Data Collection Tool for the Generalist

Directions: You will be pulling active charts of patients seen by your practice for at least 3 visits (at least one of which was a health supervision visit)
1) Pull 10 or more random patient charts
2) Pull 5 or more charts of patients with suspected or confirmed short stature or decreased growth velocity (See Identifying Charts with Growth Concerns)
3) Review all documentation related to the patient’s growth and pubertal development within the last 12 months.

Answer the questions based on actual documentation and not on memory or inference. This review is a retrospective look at the care provided.

- Questions 1 to 5 will assess your practice’s efforts to routinely measure and plot growth, assess pubertal development, and engage the family as partners in the patient’s development. These questions apply to all patients in your practice. If charts chosen randomly reveal a growth or pubertal concern or disorder, please continue answering the remaining questions.
- Questions 6 to 11 will assess your practice’s efforts to dig deeper and closely monitor patients with suspected growth or pubertal development concerns and to proactively address patient and family concerns and check for underlying psychosocial issues with the patient and family.
- Questions 12 to 14 will assess your practice’s ability to communicate with the endocrinologist when referred, to support the patient’s care plan.

All Patients

1. Were all of the following growth measurements plotted on appropriate age/gender growth charts at least once in the past 12 months?
   - For children ages 0 to 23 months, plot on WHO charts
     - Head circumference
     - Weight-for-age percentiles
     - Length-for-age percentiles
     - Weight-for-length percentiles*
     - Recommended, but not required for this exercise
   - For children age 24 months and older, plot on CDC charts:
     - Weight-for-age
     - Stature-for-age
     - BMI-for-age

     O Yes  O No

2. Is there documentation that all aforementioned growth parameters were discussed with the patient/family at the most recent health supervision visit?
   O Yes  O No

3. Was the age-appropriate presence or absence of secondary sexual characteristics documented at the most recent health supervision visit?
   O Yes  O No

   If Yes to question 3:
   3a. Is there documentation that the result of the pubertal assessment was discussed with the patient/family, if applicable, at the visit?
      O Yes  O No  O Not applicable (patient not of pubertal age, no clinical indications, or no concerns identified)
4. Is there documentation that the patient and family were asked if they had concerns about the patient’s growth or pubertal development?
   O Yes  O No

   If Yes to question 4:
   4a. If the patient or family had concerns, were the expressed concerns addressed?
      O Yes  O No  O No concerns expressed

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**CHECKPOINT #1**

Does this patient have suspected or confirmed abnormal linear growth (short stature or decreased growth velocity)?

O Yes  O No

If No to Checkpoint #1, STOP. You have completed the review for this patient.
If Yes to Checkpoint #1, please CONTINUE answering the remaining questions.

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**Patients with abnormal linear growth (short stature or decreased growth velocity)**

5. Was mid-parental height calculated and documented?
   O Yes  O No  O Not obtainable (ie, one parent not involved, child adopted without biological parent information, etc)

6. Was follow-up recommended within the suggested interval? (See the growth assessment flow diagram for suggested intervals?)
   O Yes  O No

7. If an additional work-up for the growth concern is indicated (including laboratory and imaging), has a plan for that work-up been documented in the patient’s chart? (See the growth assessment flow diagram for suggested studies when evaluating a child with abnormal linear growth as a starting point of reference.)
   O Yes  O No  O No additional work-up indicated

8. If diagnostic tests were ordered, were they completed and reviewed by the physician?
   O Yes  O No  O Unknown  O Not applicable, tests still in progress  O No tests ordered

9. Is there documentation that educational materials were provided to the patient and family about the suspected growth or pubertal development concern?
   O Yes  O No

10. Is there documentation that an assessment was made for potential growth related psychosocial issues for the patient and family?
    O Yes  O No

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**CHECKPOINT #2**

Was the patient referred to an endocrinologist to manage or investigate the growth concern?

O Yes  O No

If No to Checkpoint #2, STOP. You have completed the review for this patient.
If Yes to Checkpoint #2, please CONTINUE and answer the remaining questions.
Patients referred to endocrinologist

11. Was all of the following information sent or made available to the endocrinologist with the referral?

- [ ] History
- [ ] Physical examination
- [ ] Growth charts
- [ ] Medications, if any
- [ ] Laboratory and imaging results, if any (See the growth assessment flow diagram for suggested studies when evaluating a child with abnormal linear growth as a starting point of reference)
- [ ] Summary of case (ie, impression of growth concern)
- [ ] Assessment of psychosocial concerns
- [ ] Contact information for the referring physician
- [ ] Contact information for the patient/family

O Yes  O No

12. Was the patient’s current written care plan (or essential care and management updates) obtained from the endocrinologist within the past 12 months? (Note: It is the endocrinologist’s responsibility to develop and share the care plan with team members and to communicate important updates. It is the generalist’s responsibility to obtain and support the care plan and to communicate important health status changes.)

O Yes  O No  O Not applicable, patient has not seen the endocrinologist yet
Appendix

Identifying Charts with Growth Concerns
All practices may approach how they identify this patient population differently; below are some suggestions on how you may go about this:

• By growth-related diagnosis codes in EMR database
• By growth-related billing codes in database
• Clinician recall of patients they have been following for growth concerns
• Flagged charts of patients being followed for growth concerns (i.e., failure to thrive, short stature, abnormal or decreased growth velocity)

Age/Gender Growth Charts

• It is recommended that the WHO growth standards are used to monitor growth for infants and children ages 0 to 23 months of age in the U.S. Note: As this is a recent recommendation, you may still be using the CDC growth charts for patients 0-36 months. Or your electronic health record (EHR) system may not support CDC or WHO charts. It is advisable to discover the type of charts your EHR supports. It is strongly recommended that you transition to using the WHO growth standards.
• Use the CDC growth charts to monitor growth for children age 2 years and older in the U.S.

