



Third Joint Conference
of the
British HIV Association (BHIVA)
with the
British Association for Sexual Health and HIV (BASHH)

1-4 April 2014

Arena and Convention Centre · Liverpool

THIRD JOINT CONFERENCE
OF BHIVA AND BASHH 2014



Dr Zoe Warwick
Plymouth Hospitals NHS Trust

O29: Facilitating self-care in HIV with digital patient-controlled health records

**Oral Research Presentations Session 4:
Complications and co-morbidities**

1500-1630 Thursday 4 April 2014

BHIVA/BASHH Liverpool 2014

Prescribed Specialised Services Commissioning Intentions 2014/15-2015/16



HIV Outpatient Currencies

British HIV Association guidelines for the treatment of HIV-1-positive adults with antiretroviral therapy 2012
(Updated November 2013. All changed text is cast in yellow highlight.)

and Payment Agency

How do we adapt our model of care to meet the NHS changes?

What is the patients role in managing their care?

How do we keep them engaged?

What innovative technology can we utilise?

14/15 National Tariff Payment System

B06/S/a
2013/14 NHS STANDARD CONTRACT FOR SPECIALISED HUMAN IT
SECTION B PART 1 - SERVICES

Service Specification No.	B
Service	S
Commissioner Lead	L
Provider Lead	L
Period	
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

Definition
Human Immunodeficiency Virus (HIV) is a virus that infects and destroys cells responsible for combating infections, leaving the body susceptible to diseases it would normally be able to fight.

Without treatment, the immune system can be compromised and rare infections or cancers develop. When these are particularly serious, the person is said to have AIDS (Acquired Immune Deficiency Syndrome).

Disease progression is monitored primarily through markers of immunity (CD4 count) and HIV (viral load). Antiretroviral therapy (ART) is used to reduce virus to protect immunity. ARTs require high levels of adherence to be effective and patients can become resistant to certain drugs, requiring switching. There are a number of drug-drug interactions with ARTs which need to be avoided or managed. In addition to specialised HIV services, meeting the needs of HIV infected individuals relies on access to other services including sexual health and reproductive health, mental health, antenatal and third sector support services.

HIV can only be passed on through infected blood, semen, vaginal fluids or breast

HIV/STI Department
Public Health England

in collaboration with
The National Reference Group for
Payment by Results
and the
Department of Health



Can we engage patients through an online system?

- Pilot online system that provides:
 - Secure access for patients to medical records
 - Patients to track symptoms, take measurements and review blood results
 - Online consultations inc. Skype[®]
 - Care Plans
 - Multidisciplinary access
 - Accredited educational material



Methodology

- Implement a HIV online patient portal service, at 14 sites across the UK, using a digital patient held record – ‘Patients Know Best®’
- A structured mixed-methodologies audit process using quantitative and qualitative analyses
- Pre set-up baseline questionnaires of healthcare professionals digital experience and clinical outcomes
- Review data to explore what the results tell us about current service design and delivery

HIV services going digital: Patients Know Best®

14 NHS Trusts across the UK
(Current pilot sites)

Glasgow

Northumbria

Newcastle

Liverpool

Manchester

Wolverhampton

Chelsea& Westminster
Guys & St Thomas's
Kings College
Homerton

Cardiff

Gloucester

Bournemouth

Plymouth

Results to date

- **466** patients actively using the system
- **866** online communications (messages) between patients and clinicians
- **948** test results automatically sent to patient accounts

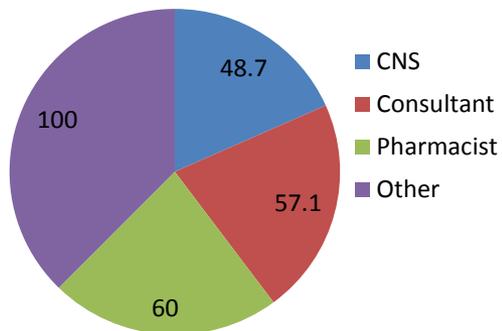
Results: Health Care Professional Survey

