IeDEA Pediatric Adherence Site Assessment Survey

Please complete the survey below.

Thank you! **Site Information:** Please enter the date this survey is being completed: Please enter the center identification code below: Please enter the site name below: Please enter the program/network for this site below: Role of the person completing this survey (Please select only one): ☐ Principal Investigator ☐ Regional Data Manager ☐ Site Manager ☐ Site Data Manager ☐ Head Clinician ☐ Head Clinical Officer ☐ Head Nurse ☐ Other Please specify other role: Training of the person completing this survey (Please select only one): □ Pediatrician Non-Pediatrician Physician/Consultant/Physician Faculty ☐ Clinical Officer ☐ Nurse ☐ Pharmacist Counselor Data Manager Research Staff Epidemiologist ☐ Other Please specify other training: Please enter the name of the person completing the survey below: Please enter the email address of the person completing the survey below: Please enter the phone number of the person completing the survey below:



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1 . Site Location: (Please select only one)		
□ Urban		
☐ Mostly Urban		
☐ Mostly Rural		
☐ Rural ☐ Unknown		
GIRHOWH		
2. What is the primary setting in w (Please select only one)	hich you provide care for H	IV-infected children?
☐ Clinic where providers care for only chil	ldren	
☐ Clinic where providers care for both adu		family clinics)
·	·	•
3. Approximate total number of HI	wexposed and inviniected	children < 14 years or age who
had a visit within the last 12 mont	ths to the HIV program at th	e facility:
	to the int program at th	ic raciney.
4 Approximate number of childre		
T. Approximate number of cimare	n currently receiving ART:	
	n currently receiving ART:	
.,	n currently receiving ART:	
.,	n currently receiving ART:	
5. Is the following service utilized		eiving ART?
5. Is the following service utilized		eiving ART?
	at your site for children rec	-
5. Is the following service utilized a. Height measured at fixed	at your site for children rec	-
5. Is the following service utilized a. Height measured at fixed intervals b. Weight measured at fixed intervals	at your site for children rec	No □
5. Is the following service utilized a. Height measured at fixed intervals b. Weight measured at fixed	at your site for children rec	No □
 5. Is the following service utilized a. Height measured at fixed intervals b. Weight measured at fixed intervals c. CD4 monitoring at fixed intervals 	at your site for children rec	No □
5. Is the following service utilized a. Height measured at fixed intervals b. Weight measured at fixed intervals c. CD4 monitoring at fixed intervals d. Viral load monitoring at fixed	at your site for children rec	No □
 5. Is the following service utilized a. Height measured at fixed intervals b. Weight measured at fixed intervals c. CD4 monitoring at fixed intervals 	at your site for children rec	No □
 5. Is the following service utilized a. Height measured at fixed intervals b. Weight measured at fixed intervals c. CD4 monitoring at fixed intervals d. Viral load monitoring at fixed intervals e. Targeted viral loads (e.g., for 	at your site for children rec	No □
5. Is the following service utilized a. Height measured at fixed intervals b. Weight measured at fixed intervals c. CD4 monitoring at fixed intervals d. Viral load monitoring at fixed intervals	at your site for children rec	No □

f. Viral resistance testing

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6. How often are the following methods currently used to measure ART adherence? (Please select only one choice for each method)				
a. Structured recall instrument:24-hour recall of missed doses,3-day, 7-day, 30-day, other recall period.	Used routinely	Used occasionally	Not used	
b. Instrument with multiple questions about adherence.				
c. Pill counts				
d. Liquid measures				
e. Pharmacy refills				
f. Electronic dose monitoring				
g. Routine viral loads				
h. Viral loads for patients suspected of non-adherence.				
i. Drug levels				
j. Assessment of adherence by clinician, but not using any structured measure				
k. Other				
Please list other methods of measuring ART adherence:				
For method 6b above, are any instru	ments validated?	☐ Yes ☐ No		
Please enter validated instrument name(s):				

