

Knowledge Burst | NICU Genomic Testing Workflow Considerations

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Learning Objectives

1. Evaluate and develop optimized clinical workflows for implementation of genomic testing in a NICU setting.
2. Identify provider/staff roles and responsibilities in the NICU genomic testing workflow.
3. Identify resources to support NICU providers in implementation of genomic testing.

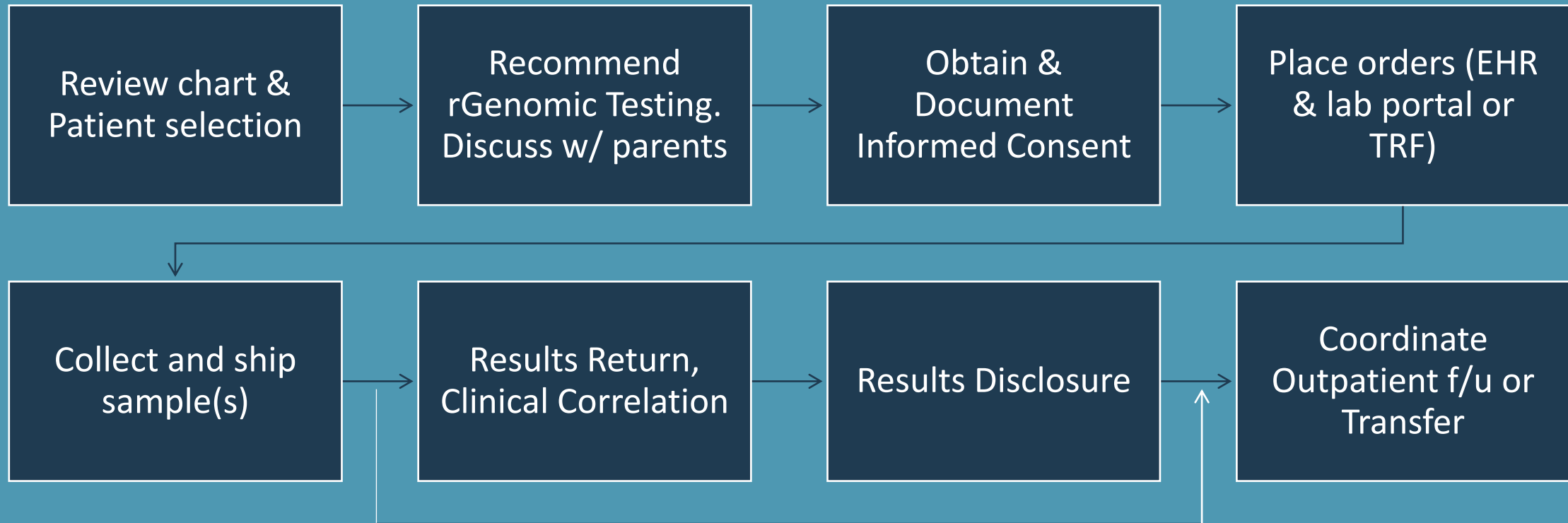


“The single biggest problem in communication is the illusion that it has taken place”

George Bernard Shaw



“Generic” Workflow



Sumedha Gate and Caroline Kielczewski



Important Considerations for Workflows

**Team
Members &
Role**

**Selection
Criteria**

**Lab, Test &
Billing**

**Orders &
Sample
Collection**

**Result
Review &
Disclosure**

Management



Small Group Collaboration



Team

- Who is/are the team leads(s)?
- Who are the team members and what are their roles?
- What other departments need to be involved, e.g., lab?
- What is the preferred mode of communication among team members?
- How is communication documented among team members?
- Who is responsible for educating the team members



Selection Criteria

- Patient Selection
 - Use your NICU criteria? BBN criteria? Hybrid?
 - What do you do when a baby does not fit the selection criteria exactly and/or you have a strong suspicion there is an underlying genetic condition?
- Test Selection
 - Is rWGS appropriate or is there a better test for the clinical suspicion?
 - Can testing be ordered on weekends?



Informed Consent (IC)

- Who will obtain IC and answer family questions?
- Will IC be obtained in person? by phone? Will you use the BBN IC video?
- What if both parents aren't available at the same time?
- Will you offer Secondary Findings?
- What documentation of consent is necessary?



Lab & Testing Considerations

- rapid ES or GS?
- What sample types are available?
- Will trio or proband only testing be performed?
- What are the TATs for ES/GS or rES/rGS at your preferred lab?
- For rES/rGS, does the test lab provide verbal preliminary results? If so, who will receive results and what is the timeline for final results



Orders and Sample Collection

- What sample types are acceptable / available?
- Who will place the order in the EHR?
- Do you have an order set / dotphrase?
- Will you submit a test lab portal order or paper test requisition form (TRF)?
- How will parent samples be obtained?
- Who completes the test lab portal order or paper TRF for patient and parents (floor RN? Send out lab, GC)?
 - Include note, phenotype, family history, parent names/DOB
- If ordering rGenomic Testing, who will receive the phone call with preliminary results?
- Does sent out lab need notification of incoming rapid sample?



Orders & Sample Collection continued...

- Who checks sample requirements?
- What is the sample type for proband and parents (blood, saliva, buccal)?
- Who maintains DNA sample kit inventory?
- Are DNA sample kits stored in the NICU or lab?
- Who will coordinate sample (proband / parents) collection and labeling in a timely manner (including obtaining signatures – lab dependent)?
- If baby and parent samples are collected at different times/days, where are they stored until all samples are obtained
- Who will package and ship sample(s) to test lab (ideally all samples sent together)?
- Is your send out lab able to process parent samples if they are unregistered patients?



Results Review & Return

- Who primarily conducts results review and interpretation?
- Who receives and documents verbal preliminary results? How are they documented? Where and with what information?
 - Gene name, c. p. and preliminary classification
- Will preliminary results be reviewed over the weekend?
- Will preliminary results be disclosed to family? Can this occur over the weekend?
 - Who receives final results?
 - Are secondary findings disclosed at the same time as results related to primary clinical concern?
 - How are results communicated between team members?



Results Review & Return continued

- If baby is still admitted, who discusses results and plan with family?
- If baby is transferred, who communicates with recipient NICU RE test ordered/resulted?
- If baby is discharged
 - Who discloses results?
 - Does family need a follow up visit for results?
 - Who coordinates outpatient referrals?
- If baby dies, how are results communicated?
 - Are results documented in the deceased's chart? Or in a family member's chart



Management & Follow Up

- Are other labs / imaging needed?
- What does outpatient follow up look like?
 - Genetics? Other referrals needed?
 - Who follows up on genetics referral?
- Are there other at risk relatives to test?
- Is additional genetic testing needed?