Response to questionnaire

Clinical Nurse Specialist	8
Consultant	14
Pharmacist	2
Other	3

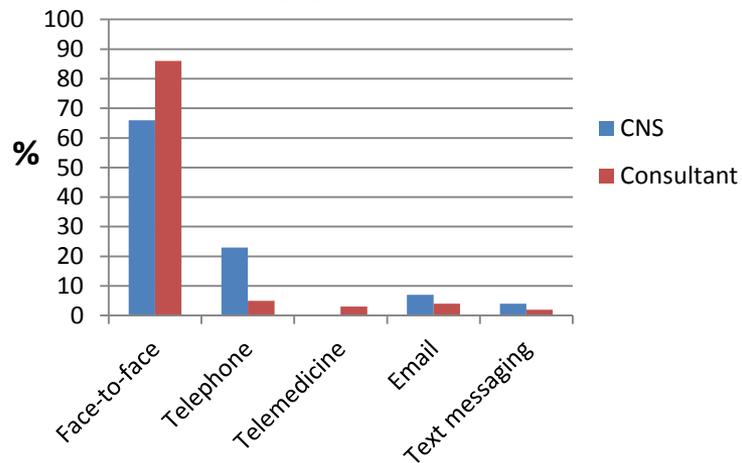
Response rate 30%

How many patients do you see per month?



