

Follow-up and Parent Engagement Toolkit

This toolkit includes resources to assist clinicians with providing education to parents about the importance of follow-up after discharge from the emergency department and for parent engagement for infants 22 to 28 days of age and for infants 29 to 60 days of age with positive urinalyses (UAs). These resources are not comprehensive of all methods to provide education and engage parents, but can be used as a guide:

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Appropriate Follow-Up

Metric:

75% of infants 22-60 days of age discharged from the emergency department have documented education with parents about the importance of follow-up within 1 calendar day.

Smartphrase:

.FUfebrileinfants

The parents/guardians received counseling and education about the symptoms to monitor at home that should prompt immediate re-evaluation by a healthcare provider. The parents/guardians received counseling about the importance of follow-up within 1 calendar day. The infant's primary care provider on call was contacted to arrange follow-up.

Verbal Instructions:

The test results we have now show that your baby's fever is likely caused by a virus. Most viruses will get better without antibiotics. However, we won't know for sure if your baby has bacteria causing the fever until tests called cultures have results in 24 to 36 hours. It is important that you closely monitor how your baby is doing at home. Please call your baby's primary care doctor or return to the emergency room if there is any change in how your baby looks, like a blue color to the skin; if your baby is breathing too fast or too slow; if your baby is not acting well or is too sleepy, irritable, or is crying a lot and is not able to be consoled; if your baby is vomiting, not feeding well, or making fewer wet diapers. If your baby is in distress, please call 911.

It is very important that you follow-up with your baby's primary care doctor in the next 24 hours. Please call your primary care doctor by tomorrow to discuss how your baby is doing and to schedule a follow-up visit.

Written Instructions (English):

Your baby's fever is likely caused by a virus. Most viruses get better without treatment. However, we won't know for sure if your baby has bacteria causing the fever until tests called cultures have results in 24 to 36 hours. Please closely monitor how your baby is doing at home. Call your baby's primary care doctor or return to the emergency room if there is any change in how your baby looks, like a blue color to the skin; if your baby is breathing too fast or too slow; if your baby is not acting well or is too sleepy, irritable, or is crying a lot and is not able to be consoled; if your baby is vomiting, not feeding well, or making fewer wet diapers. If your baby is in distress, please call 911.

It is very important that you follow-up with your baby's primary care doctor in the next 24 hours. Please call your primary care doctor by tomorrow to discuss how your baby is doing and to schedule a follow-up visit.

Written Instructions (Spanish):

Probablemente la fiebre de su hijo sea causada por un virus. La mayor parte de los virus mejoran sin tratamiento. Sin embargo, no estaremos seguros de si su bebé tiene bacterias que causan la fiebre hasta que estén disponibles los resultados de pruebas llamadas cultivos, en 24 a 36 horas. Controle de cerca cómo está su bebé en casa. Llame al médico de cabecera de su hijo o regrese a la sala de emergencias si hay algún cambio en la forma cómo se ve su bebé, como por ejemplo coloración azul de la piel; si su bebé está respirando demasiado rápido o demasiado lento; si su bebé no está actuando bien o si está muy adormilado, irritable o si llora mucho y no se lo puede consolar; si su bebé está vomitando, no se alimenta bien, o moja menos pañales. Si su bebé está en situación precaria, llame al 911.

Es muy importante que haga un seguimiento con el médico de cabecera de su bebé las próximas 24 horas. Llame a su médico de cabecera al día siguiente para hablar sobre cómo está su bebé y programar una visita de seguimiento.

Parent Engagement – CSF and Disposition for Infants 22-28 Days

Shared decision-making description:

The Agency for Healthcare Quality and Research (AHRQ) SHARE Approach is one model for shared decision-making (please see attached PDFs):

**The SHARE Approach:
A Model for Shared Decision Making**

The SHARE Approach is a five-step process for shared decision making that includes exploring and comparing the benefits, harms, and risks of each option through meaningful dialogue about what matters most to the patient.

- STEP 1** **S**eek your patient's participation.
- STEP 2** **H**elp your patient explore & compare treatment options.
- STEP 3** **A**ssess your patient's values and preferences.
- STEP 4** **R**each a decision with your patient.
- STEP 5** **E**valuate your patient's decision.

Shared decision making occurs when a health care provider and a patient work together to make a health care decision that is best for the patient. The optimal decision takes into account evidence-based information about available options, the provider's knowledge and experience, and the patient's values and preferences.

 **AHRQ**
Agency for Healthcare
Research and Quality

STEPS for Shared Decision Making

Step 1: Seek the parent's participation

- Communicate that there is a choice to be made between two options and invite the parent to be involved in the decision.

Step 2: Help the parent explore and compare options

- Discuss the potential harms and benefits of each option.

