## Ukraine Paediatric HIV Cohort Enrolment data collection form

Child Identification r	number:	Date form completed	d (dd/mm/yy):
Centre:		Paediatrician:	
Demographics and H	V history		
Child's date of birth (dd	//mm/yy):	Coul	ntry of birth:
Sex	Birth weight (g)	Birth length (cm)	Gestational age (completed weeks)
Male / Female			,
What was the child's m	ost likely mode of HIV	acquisition?	
Mother-to-child Unknown	transmission Y / N	•	cts / transfusion Y / N
Were any antiretrovira	al drugs for PMTCT red	ceived by the mother an	d/or child?
Mother: single dose Ne	virapine Y / N Zido	vudine Y / N HAAF	RT: Y / N If yes for ZDV or HAART:
Infant: single dose Nev	irapine Y / N Zido	vudine Y / N (for	for weeks? weeks)
When was this child dia	agnosed as HIV-infected	d? (dd/mm/yy)	
Date of most recent po	sitive HIV antibody test	(dd/mm/yy)	
What is the living situa	ation of this child?		
Living with family	(please specif	y, eg mother, father etc	·)
Living in an institution	_		
Other (please specify)			
If available, please pr	ovide the following inf	formation on the child	's <u>mother</u> :
Maternal age at deliver	y of this child:	years	
Marital status: single	/ married / coha	biting / divorced /	widowed / unknown
Age at leaving full-time	education:	years	
Number of living childre	en (including the current	t child)	
Employment status: n	ot in paid employment	/ in part-time employme	ent / in full-time employment / unknown
	r have a history of injectilid may have had neon		r past use) – this may have been reported ne. Y / N

Immunological and virological status
Please give available results from initial date of HIV diagnosis (only one height/weight per year required):

Date	CD4 count (cells/mm³)	CD4%	Total lymphocytes	HIV RNA load (copies/ml)	Height (cm)	Weight (kg)

<u>Clinical status</u>		
Has this child been diagnosed with AIDS?		Y / N
Date of AIDS diagnosis: AIDS indicate	or disease:	
Has the child ever had any of the following? If yes, please	e provide d	late of onset:
Unexplained moderate malnutrition	Y / N	
Unexplained persistent diarrhoea (>13 days)	Y / N	
Unexplained persistent fever (>1 month)	Y / N	
Persistent oral candidiasis (after first 6-8 weeks of life)	Y / N	
Oral hairy leukoplakia	Y / N	
Acute necrotizing ulcerative gingivitis or periodontitis	Y / N	
Lymph node tuberculosis	Y / N	
Pulmonary tuberculosis	Y / N	
Severe recurrent bacterial pneumonia	Y / N	
Symptomatic lymphoid interstitial pneumonitis	Y / N	
Chronic HIV-associated lung disease	Y / N	
Unexplained severe wasting, stunting or severe malnutrition	Y / N	
Pneumocystis pneumonia	Y / N	
Recurrent severe bacterial infections(excluding pneumonia)	Y / N	
Chronic HSV infection	Y / N	
(orolabial or cutaneous of >1 mth duration or visceral at any si	ite)	
Extrapulmonary tuberculosis	Y / N	
Kaposi sarcoma	Y / N	
Oesophageal candidiasis	Y / N	
(or candidiasis of trachea, bronchi or lungs)		
Central nervous system toxoplasmosis (after age 1 mth)	Y / N	
HIV encephalopathy	Y / N	
CMV infection: retinitis or another organ (after age 1 mth)	Y / N	
Extrapulmonary cryptococcosis (including meningitis)	Y / N	
Disseminated endemic mycosis	Y / N	
(extrapulmonary histoplasmosis, coccidiomycosis)		
Chronic cryptosporidiosis	Y / N	
Chronic isosporiasis	Y / N	
Disseminated non-tuberculous mycobacterial infection	Y / N	
Cerebral or B-cell non-Hodgkin lymphoma	Y / N	
Progressive multifocal leukoencephalopathy	Y / N	
Symptomatic HIV-associated nephropathy	Y / N	
HIV-associated cardiomyopathy	Y / N	

# Has the child had any of the following within the past 6 months?

If yes,	provide	date	of	onset:
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Persistent generalized lymphace Persistent hepatosplenomegaly Papular pruritic eruptions Extensive wart virus infection Extensive molluscum contagios Fungal nail infections Recurrent oral ulcerations Unexplained persistent parotid Lineal gingival erythema Herpes zoster Recurrent or chronic upper resp (otitis media, otorrhoea, sinusiti	um enlargement piratory tract infections	Y/N Y/N Y/N Y/N Y/N Y/N Y/N Y/N Y/N Y/N			
Has the child been hospitalize	ed in the past 6 months	s?	Y/N	If yes, please	e provide:
Duration of stay: Days					
Reason:					
Coinfections Was this child born to a mother  If this child is aged ≥18 month		,			
Anti-HCV	Positive / Negative	Date:			/ Not tested
Was this child's <b>mother</b> :	HBsAg positive? HBeAg positive?			ever tested ever tested	
Has this child been vaccinated	against HBV? Y / I	N / un	known		
What is the HBV status of this of	hild?				
HBsAg	Positive / Negative	Date:		1	not tested
HBeAg	Positive / Negative	Date:		/	not tested
	If this child is HCV sero				

# **Treatment**

Has the child <u>ever\_received any</u> antiretroviral therapy (excluding PMTCT prophylaxis)?