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(Please select only one) Caregiver		
☐ Child☐ Both caregiver and child☐		
Both caregiver and child		
8. At what age does your site begin	asking children directly a	bout adherence?
(ує	ears)	
9. Is the following type of adheren	ce support available at you	r site?
	Yes	No
a. Pill Boxes		
b. Counseling by dedicated adherence counselor		
c. Counseling by social worker		
d. Counseling by pharmacy personnel		
e. Counseling by clinical staff		
f. Counseling by physicians		
g. Case management		
h. Educational classes on adherence		
i. Support groups for caregivers		
j. Support groups for children/adolescents		
k. Peer adherence supporters or treatment buddies		
I. Home visits		
m. SMS adherence reminders		
n. Nutritional support		
o. Other		
Please list other methods of adherence	support:	
		The state of the s
 Does your site routinely give pat medicine to take them beyond thei 		
medicine to take them beyond thei	r next clinic appointment (aka, medication tail):
☐ Yes ☐ No		
— If Yes, what medication amount is provided (Please select only one)	?	
□ extra medication for 1-3 days□ extra medication for 4-30 days□ extra medication for >30 days		

11. CASE STUDY: A 4-month-old infant with a positive HIV DNA PCR and confirmatory positive HIV RNA PCR presents to your site. The infant has no prior ART exposure.

a. Which criteria would your site use for starting ART for th	is infant? (Please select all that apply)
 □ All 4-month-old HIV-positive children are started on ART □ Start if WHO Stage 3 or 4 □ Start if CDC class C □ Start if CDC class B □ Start if CD4 % < 25% □ Start if CD4 % < 20% □ Start if CD4 % < 15% □ Start if having clinical symptoms of HIV regardless of oth symptomatic (e.g., IMCI guidelines) □ Other 	
Please list other criteria for starting ART:	
b. Does your site use a purely age-based criteria for initiati automatically started?	ng ART by which all children less than a specific age ar
☐ Yes ☐ No	
If Yes, please enter the age at which all HIV-positive children are initiated:	(age in years)
c. Which 3 antiretroviral medications would a clinician at you 4-month-old child?	our site typically select for a first-line regimen for this
Medication 1 (Please select only one)	☐ Abacavir (ABC) ☐ Atazanavir (ATV) ☐ Darunavir (DRV) ☐ Delavirdine (DLV) ☐ Didanosine (ddl) ☐ Efavirenz (EFV) ☐ Emtricitabine (FTC) ☐ Indinavir (IND) ☐ Lamivudine (3TC) ☐ Lopinavir/ritonavir (LPV/rit) ☐ Nelfinavir (NFV) ☐ Nevirapine (NVP) ☐ Saquinavir (SQV) ☐ Stavudine (d4T) ☐ Tenofovir (TDF) ☐ Zidovudine (ZDV/AZT)
Medication 2 (Please select only one)	☐ Abacavir (ABC) ☐ Atazanavir (ATV) ☐ Darunavir (DRV) ☐ Delavirdine (DLV) ☐ Didanosine (ddl) ☐ Efavirenz (EFV) ☐ Emtricitabine (FTC) ☐ Indinavir (IND) ☐ Lamivudine (3TC) ☐ Lopinavir/ritonavir (LPV/rit) ☐ Nelfinavir (NFV) ☐ Nevirapine (NVP) ☐ Saquinavir (SQV) ☐ Stavudine (d4T) ☐ Tenofovir (TDF) ☐ Zidovudine (ZDV/AZT)