Step 3: Assess the parent's values and preferences

- Encourage the parent to talk about what matters most to him/her in making the decision (i.e., his or her values) and if he/she has a preference for one of the options.

Step 4: Reach a decision with the parent

- Make a decision together.

Step 5: Evaluate the parent's decision

- Evaluate the outcomes of the decision. *This step involves follow-up to assess the outcome of the decision, but does not happen during the shared decision-making process in the ED.*

Parent Engagement – CSF

Metric:

75% of infants 22-28 days of age with normal inflammatory markers and negative UA have documented physician-parent discussion about the harms/benefits of having CSF obtained.

Smartphrase:

.SDMCSFfebrileinfants

I did shared decision-making with the parents/guardians regarding performing a lumbar puncture. I discussed the harms/benefits of performing a lumbar puncture, including the risks of bacterial meningitis vs. the risks of a serious complication from lumbar puncture. I elicited the parents'/guardians' values and preferences about the decision. After consideration of the harms/benefits, the parents and I jointly decided [to obtain/not obtain a lumbar puncture].

Shared decision-making script template (mapped to each Step):

Step 1: Seek the parent's participation

The results of the urine and blood tests mean that your baby probably doesn't have a bacterial infection. However, there is still a possibility that your baby has bacterial meningitis. There are two options for your baby – to have a spinal tap now or to be admitted to the hospital without having a spinal tap. It is important for me to know how you feel about a spinal tap for your baby.

Step 2: Help the parent explore and compare options

The first option is for your baby is to have a spinal tap. The potential benefits of the spinal tap are that you will know for sure if your baby has bacterial meningitis. If the spinal tap shows that your baby might have bacterial meningitis, treatment can be started right away. If the results of the spinal tap show that your baby probably doesn't have bacterial meningitis, your baby might be able to go home from the emergency room and not be admitted to the hospital. The potential harms of the spinal tap are discomfort for your baby, the possibility that the spinal tap isn't successful, and rare serious complications like bleeding, infection, or injury to the nerves which happen in an estimated 1 out of 1,000 (or 0.1%) babies.

The second option is for your baby to be admitted to the hospital without having a spinal tap. The benefits of your baby not having a spinal tap are to avoid the risks of spinal tap, including discomfort, the possibility that the spinal tap isn't successful, and rare serious complications. The potential harms of not having a spinal tap are that your baby has an estimated 1 out of 1,000 (0.1%) chance of having bacterial meningitis that will be diagnosed later may cause injury to your baby's brain. The potential harms of being admitted to the hospital are disruption of your family's routine, your baby getting a different infection in the hospital, and the costs of the admission.

Step 3: Assess the parent's values and preferences

Now that I've explained the possible harms and benefits of your baby having or not having a spinal tap, can you please tell me what you understand about the two options and what is important to you in deciding what to do?

Now I'd like to learn which option you prefer. Do you prefer that your baby has a spinal tap or gets admitted without having a spinal tap, or do you not have a preference?

Step 4: Reach a decision with the parent

We have decided that your baby [will have a spinal tap/will be admitted without having a spinal tap].

Step 5: Evaluate the parent's decision

This step involves following up to assess the outcome of the decision. For example, if the baby did not have a lumbar puncture, was the baby subsequently diagnosed with bacterial meningitis? Or if the baby had a lumbar puncture, was the spinal tap successful?

Parent Engagement – Disposition

Metric:

75% of infants 22-28 days with normal inflammatory markers, negative UA, and normal CSF have documented physician-parent discussion about the harms/benefits of hospitalization vs. discharge from the ED after one dose of parenteral antibiotic therapy.

Smartphrase:

.SDMDispofebrileinfants

I did shared decision-making with the parents/guardians about hospitalization vs. discharge home from the ED after one dose of ceftriaxone. I discussed the harms/benefits of hospitalization vs. discharge home, including the risks of subsequent hospitalization and the risks of a delayed diagnosis of bacteremia or bacterial meningitis. I elicited the parents'/guardians' values and preferences about the decision. After consideration of the harms/benefits, the parents and I jointly decided on [hospitalization/discharge home from the ED with 24-hour follow-up].

Shared decision-making script template (mapped to each Step):

Step 1: Seek the parent's participation

The results of the spinal tap mean that your baby probably doesn't have bacterial meningitis. However, there is still a possibility that your baby has a bacterial infection. There are two options for your baby – to be admitted to the hospital or to be discharged home from the emergency room after one dose of an antibiotic. It is important for me to know how you feel about this decision.

Step 2: Help the parent explore and compare options

The first option is for your baby to be admitted to the hospital. The potential benefits of admission are that your baby can be monitored by doctors and nurses for signs of infection. If your baby shows signs of infection, treatment can be given immediately. If your baby is not feeding well or is making fewer wet diapers, fluids can be given through an IV. The potential harms of being admitted to the hospital are disruption of your family's routine, your baby getting a different infection in the hospital, and the costs of the admission.

