Clinic Network Collaboration and Patient Tracing To Maximize Retention in HIV Care

James McMahon MBBS MPH PhD
Department of Infectious Diseases, Alfred Hospital and Monash University
Department of Infectious Diseases, Monash Medical Centre
Centre for Population Health, Burnet Institute

Burnet Institute | Monash Health | MONASH University | TheAlfred

Victorian Initiative for Patient Engagement and Retention (VIPER)

- 2014 – mutual interest in establishing whereabouts of patients
  - Primary care – patient interrupted treatment and admitted to Alfred with opportunistic infection
  - Alfred – Quality audit of lost to follow-up
  - Other sites – also thinking about these issues

➔ Collaboration to establish degree of retention, transfer, LTFU across major HIV care sites

Background

- Sites
  - Hospitals – Alfred Health, Monash Medical Centre, Royal Melbourne Hospital
  - Melbourne Sexual Health Centre
  - High caseload clinics
    - Prahran Market Clinic
    - Northside Clinic
    - Centre Clinic
- Estimated 6300 PLHIV in Victoria[1]

1 2014 Kirby ASR

Aims


Clinic Network Collaboration and Patient Tracing to Maximize Retention in HIV Care

James H. McMahon[1,2,3]*, Richard Moore[4], Beng Eu[5], Ban-Kiem Tee[6], Marcus Chen[7,8], Carol El-Hayek[9], Alan Street[9], Ian Woolley[7,8], Andrew Buggie[7], Danielle Collins[9], Nicholas Medland[7], Jennifer Hoy[7], for the Victorian Initiative for Patient Engagement and Retention (VIPER) study group[¶]

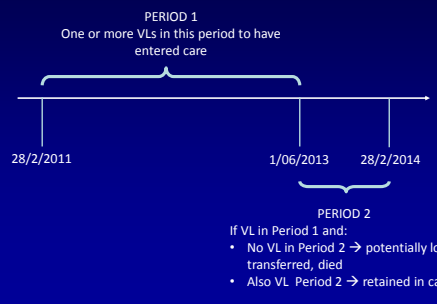
PLOS ONE | DOI:10.1371/journal.pone.0127726 May 26, 2015

- Determine whether people previously engaged in HIV care and who now have 'unknown outcomes' have died, transferred their care or become disengaged from care
- Obtain site-level estimates of the proportion retained in HIV care and lost to follow-up
- Identify individuals with unknown outcomes who are subsequently able to re-engage in HIV care
- Identify reasons for disengagement

Methods

- Identify PLHIV who received HIV care from 1/3/2011 - 31/5/2013
  - Defined as ≥ 1 attendance with HIV viral load
- Establish who did not have a viral load 31/5/2013 – 28/2/2014 (9 month period)

Methods



Methods

- For the group potentially lost / transferred
  - ➢Determine if attending HIV care elsewhere (e.g. results, transfer of medical records request)
  - ➢Cross-reference partially de-identified data with other network sites
  - ➢Cross reference with Burnet registry
  - ➢If no evidence of HIV care elsewhere then attempt contact to patient

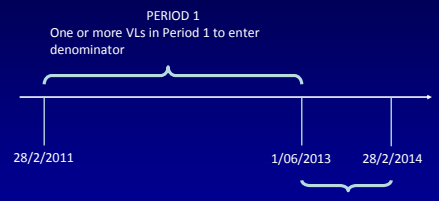
Methods

- People who can be contacted and not in HIV care:
  - Invited to re-engage in HIV care (original or external site)
  - Asked reasons why disconnected from care :
    - Feeling well, too busy, financial barriers, issues with transport to clinic, any additional factors

Potential Outcomes

Classification	Description
Retained in care	Viral load performed at an outside laboratory in the 9 month period
Retained with irregular viral load	Evidence of ongoing contact, including prescribing and dispensing of ART, within the 9 month period but no viral load performed
Retained at an external site	Viral load in Period 1 but never attended the site for HIV care. Mainly applicable to hospital sites where viral load performed but individual not receiving HIV care
Shared care	Evidence that attends >1 site regularly for HIV care. For people attending primary care and a hospital site. Considered retained in care
Died	
Confirmed transfer	Evidence receiving care from another HIV service provider (e.g. transfer of records request, medical correspondence, results) including name of the site
Unconfirmed transfer	Planned for transfer elsewhere but no documentation to confirm
Unknown	No information of where care was occurring or whether person was alive