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Medication 3 (Please select only one)	☐ Abacavir (ABC) ☐ Atazanavir (ATV) ☐ Darunavir (DRV) ☐ Delavirdine (DLV) ☐ Didanosine (ddl) ☐ Efavirenz (EFV) ☐ Emtricitabine (FTC) ☐ Indinavir (IND) ☐ Lamivudine (3TC) ☐ Lopinavir/ritonavir (LPV/rit) ☐ Nelfinavir (NFV) ☐ Nevirapine (NVP) ☐ Saquinavir (SQV) ☐ Stavudine (d4T) ☐ Tenofovir (TDF) ☐ Zidovudine (ZDV/AZT)
d. After the infant has been on ART for at least one montl the clinic for this infant who is less than one year of age?	h, how often would you schedule follow-up appointments at ? (Please select only one)
 □ Every 2 weeks □ Once a month □ Every other month □ Every 6 months □ Once a year □ Other 	
Please list other followup appointment schedules:	
e. After the infant's first 6 months on ART, the CD4% do you suspect that adherence may be an issue. What strat employ for an infant on ART with adherence concerns? (
Adherence counseling for parent or caregiver More frequent follow-up in clinic Viral load immediately Viral load at some point in future Repeat CD4 immediately CD4 at some point in future Viral resistance testing immediately Viral resistance testing at some point in future Home visit or community health worker follow-up Institute pill counts or liquid volume measurements Dose-timing monitoring, such as MEMS cap or Wisepil Directly observed therapy Plasma drug concentrations Hair drug concentrations Other	
Please list other strategies for adherence concerns: f. You determine that an HIV-infected infant has failed fire	
a standard second-line regimen available at your site for	r a child of this age?
☐ Yes ☐ No	

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If Yes, what medicines would typically be selected for your second-line regimen for an infant < 12 months?	Abacavir (ABC) Atazanavir (ATV) Darunavir (DRV) Delavirdine (DLV) Didanosine (ddl) Efavirenz (EFV) Emtricitabine (FTC) Indinavir (IND) Lamivudine (3TC) Lopinavir/ritonavir (LPV/rit) Nelfinavir (NFV) Nevirapine (NVP) Saquinavir (SQV) Stavudine (d4T) Tenofovir (TDF) Zidovudine (ZDV/AZT) Other Medicines

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Please enter other medicines:

12. CASE STUDY: A 3-year-old child with a positive HIV ELISA Antibody Test and clinical symptoms consistent with HIV (poor growth, lymphadenopathy, history of recurrent infections) presents to your site. The child has no prior ART exposure or treatment.

a. Which criteria would your site use for starting ART for this chil	ld? (Please select all that apply)
 □ All HIV-positive children 3 years of age are started on ART □ Start if WHO Stage 3 or 4 □ Start if CDC class C □ Start if CDC class B □ Start if CD4 % < 25% □ Start if CD4 % < 20% □ Start if CD4 % < 15% □ Start if CD4 count < 500 cells/ml □ Start based only on having clinical symptoms of HIV, no other □ Other 	tests to be obtained (e.g., IMCI guidelines)
Please list other criteria for starting ART:	
b. Which 3 antiretroviral medications would a clinician at your sit who is 3 years old?	te typically select for a first-line regimen for a child
Medication 1 (Please select only one)	Abacavir (ABC) Atazanavir (ATV) Darunavir (DRV) Delavirdine (DLV) Didanosine (ddl) Efavirenz (EFV) Emtricitabine (FTC) Indinavir (IND) Lamivudine (3TC) Lopinavir/ritonavir (LPV/rit) Nelfinavir (NFV) Nevirapine (NVP) Saquinavir (SQV) Stavudine (d4T) Tenofovir (TDF) Zidovudine (ZDV/AZT)
Medication 2 (Please select only one)	☐ Abacavir (ABC) ☐ Atazanavir (ATV) ☐ Darunavir (DRV) ☐ Delavirdine (DLV) ☐ Didanosine (ddl) ☐ Efavirenz (EFV) ☐ Emtricitabine (FTC) ☐ Indinavir (IND) ☐ Lamivudine (3TC) ☐ Lopinavir/ritonavir (LPV/rit) ☐ Nelfinavir (NFV) ☐ Nevirapine (NVP) ☐ Saquinavir (SQV) ☐ Stavudine (d4T) ☐ Tenofovir (TDF) ☐ Zidovudine (ZDV/AZT)