No / Yes (if yes, please specify below. If ongoing, leave date stopped column blank)

Drug	Total daily dose	Dose unit (mg or ml)	Frequency per day (1)	Formulation (2)	Start date	End date (blank if use ongoing)	Reason for stopping (3)

		1		
		1		

- (1) Frequency per day: 1=1 daily dose / qd; 2=2 daily doses/bid;3=3 daily doses/tid (2) Formulation: 1 = tablet/capsule/gelcap; 2 = liquid/syrup/suspension; 3 = combination of 1 and 2; 4= other
- (3) Reason for stopping: coding as follows:

1 = Treatment failure (i.e. virological, immunological, and/or	92.2 = Treatment too complex
clinical failure)	92.3 = Drug interaction
2 = Abnormal fat redistribution	93 = Structured Treatment Interruption (STI)
3 = Concern of cardiovascular disease	94 = Patient's wish/decision
4 = Hypersensitivity reaction	94.1 = Non-compliance
5 = Toxicity	95 = Physician's decision
70 = Pregnancy – toxicity concerns	98 = Other causes
92 = Availability of more effective treatment	99 = Unknown
92.1 = Simplified treatment available	

## **Prophylaxis**

Has the child ever received any prophylaxis (e.g. to prevent PCP, TB etc) No / Yes

Drug name	Date started	Date stopped	Currently taken?
			Yes / No

<u>Measurements</u>	Date of measurements	(dd/mm/yy) .			
(Weight and height to be re	ecorded on the table on pa	age 1)			
Waist circumference (cm)		Hip circumf	f <b>erence</b> (cm	າ)	
Tanner score for pubertal	stage (I - V):				
For girls: age at menarche (y	years and months)	or not yet ap	plicable □		
Blood pressure (mm/Hg): Please perform 3 measurem			3	•	
Other tests Please prov	vide results:				
Date blood drawn (dd/mm/yy	y)	Dlagge ring:			
Total cholesterol (mg/dl):		Please ring: Fasting /		)	
Triglycerides (mg/dl):		Fasting /	non-fasting	9	
ALT (U/I):					
Neutrophils (cells/mm³):					
Haemoglobin (g/dl):					
Does the child have impaired Does the child have impaired (i.e. fasting glucose <126 mg post oral glucose tolerance t	d glucose tolerance? g/dl_ <u>and</u> glucose value 2 ho	,		Yes / Yes /	No No

## **Body fat redistribution**

Please complete the following table, with one tick  $(\sqrt{})$  per row.

"Mild" symptoms are defined as those only noticeable when specifically inspected, "moderate" as readily obvious to the child / carer and "severe" as obvious to a casual observer.

	Normal	Mild	Moderate	Severe
Fat loss				
Face (sunken cheeks, sunken eyes, prominent zygomatic arch)				
Arms (skinny; prominent veins, muscularity and bones)				
Legs (skinny; prominent veins, muscularity and bones)				
Buttocks (loose skin folds, prominent muscles, loss of				
contour and fat, hollowing)				
Fat accumulation				
Trunk (increase in abdominal girth)				
Base of neck / back ("buffalo hump")				
Breast enlargement				

## **Children with HCV coinfection**

	Please 6	complete	this section	າ if this	child is:
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- Aged >18 months
- Seropositive for HCV antibodies

HCV genotype (if available):				
Has this child had a liver biopsy?	N / Y		date:	
	result:			
Has this child had a fibroscan/ultrasound?	N /	Υ	date:	
	result:			
Has this child received treatment for HCV infec	tion or is su	uch treatment c	ongoing?	N / Y
Reason for starting treatment:				
Drug(s):		Doses:		
Start date: Stop d	late (leave	blank if ongoin	g):	
Was this treatment stopped prematurely?	N / Y	/		
	If yes, rea	ason:		
What was the outcome of treatment (e.g. early	virologic re	esponse, sustai	ned virologic resp	oonse) ?

If any HCV RNA PCR test results are a	valiable, please provide them here (before, during and after treatment):
HCV RNA copies/ml	Date blood drawn:
HCV RNA copies/ml	Date blood drawn:
HCV RNA copies/ml	Date blood drawn:

Please report any ALT measurements on page 4.