Methods – Proportions

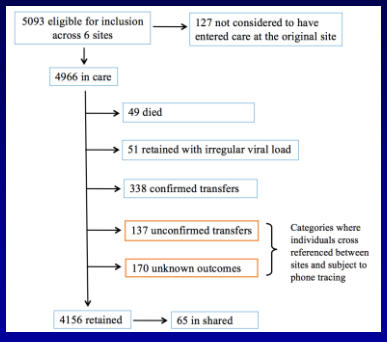


PERIOD 2
- No VL in Period 2 but VL performed in Period 1 in the numerator
- If only VL in Period 2 then exclude from numerator and denominator

Methods

- Outcomes compared pre- and post-intervention
- Compared additional baseline factors for patients with unknown outcomes who remained disengaged from care to those who transferred or returned to care
  - Categorical outcomes compared McNemar's test for paired groups, Chi-squared or Fisher's exact test for unpaired groups, continuous outcomes by Student's t-test and non-normal continuous outcomes by Wilcoxon rank-sum test (Stata v12)
- Ethical review boards at The Alfred, Monash Health and RMH approved the study for all sites

Results



Results

- Across 6 sites 5093 had HIV viral loads performed from 1/3/2011 – 31/5/2013
  - 127 individuals (119 hospital sites, 8 MSHC) classified as 'Retained in care at external site, and excluded → 4966 individuals considered in care at their respective sites
- Kirby 2014 ASR estimated 6300 PLHIV in Victoria. 4966 / 6300 = 78.8%

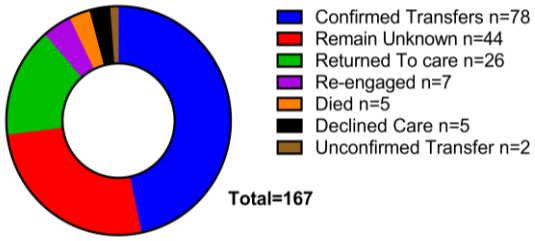
Results

		Individuals in care[a]	Outcome									
			Unknown[b] n, (%)		Unconfirmed transfer[c] n (%)		Confirmed transfer[d] n, (%)		Retention[e] %		Retention inc. confirmed transfer[f] %	
Pre- or Post-intervention			Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Site	SPC 1	805	11 (1.4)	1 (0.1)[g]	23 (2.9)	6 (0.7)[g]	30 (3.7)	51 (6.3)[g]	92.0	92.5	95.8	98.8[g]
	SPC 2	1102	14 (1.3)	4 (0.5)[g]	40 (3.6)	32 (2.9)[g]	25 (2.3)	40 (3.6)[g]	89.9	90.1	92.2	93.7[g]
	SPC 3	464	13 (2.8)	5 (1.1)[g]	5 (1.1)	1 (0.2)	39 (8.4)	49 (10.6)[g]	84.7	84.7	93.1	95.3[g]
	TMC 1	1188	61 (5.1)	13 (1.2)[g]	23 (1.9)	11 (0.9)[g]	114 (9.6)	161 (13.6)[g]	80.6	81.2	90.2	94.8[g]
	TMC 2	255	14 (5.5)	6 (2.4)[g]	12 (4.7)	5 (2.0)*	4 (1.6)	16 (6.3)[g]	84.3	85.1	85.9	91.4[g]
	SHC	1152	57 (4.9)	18 (1.7)[g]	34 (3.0)	16 (1.4)[g]	126 (10.9)	166 (14.4)[g]	80.1	81.3[g]	91.1	95.7[g]

NOTES: SPC, specialist primary care; TMC, tertiary medical centre; SHC, sexual health centre; * p<.05 for comparison to pre-intervention figure (McNemar's test); * p<.01 for comparison to pre-intervention figure (McNemar's test)
[a] individuals with at least one HIV viral load from 1/3/2011 to 31/5/2013 at the site excluding individuals who had not received HIV care at the site and were known to be in HIV care at an external site
[b] Individuals with unknown outcomes
[c] Individuals thought to have transferred care but no evidence in medical records to confirm that transfer occurred
[d] Evidence in medical records that care was transferred
[e] Individuals in care at the site or sharing with another site as a proportion of all individuals in care
[f] Defined as for retention but considers confirmed transfers also retained in care

