

Patient Experience in Clinical Trials



NHIVNA 17-19th June 2015



POSITIVELY UK

anamiba@positivelyuk.org

My Treatment Background



POSITIVELY UK

My Experience

Why join the trial?

- Personal
- Clear Benefits
- Wider reasons

PIVOT – Protease Inhibitor monotherapy Vs Ongoing Tripple-therapy

A randomised control trial of a strategy of switching to boosted protease inhibitor monotherapy vs continuing combination antiretroviral therapy for the long term management of HIV-1 infected patients who have achieved sustained virological suppression on highly-active ARV therapy



My Experience

FOH5102 SC29288E ANGELINE NAMBA Dr Lucy Garvey F 17-03-1967

T-cell subsets Date first +ve HIV 17.11.1993

Date	CD3+%	CD4+%	CD6+%	CD3+	CD4+	CD6+	Ratio
03.10.14	72.8	45	26.1	1240	780	440	1.7
09.08.13	75.0	44	26.5	1180	650	460	1.5
04.07.13	74.7	44	29.7	1250	760	590	1.5
11.04.13	75.7	40	33.7	1220	650	540	1.2
17.01.13	76.1	41	32.6	1060	580	460	1.3
25.10.12	71.5	44	28.3	1000	570	420	1.3
07.08.12	80.0	49	30.0	1180	730	440	1.6
10.07.12	75	40	34	1070	570	490	1.16
20.06.12	76	39	36	1260	650	590	1.09
24.05.12	75	40	35	1080	580	490	1.20
23.02.12	74	38	36	660	440	400	1.10
22.11.11	72	34	36	1080	510	540	0.94

Reported Adherence over preceding Month

Date	Adherence(%)
23.10.12	98
11.12.09	96
24.04.09	>97
31.08.07	98

ADD a new Adherence record

Antiretrovirals Click on line to inspect/alter

Drug	Start	Stop
TEMOFIVIR	25.06.12	→
EMTRICITABINE	25.06.12	→
DARUNAVIR (B) (NC)	08.06.12	23.10.12
DARUNAVIR (D) (NC)	20.08.11	08.06.12
ZIDOVUDINE (AZT)	24.04.05	13.04.10
LAMIVUDINE (3TC)	24.04.05	13.04.10
HAETIR (gag)	24.04.05	19.08.11
ZIDOVUDINE (AZT)	25.09.98	26.11.98

ADD a new Drug record

→ in Stop means continuing

HIV viral loads

Date	Copies/ml	Log value	Method
07.08.12	<50	1.70	→
18.07.12	<50	1.70	→
20.04.12	205	2.31	→
08.06.12	306	2.59	→
31.05.12	542	2.73	→
24.05.12	142	2.15	→
13.02.12	<50	1.70	→
21.11.11	<50	1.70	→

View GRAPHs for this patient

Demographics CD4/Viral Chem/Haem Diags/Alerts Hepatitis GLN/Toxo Resistance CVD / TDM Pharmacy Virtual Clinic

Complete your editing and then you can click on these tabs to see other types of record

SELECT another patient SEE graph of this patient Print GP report Finish

Time-out in minutes set at 20

Patient Involvement in Clinical Trials

Engaging women

The reality

A 3rd of people living with HIV in the UK are women

70% are from BME communities
10,000 in London

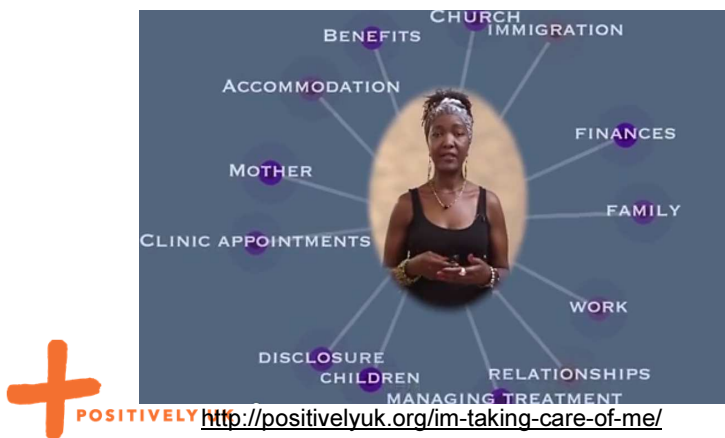
Majority are of childbearing age though age range increasing



?

Barriers to engaging women

Issues and barriers to participation



A few more barriers

Some reasons why People Living with HIV don't participate

- Lack of awareness.
- Don't think they qualify.
- Fear.
- Inconveniences.
- They intended to participate.
- Don't want placebo studies ie suboptimal
- Negative media re clinical trials



Patient Involvement in Clinical Trials

Engaging women in clinical trials

What can you do?

Narrative

'Ubuntu'

What's in it for women/their communities

Facilitation



Acknowledgements

Clinical Trials team at Imperial (St Mary's Hospital
Paddington)



Special thanks to Scott Mullaney

Patient Involvement in Clinical Trials

Questions



anamiba@positivelyuk.org