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1 496 3 57 10
☐ Abacavir (ABC) ☐ Atazanavir (ATV) ☐ Darunavir (DRV) ☐ Delavirdine (DLV) ☐ Didanosine (ddl) ☐ Efavirenz (EFV) ☐ Emtricitabine (FTC) ☐ Indinavir (IND) ☐ Lamivudine (3TC) ☐ Lopinavir/ritonavir (LPV/rit) ☐ Nelfinavir (NFV) ☐ Nevirapine (NVP) ☐ Saquinavir (SQV) ☐ Stavudine (d4T) ☐ Tenofovir (TDF) ☐ Zidovudine (ZDV/AZT)
he child was 5 years old? (Please select only one)
nth, how often would you schedule follow-up appointments a
or one year, but the child's CD4% does not improve and the stioning the child's mother, you suspect that adherence may at your site typically employ for a now 4-year-old child on A
s epill
first-line therapy at 4 years of age. Would you have ite for a child of this age?
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If Yes, what medicines would typically be selected for your second-line regimen for a child less than 5 years of age?	☐ Abacavir (ABC) ☐ Atazanavir (ATV) ☐ Darunavir (DRV) ☐ Delavirdine (DLV) ☐ Didanosine (ddl) ☐ Efavirenz (EFV) ☐ Emtricitabine (FTC) ☐ Indinavir (IND) ☐ Lamivudine (3TC) ☐ Lopinavir/ritonavir (LPV/rit) ☐ Nelfinavir (NFV) ☐ Nevirapine (NVP) ☐ Saquinavir (SQV) ☐ Stavudine (d4T) ☐ Tenofovir (TDF) ☐ Zidovudine (ZDV/AZT) ☐ Other Medicines	

Confidential- Site Name ______ Date _____

Please enter other medicines:

13. CASE STUDY: A 7-year-old orphan with a positive HIV ELISA Antibody Test and clinical symptoms consistent with HIV (poor growth, lymphadenopathy, history of recurrent infections) presents to your site. The child has no prior ART exposure or treatment.

a. Which criteria would your site use for starting ART for	this child? (Please select all that apply)
☐ All HIV-positive children 7 years of age are started on ☐ Start if WHO Stage 3 or 4 ☐ Start if CDC class C ☐ Start if CDC class B ☐ Start if CD4 % < 25% ☐ Start if CD4 % < 20% ☐ Start if CD4 % < 15% ☐ Start if CD4 count < 500 cells/ml ☐ Start if CD4 count < 350 cells/ml ☐ Start if CD4 count < 250 cells/ml ☐ Start based only on having clinical symptoms of HIV, n ☐ Other	
Please list other criteria for starting ART:	
b. Which 3 antiretroviral medications would a clinician at child?	your site typically select for a first-line regimen for this
Medication 1 (Please select only one)	☐ Abacavir (ABC) ☐ Atazanavir (ATV) ☐ Darunavir (DRV) ☐ Delavirdine (DLV) ☐ Didanosine (ddl) ☐ Efavirenz (EFV) ☐ Emtricitabine (FTC) ☐ Indinavir (IND) ☐ Lamivudine (3TC) ☐ Lopinavir/ritonavir (LPV/rit) ☐ Nelfinavir (NFV) ☐ Nevirapine (NVP) ☐ Saquinavir (SQV) ☐ Stavudine (d4T) ☐ Tenofovir (TDF) ☐ Zidovudine (ZDV/AZT)
Medication 2 (Please select only one)	☐ Abacavir (ABC) ☐ Atazanavir (ATV) ☐ Darunavir (DRV) ☐ Delavirdine (DLV) ☐ Didanosine (ddl) ☐ Efavirenz (EFV) ☐ Emtricitabine (FTC) ☐ Indinavir (IND) ☐ Lamivudine (3TC) ☐ Lopinavir/ritonavir (LPV/rit) ☐ Nelfinavir (NFV) ☐ Nevirapine (NVP) ☐ Saquinavir (SQV) ☐ Stavudine (d4T) ☐ Tenofovir (TDF) ☐ Zidovudine (ZDV/AZT)