7 re-engaged in care, 5 declined returning to care despite contact

Outcomes of Individuals with Unknown Outcomes post-intervention



Reasons for Disengagement

32 individuals interrupted care with 29 providing repsonses

Reason Category	Specific Reason*	Number of times reported
Well and Busy	Felt well[2]	12
	Longterm non-progressor "so won't get sick"	1
	Too busy[3]	7
Structural Barriers	Difficulty attending clinic[2] (e.g. transport, parking, long wait time)	5
	Difficulty arranging review	1
	Financial[2]	2
Psychosocial	Psychosocial stressors (unspecified)	5
	Difficulty accepting HIV diagnosis	2
	Wanting to ignore HIV	2
	Apathy and lowered mood	1
Other	Wanted a break from care	2
	Overseas for extended period	2
	Negative interaction with site	1
	Ran out of ART	1
	Incarcerated	1
	Don't believe in conventional treatments	1
	Needle phobia	1

NOTES:
* Despite being specific reasons listed on the questionnaire no individuals reported physical symptoms or problems from ART contributing to interruption
[2] Specific reasons listed on the questionnaire

Risk Factors for Disengagement – Baseline Characteristics

Characteristic	People with unknown outcomes pre-intervention[a] (n=164)	Re-entered or transferred care (n=111)	Remained unknown, died or declined (n=53)	p value
Age (± SD)	39.9 ± 9.8	40.9 ± 10.2	38.3 ± 8.8	0.3
Gender (% male)	91.5 %	90.1 %	92.5 %	0.8
Transmission risk category (% MSM)[b]	67.0 %	71.8 %	58.5 %	0.11
Non-English speaking background[c]	24.2 %	17.1 %	32.5 %	0.26
Medicare card holders[d]	95.7 %	97.3 %	92.5 %	0.21
Receiving ART at last visit	56.7 %	60.4 %	49.1 %	0.17
Active psychiatric condition[e]	25.6 %	20.7 %	55.6 %	0.04
Viral load copies/mL (Median, IQR)	127 (UD – 21212)	99 (UD – 18300)	600 (UD – 46100)	0.15

NOTES: MSM, men who have sex with men; ART, antiretroviral therapy; UD, undetectable; Characteristics compared by χ2 test or Fisher's exact test if cell frequencies ≤5 apart from age (students' t-test) and viral load (Wilcoxon rank sum test)
[a] Intervention of cross referencing data between sites and phone tracing for those still with unknown outcomes
[b] MSM as compared to non-MSM categories (IDU, combined IDU/MSM, Heterosexual, Unknown)
[c] Born outside of Australia and first language is not English
[d] Holder of Medicare card that allows access to publicly funded healthcare
[e] Receiving medication for a psychiatric condition (e.g. depression, anxiety, schizophrenia, bipolar affective disorder) or documented symptomatic psychiatric condition at last visit

Discussion

- High levels of retention, low LTFU
- Still identified individuals interrupting care and re-engaged patients
- Identify individuals with poor outcomes
  - Lymphoma off treatment in 2 people
- Retention data consistent with national and local data → 87-93% in care receiving ART and 89-94% of those suppressed[1]

1 2014 Kirby ASR, 2012 Alfred ID Unit Quality Audit

Discussion

- International retention data
  - Denmark, Sweden, France, Belgium 90-92%[1]
  - Canada 85-90%[2]
  - US MSM 66%[3]
- Most improvement post intervention was due to reclassification of individuals as confirmed transfers
- Advantage of linking individual level data

1 Van Beckhoven JIAS 2014, Helleberg PLoS One 2013, Supervie CROI 2013
2 Nosyk Lancet ID 2014 3 Singh MMWR 2010

Discussion

- Tracing would have been improved with up to date phone details
  - Ability to record email addresses in clinical record systems and use these to trace
- 'Felt well/too busy' reason for interruption highlights
  - Maintain awareness around need for HIV care
  - Flexible arrangements to access care

Discussion

- Different definitions of retention (e.g. time without VL) may have provided different results
- No distinction between initiating care and maintained in longer term care
- This study included largest sites in Victoria → ? Different results elsewhere

Acknowledgements

- Support from an investigator initiated unrestricted Gilead Fellowship Grant
- The Victorian Initiative for Patient Engagement and Retention (VIPER) group:
  - Richard Moore, Beng Eu, Ban-Kiem Tee, Marcus Chen, Carol El-Hayek, Alan Street, Ian Woolley, Andrew Buggie, Danielle Collins, Nicholas Medland, Jennifer Hoy, James McMahon
- Melissa Bryant for assistance with ethical review board submission across institutions