

PICU Follow Up Clinic - June 2024

Questions:

We are starting discussions around the development of a PICU Follow Up Clinic at ORG A. We would appreciate any insight you might provide from your organization/experiences.

Does your hospital have an ICU Follow Up Clinic?

Which specialties/disciplines see patients in this clinic?

What is the criteria for patient follow up in this clinic?

What is the frequency of patient follow up in this clinic?

Any other information that you feel would be helpful?

Responses Received: It appears that there aren't any true Pediatric ICU follow up clinics amongst our groups yet!

ORG B

Does your hospital have an ICU Follow Up Clinic? We do! ORG B offers this clinic for children who were in the NICU and also those with congenital heart disease and spent time in the CVICU in infancy.

Which specialties/disciplines see patients in this clinic?

- For NICU follow up, children are seen by certified nurse practitioner or neonatology, OT or PT, and neuropsychology.
- For the cardiac patients, children are seen by OT, neuropsychology, and a certified nurse practitioner.

What is the criteria for patient follow up in this clinic?

- For NICU follow up eligibility criteria: Must meet at least one of the following:
 - GA less than 33 weeks
 - Birth weight 1500g or less
 - Growth restriction > 2SD
 - Congenital diaphragmatic hernia

- Neuro concern such as HIE, hydrocephalus, severe IVH (gr. 3-4), seizures, stroke, significant neuroimaging abnormality
- Intensive medical intervention such as ECMO
- Congenital infection
- Fetal surgery
- NAS requiring scheduled medication
- Other, at discretion of neonatology/NP
- For the cardiac patients, we follow the Cardiac Neurodevelopmental Outcomes Collaborative (CNOc) guidelines and recently updated AHA Scientific Statement (Sood et al, Circulation. 2024;149:e00–e00. DOI: 10.1161/CIR.0000000000001211).

What is the frequency of patient follow up in this clinic?

- For NICU follow up, patients are seen at 6-months and 12-months adjusted age. They are then seen again at 2-year chronological age and possible 3-year chronological age if there are concerns at the 2-year evaluation. Some children are also seen at 4-1/2 years by neuropsychology. The Bayley 4 is done by OT or PT at all but the 4-1/2-year visit. Neuropsychology sees these older children.
- For the cardiac patients, the assessments are around 18 months, 3 years, and 5 years. We are currently working with our team to extend follow up to older at-risk patients at key transition points (third to fourth grade, middle school entry, high school entry, and transition to adulthood) again, following CNOc and AHA guidelines for assessment.

Any other information that you feel would be helpful?

We had an established NICU follow up clinic for many years but the transition to a more encompassing ICU follow-up clinic was challenging. It was very important to identify key stakeholders and 'champions' for the program. We then had several planning meetings after thoroughly reviewing the literature and talking to other programs about how they did it. CNOc even has a special interest group dedicated to helping facilities develop these programs.

ORG C

We did try to start one, but the consultant left ORG C after starting and no one was able to take it over. Very interested in responses if possible to share with us! Thank you!