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Medication 3 (Please select only one)	☐ Abacavir (ABC) ☐ Atazanavir (ATV) ☐ Darunavir (DRV) ☐ Delavirdine (DLV) ☐ Didanosine (ddl) ☐ Efavirenz (EFV) ☐ Emtricitabine (FTC) ☐ Indinavir (IND) ☐ Lamivudine (3TC) ☐ Lopinavir/ritonavir (LPV/rit) ☐ Nelfinavir (NFV) ☐ Nevirapine (NVP) ☐ Saquinavir (SQV) ☐ Stavudine (d4T) ☐ Tenofovir (TDF) ☐ Zidovudine (ZDV/AZT)
 c. After the child has been on ART for at least one mont the clinic for this 7-year-old? (Please select only one) 	th, how often would you schedule follow-up appointments at
 □ Every 2 weeks □ Once a month □ Every other month □ Every 6 months □ Once a year □ Other 	
Please list other followup appointment schedules:	
	CD4 count does not improve and the child has a new d's grandmother, you suspect that adherence may be an t your site typically employ for a 7-year-old child on ART
 □ Adherence counseling for caregiver □ More frequent follow-up in clinic □ Viral load immediately □ Viral load at some point in future □ Repeat CD4 immediately □ CD4 at some point in future □ Viral resistance testing immediately □ Viral resistance testing at some point in future □ Home visit or community health worker follow-up □ Institute pill counts or liquid volume measurements □ Dose-timing monitoring, such as MEMS cap or Wisep □ Directly observed therapy □ Plasma drug concentrations □ Other 	pill
Please list other strategies for adherence concerns:	
 e. You determine that an HIV-infected child has failed for a standard second-line regimen available at your sit 	
☐ Yes ☐ No	

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If Yes, what medicines would typically be selected for your second-line regimen for a child more than 5 years of age but less than 12 years of age?	

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Please enter other medicines:

4. Medication availability - Please indi	cate which medications your site usually has available
Abacavir (ABC) available?	☐ Yes ☐ No
Pediatric fomulation available?	☐ Yes ☐ No
Problems with stockouts?	☐ Rare ☐ Sometimes ☐ Common
Atazanavir (ATV) available?	☐ Yes ☐ No
Pediatric fomulation available?	☐ Yes ☐ No
Problems with stockouts?	☐ Rare ☐ Sometimes ☐ Common
Darunavir (DRV) available?	☐ Yes ☐ No
Pediatric fomulation available?	☐ Yes ☐ No
Problems with stockouts?	☐ Rare ☐ Sometimes ☐ Common
Delavirdine (DLV) available?	☐ Yes ☐ No
Pediatric fomulation available?	☐ Yes ☐ No
Problems with stockouts?	☐ Rare ☐ Sometimes ☐ Common
Didanosine(ddl) available?	☐ Yes ☐ No
Pediatric fomulation available?	☐ Yes ☐ No
Problems with stockouts?	☐ Rare☐ Sometimes☐ Common
Efavirenz (EFV) available?	☐ Yes ☐ No
Pediatric fomulation available?	☐ Yes ☐ No
Problems with stockouts?	☐ Rare ☐ Sometimes ☐ Common
Emtricitabine (FTC) available?	☐ Yes ☐ No
Pediatric fomulation available?	☐ Yes ☐ No
Problems with stockouts?	☐ Rare ☐ Sometimes ☐ Common
Indinavir (IND) available?	☐ Yes ☐ No
Pediatric fomulation available?	☐ Yes ☐ No
Problems with stockouts?	☐ Rare ☐ Sometimes ☐ Common
Lamivudine (3TC) available?	☐ Yes ☐ No
Pediatric fomulation available?	☐ Yes ☐ No
Problems with stockouts?	☐ Rare ☐ Sometimes ☐ Common

☐ Yes ☐ No

☐ Common

☐ Rare ☐ Sometimes

Pediatric fomulation available?

Problems with stockouts?

