



Essential Information for Children with Special Healthcare Needs

HL7 Patient Care Work Group
Update

Tuesday – 9/12/2017

Aim & Scope

- Design a clinical reference for children that require complex medical care (entering new environments)*
 - reuse existing elements (e.g., section templates)
 - medications
 - immunizations
 - allergies
 - problems
 - plan of care**
 - provide detailed contact information for primary and subspecialty health care providers
 - develop a model for contingency-based plan of care (personalized to an individual's need)
 - medical devices (e.g. tracheostomy, g-tube, etc...)

a.k.a.

- Personal Health Record...
 - Portable Health Record....
 - Emergency Information Form....
- ...for Children with Special Healthcare Needs

Example references:

- Emergency Information Form for Children with Special Needs (AAP/ACEP)
- Portable Health Record for Children, Youth or Adults with Genetic Conditions (Hawaii)
- CMS Form 485 – Home Health Certification Plan of Care

Emergency Information Form for Children With Special Needs

American College of
Emergency Physicians*

American Academy
of Pediatrics



Date form completed 1/1/97
By Whom J. Heart, MD

Revised 5/15/98 Initials JH
Revised Initials

Last name:

Name: Blue, Little B.		Birth date: 7/4/96	Nickname: LB
Home Address: 1313 Mockingbird Lane, Anytown, USA, 11111		Home/Work Phone: 900-555-1212 (home) 777-8899 (work)	
Parent/Guardian: Sandra Blue, mother	Emergency Contact Names & Relationship: Beatrice Blue,		
Signature/Consent*: <i>Sandra Blue</i>	grandmother		
Primary Language: English	Phone Number(s): 900-444-5566		
Physicians:			
Primary care physician: Marcus Welby, MD		Emergency Phone: 1-800-KIDS-RUS	
		Fax: 000-000-0000	
Current Specialty physician: P. Card. Jim Heart, MD		Emergency Phone: 000-000-0000	
Specialty:		Fax: 000-000-0000	
Current Specialty physician: P. Neuro. Joe Neuro, MD		Emergency Phone: 000-000-0000	
Specialty:		Fax: 000-000-0000	
Anticipated Primary ED: Smallville Hospital		Pharmacy:	
Anticipated Tertiary Care Center: Childrens All Star Regional Med Center			

Diagnoses/Past Procedures/Physical Exam:

1. tetralogy of Fallot with pulmonary atresia; RV to PA

conduit 2/97 VSD left, ductus and collaterals ligated

Baseline physical findings: gr III harsh murmur, few crackles

at base of left lung, liver down 5 cm.

Features to include...

■ Devices

- Tubes, drains
 - (see Pressure Ulcer domain analysis model)

■ Contingency plan

- e.g., if _____ then consider _____

■ Directives and preferences

- Communication preferences
- Vascular access

Storyboards

- Currently mapping use cases to evaluate mapping to c-CDA and FHIR

- Capturing additional content on wiki:

http://wiki.hl7.org/index.php?title=Essential_Information_for_Children_with_Special_Healthcare_Needs

- Additional input welcomed.

- Contact: Michael Padula padula@email.chop.edu