 2017
- Informed that treatment would change but didn't ask for explanation. Only discovered different type on arriving at home from pharmacy.
- Missed a few days but started taking medication regularly thereafter. However, started experiencing serious side effects and went back after 2 weeks. Nurse encouraged her to continue; that the side effects will stop eventually. No change in side effects.
- Subsequently stops taking medication. Needs extra support to resume treatment.



* 3-4 Additional Clinic Visits



Shared Decision Making Project

Engaging Key Stakeholders

- Patient Organisations – Outside London
- NHS England
- BHIVA- Letters
- Key HIV Organisations i.e. THT, NAT
- Round Table - Houses of Parliament



Key Issues

- | | | |
|---|-----------------------------------|--|
| 1 | Information | Ensuring appropriate and timely information |
| 2 | Valuing Patient Experiences/Views | Patient wellbeing/rights vs commissioning and economics decisions |
| 3 | Audit of Programme | A case for audit to determine impact on individual or diverse groups of patients |
| 4 | Innovation | Cost saving measures vs innovation, scientific research, what do patients think? |
| 5 | Investment | Re-investment of savings made in HIV services. Need for 'ring fence' ? |

Thank You!

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Any Questions?

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