			Page 16
15. Are third-line ART options	available for o	children?	i age 10
☐ Yes ☐ No			
Please list third-line ART option 1			
Please list third-line ART option 2			
Please list third-line ART option 3			
Please list third-line ART option 4			
Please list third-line ART option 5			
Please list third-line ART option 6			
Please list third-line ART option 7			
Please list third-line ART option 8			
Please list third-line ART option 9			
Please list third-line ART option 10			
a. 1st line ART		_	
b. 2nd line ARTc. OI prophylaxisd. Routine follow-upe. Travel to clinic			
c. OI prophylaxisd. Routine follow-upe. Travel to clinic			
c. OI prophylaxisd. Routine follow-upe. Travel to clinicf. CD4 counts			
c. OI prophylaxis d. Routine follow-up e. Travel to clinic f. CD4 counts g. Viral loads	ceceived train	ing on counseling the fo	ollowing populations?
c. OI prophylaxis d. Routine follow-up e. Travel to clinic f. CD4 counts g. Viral loads 17. Have any staff at your site i	received train		ollowing populations?
c. OI prophylaxis d. Routine follow-up e. Travel to clinic f. CD4 counts g. Viral loads 17. Have any staff at your site is a. Families		ing on counseling the fo	ollowing populations?
c. OI prophylaxisd. Routine follow-upe. Travel to clinicf. CD4 counts			ollowing populations?
c. OI prophylaxis d. Routine follow-up e. Travel to clinic f. CD4 counts g. Viral loads 17. Have any staff at your site i a. Families b. Parents or caregivers c. Children or adolescents	Yes	No	
c. OI prophylaxis d. Routine follow-up e. Travel to clinic f. CD4 counts g. Viral loads 17. Have any staff at your site i a. Families b. Parents or caregivers c. Children or adolescents	Yes	No	
c. OI prophylaxis d. Routine follow-up e. Travel to clinic f. CD4 counts g. Viral loads 17. Have any staff at your site is a. Families b. Parents or caregivers c. Children or adolescents 18. Have any staff at your site is yes	Yes 	No 	ng for medication adhei
c. OI prophylaxis d. Routine follow-up e. Travel to clinic f. CD4 counts g. Viral loads 17. Have any staff at your site i a. Families b. Parents or caregivers c. Children or adolescents 18. Have any staff at your site i Yes No	Yes 	No 	ng for medication adhei

20. Have any staff at your site received specific train	ning on counseling related to disclosure of
HIV status to children?	
☐ Yes ☐ No	
21. Does your site have a protocol for disclosure of	HIV status to children?
☐ Yes ☐ No	
a. If Yes, date protocol was initiated:	
b. If Yes, was the protocol designed locally or was it borrowed/adapted from another program?	☐ Designed locally☐ Borrowed/adapted
Please identify the materials or protocol that are used:	
22.Is there a recommended age for disclosure of HI	V status to children?
☐ Yes ☐ No	
a. If Yes, at what age is the disclosure process started?	
b. If Yes, at what age is the disclosure process completed?	
23. Are disclosure counseling services offered?	
☐ Yes ☐ No	
a. If Yes, by whom (please check all that apply)?	
☐ Physicians ☐ Nurses ☐ Other clinicians ☐ Counselors ☐ Social worker ☐ Other	
Please specify others who provide disclosure counseling services:	
b. If Yes, to whom are the disclosure counseling services offered	d? (Please select only one)
☐ Caregivers☐ Children☐ Both caregivers and children	

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24. Who participates in the disclosure process? (Please check all that apply)
☐ Caregivers ☐ Physicians ☐ Nurses ☐ Other clinicians ☐ Counselors ☐ Social worker ☐ Other
Please specify others who participate in the disclosure process:
25.Is disclosure status collected routinely at your site?
☐ Yes ☐ No
a. If Yes, method of collection (Please check all that apply)
☐ Interview with caregiver ☐ Interview with child ☐ Other
Please list other methods of collection:
b. If Yes, who collects disclosure status? (Please check all that apply)
☐ Physicians ☐ Nurses ☐ Other clinicians ☐ Counselors ☐ Social worker ☐ Other
Please list others who routinely collect disclosurestatus:
c. If Yes, how often is disclosure status collected? (Please select only one)
 □ Every month □ Every three months □ Every six months □ Once a year □ Other
Please list other frequency for the collection of disclosure status:
d. If Yes, are the disclosure status data stored electronically (i.e. entered into a computer)?
☐ Yes ☐ No
e. If disclosure status is routinely collected, is the associated date recorded?"
☐ Yes ☐ No
26.In your estimation, what percentage of children at your site know that they are HIV-infected by the time they reach 14 years of age?
(%)