The second option is for your baby to be discharged home from the emergency room after one dose of an antibiotic. The benefits of your baby going home from the emergency room include avoiding the potential harms of being admitted to the hospital. You may also have less disruption to your family's routine. The potential harms of going home from the emergency room are that your baby still has a small chance of having a bacterial infection. You will need to closely monitor your baby at home for any signs that he/she is getting sicker. If he/she is getting sicker, you will need to return to the emergency room.

Step 3: Assess the parent's values and preferences

Now that I've explained the possible harms and benefits of your baby being admitted to the hospital or discharged home from the emergency room after one dose of an antibiotic, can you please tell me what you understand about the two options and what is important to you in deciding what to do?

Now I'd like to learn what you prefer. Do you prefer that your baby be admitted to the hospital or discharged home after one dose of an antibiotic?

Step 4: Reach a decision with the parent

We have decided that your baby [will be admitted to the hospital/will be discharged from the emergency room after one dose of an antibiotic].

Step 5: Evaluate the parent's decision

This step involves following up to assess the outcome of the decision. For example, if the baby was discharged home, did the baby return to the emergency department? Or if the baby was admitted to the hospital, did the baby have any complications?

Parent Engagement – Oral Antibiotics for Infants 29-60 Days with Positive UAs

Metric:

75% of infants 29-60 days with a positive UA, negative inflammatory markers, and normal CSF (if obtained) have documented physician-parent discussion about the harms/benefits of oral vs. parenteral antibiotic therapy and are discharged home on ORAL antibiotic therapy (with or without one dose of parenteral antibiotic therapy prior to discharge).

Smartphrase:

.SDMOralAntbxfebrileinfants

I did shared decision-making with the parents/guardians about intravenous vs. oral antibiotics for empiric treatment of UTI. I discussed the harms/benefits of intravenous antibiotics and hospitalization vs. oral antibiotics and discharge home, including the risks of hospitalization and the risks of subsequent hospitalization if the infant gets sicker at home. I elicited the parents'/guardians' values and preferences about the decision. After consideration of the harms/benefits, the parents and I jointly decided on [intravenous antibiotics and hospitalization (or) discharge home on oral antibiotics with/without one dose of ceftriaxone].

Shared decision-making script template (mapped to each Step):

Step 1: Seek the parent's participation

The results of urine testing mean that your baby probably has a urinary tract infection. There are two options for your baby – to be admitted to the hospital and treated with antibiotics given through an IV, or to treat with antibiotics by mouth at home, after one dose of an antibiotic given through an IV in the emergency room. It is important for me to know how you feel about this decision.

Step 2: Help the parent explore and compare options

The first option is for your baby to be admitted to the hospital and given treatment with antibiotics through an IV. The potential benefits of admission and treatment with antibiotics through an IV are that your baby can be monitored by doctors and nurses for signs that your baby is getting sicker. If your baby is not feeding well or is making fewer wet diapers, fluids can be given through the IV. The potential harms of being admitted to the hospital are potential complications of multiple IV pokes, infiltration or complications from having an IV, your baby getting a different infection while in the hospital, disruption of your family's routine, and the costs of the admission.

The second option is for your baby to be treated with antibiotics by mouth at home after one dose of an antibiotic given through an IV in the emergency room. The benefits of your baby being treated with antibiotics by mouth at home include avoiding the potential harms of being admitted to the hospital. You may also have less disruption to your family's routine. Your baby may also avoid complications

from having an IV. The potential harms of going home from the emergency room are that your baby may get sicker while at home. You will need to closely monitor your baby at home for any signs that he/she is getting sicker. If he/she is getting sicker, you will need to return to the emergency room.

Step 3: Assess the parent's values and preferences

Now that I've explained the possible harms and benefits of your baby being admitted to the hospital and treated with antibiotics through an IV, or being treated with antibiotics by mouth at home after one dose of an antibiotic given through an IV, can you please tell me what you understand about the two options and what is important to you in deciding what to do?

Now I'd like to learn what you prefer. Do you prefer that your baby be admitted to the hospital and treated with antibiotics through an IV or treated with antibiotics by mouth at home, after one dose of antibiotics given through an IV in the emergency room?

Step 4: Reach a decision with the parent

We have decided that your baby [will be admitted to the hospital and treated with antibiotics through an IV/will be treated with antibiotics by mouth at home, after one dose of an antibiotic through an IV].

Step 5: Evaluate the parent's decision

This step involves following up to assess the outcome of the decision. For example, if the baby was discharged home on oral antibiotics, did the baby return to the emergency department? Or if the baby was admitted to the hospital, did the baby have any complications?