Average DNA (Did Not Attend) 13%

Proportion of time spent on different contacts

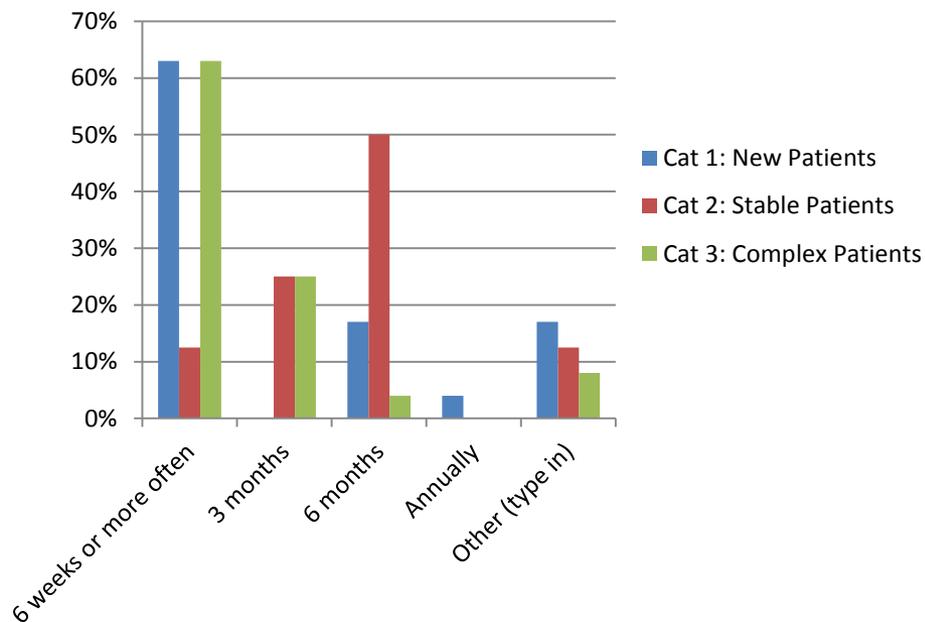


Results: HCP survey

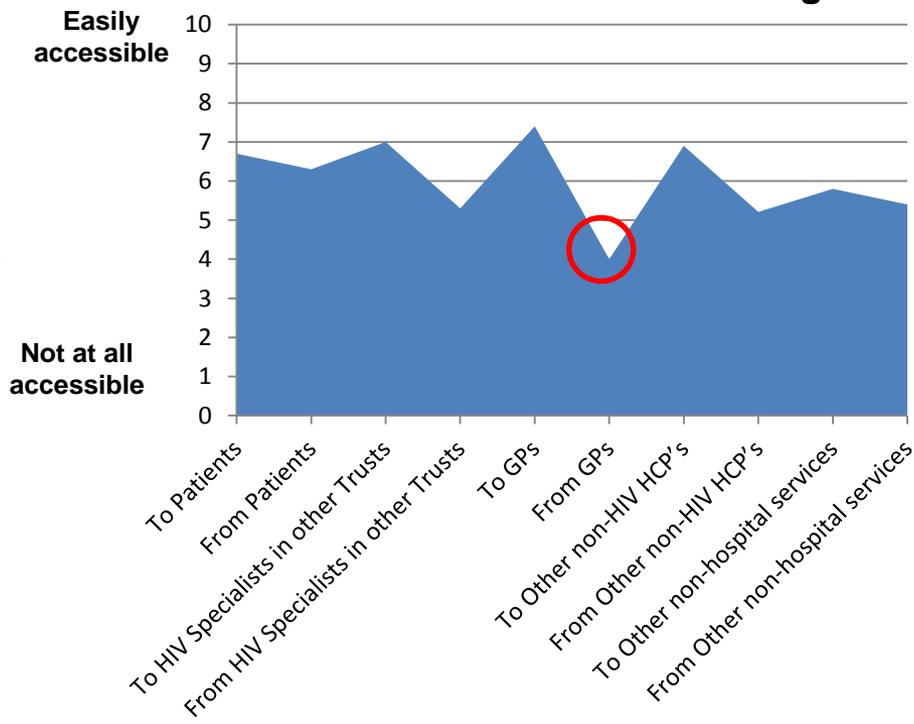
Amount of time spent with each type of patient per appointment

	10 or less	10 to 20	20 to 30	30 to 45	45 mins +
Cat 1: New patients	4%	33%	21%	0%	42%
Cat 2: Stable patients	12.50%	30%	42%	8%	8%
Cat 3: Complex patients	9%	9%	30%	39%	13%

How often each category of patient is seen



How easy is it to access medical information from the following



Results: HCP experiences

“Once our patients are familiar with PKB, I feel they will have confidence contacting us knowing they will receive a quick, confidential and safe reply via PKB”

“Patient held records have the potential to increase patient engagement / ownership of their care.

This may result in better adherence and improved patient outcomes

This system supports virtual working improving productivity and freeing up clinic time for more complex patients”

“Having three way conversations between the patient, consultant and CNS to organise a switch in ARVs was made possible with PKB that we could never have done as well over email. I was able to upload the blood results after the switch ("safety bloods") so its an example of a totally integrated episode of care.

“Enables us to deliver nurse-led services and community based clinics and reduces hospital visits. Facilitates patient feedback on services and helps us measure patients experience”

Results: Patient experiences

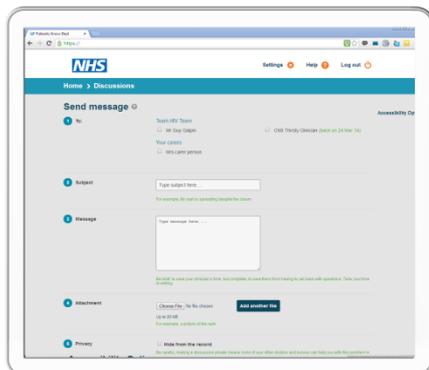
"A patient sent a message via PKB with a photo attachment showing facial and scalp pustular lesions and feeling unwell and said that he could not get an appointment to see his GP on the same day. I advised him that he could be seen in our emergency clinic that afternoon instead and indeed he was seen, examined and treated on the same day".

Dr Ed Ong, Newcastle



"...I had some bloods done on Friday morning (about 11:00am) and the results showed up on my personal PKB account late that afternoon, I also received an email telling me they were available to view on my account.

How cool is that?"
Patient, London



"A patient was concerned by his CD4 count results as they had dropped and contacted the Consultant via PKB to ask for his advice.

The Consultant replied and advised that it was because the patient had been ill recently and was nothing to worry about, the patient responded immediately to say that he was relieved". **Dr Ed Ong, Newcastle**

Conclusions

- To date patients have demonstrated engagement and enthusiasm for this patient-held record and online Consultation facility
- Currently clinicians feel two way communication with other healthcare workers, particularly GPs could be improved.
- The majority of consultations are face to face even for stable patients.
- Patient empowerment and self management are important to improving HIV care in the UK

Acknowledgements

- All the patients who have signed up to the patient held record
- The NHS staff that have worked to enable this pilot
- The support team at Patients Know Best®
- Janssen for sponsoring and initiating the pilot



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