Health Supervision Visit
Intervals recommended by the AAP for preventive pediatric health care (as outlined in Periodicity Schedule) include: at birth; age 2-4 days; 2 weeks; 2, 4, 6, 9, 12, 15, 18 and 24 months; and yearly through age 21.

Pubertal Assessment

✓ A detailed description of pubertal status should be documented at least once yearly and include that the breast and genitalia (for girls) or genitalia alone (for boys) have been examined.
✓ Sexual Maturity Rating (SMR) documentation is recommended for both males and females.
  – In female patients, it is appropriate to document that the external genital anatomy is that of a normal female.
  – In male patients, it is appropriate to document that the genitalia are normal and specifically that both testes are scrotal.
  – Any anatomic variants or issues of early or delayed onset should be specifically described and a plan established for appropriate further evaluation.

Mid-parental Height (MPH) Calculations

Mid parental height can be calculated in the following two ways:

MPH calculation (inches):
For girls: ((Father's height - 5 inches) + Mother's height) divided by 2
For boys: ((Mother's height + 5 inches) + Father's height) divided by 2
1 standard deviation (SD) = 2 inches
2 SD = 4 inches
Target height range = mid-parental height +/- 4 inches.
1 inch = 2.54 cm

MPH calculation (centimeters):
For girls: ((Father's height - 13 cm) + Mother's height) divided by 2
For boys: ((Mother's height + 13 cm) + Father's height) divided by 2
1 standard deviation (SD) = 5.1 cm (many clinicians round to 5)
2 SD = 10.2 cm (rounded to 10 cm)
Growth Surveillance and Linear Growth Failure

Target height range = mid-parental height +/- 10.2 cm

Based on statistics, it would be expected that 95% of children be within ~2-4 inches above or below this MPH calculation.

Psychosocial Issues (Growth and Pubertal Development-related)
Among others, identify and address the following psychosocial issues based on the patient’s age, patient/family requests, and clinical indications founded on your team’s assessment:

1. Coping with growth and pubertal development disorders, including peer relations and social adjustment
2. Family involvement
3. Non-adherence
4. Anxiety and depression
5. Disordered eating behaviors
6. Risk-taking behaviors such as drug abuse, alcohol, and tobacco use
7. Contraception
8. Preparing for college
9. Communication with parents and with growth care team
10. Transition to adult health care

Note: This list is not intended to be an exhaustive inventory of psychosocial issues requiring surveillance, but rather some essential and practical issues common in growth and pubertal care.

Written Care Plan
An effective care plan for growth concerns should meet all of the patient/family’s medical, psychosocial, and educational needs. It should have the following characteristics: It should be comprehensive, guideline-based, developed in partnership with the family (and, when appropriate, the patient), understandable by the patient and family, provided in a coordinated and comprehensive manner to the patient’s medical home and referral provider(s), and inclusive of a medical summary with condition-specific action plans.

Common elements of a comprehensive guideline-based care plan for growth-related care:
- Growth diagnosis(es)
- Treatment plan
- Coexisting diagnoses
- Medications, supplements, vitamins, dosages
- Other therapies
- Allergies
- Recent clinical exam results
- Recent diagnostic test results
- Extracurricular activity involvement
- Hospitalizations
- Educational status
- Sleep habits
- Psychosocial issues
- Patient or family concerns
- Recommended physical activity, with any needed adaptations
- Recommended dietary adaptations or changes
- Patient or family limitations to following the plan
- Educational materials that were provided to patient/family
- Team members, and their roles, responsibilities, and contact information;
- A medical summary with condition-specific action plans
- Transition plan to adult care (as appropriate).
Growth Assessment Flow Diagram

Evaluation of a child with abnormal linear growth

The evaluation of growth is an integral part of the health supervision exam and pediatric physicians must assess growth and development of children on a regular basis. When a child has short stature or is suspected of having poor linear growth, coordinated efforts can identify if a growth problem exists, and if so, what steps are necessary to evaluate this problem.

A growth assessment flow diagram like the one below may be helpful in developing a plan for patient evaluation. Since clinical practice varies, a discussion with a pediatric endocrinologist is strongly recommended to determine how this flow fits with his or her particular recommendations for assessing growth.

**Child Health Supervision Visit:** Height, Weight, Head Circumference (if applicable), BMI (if applicable) plotted on Growth Curve Form. Mid-parental height calculation performed. Growth parameters reviewed with family in context of gender, age, and genetic growth expectations.

- **NO**
  - Schedule follow-up growth assessment: 1 month if <1 year; 2–4 months if 1–3 years; 3–6 months if >3 years of age.
  - Abnormal growth pattern found at follow-up?
    - **YES**
    - Child has abnormal linear growth pattern; Physical exam including pubertal staging, symptoms, history suggestive of specific disorder or disease state?
      - **NO**
        - Consider laboratory and imaging assessment options below for growth evaluation; Schedule Follow-up; Contact specialist to discuss patient if appropriate.
      - **YES**
        - Obtain laboratory and imaging specific to suspected disorder; Contact specialist to discuss patient if appropriate.
    - **NO**
      - Physical exam, symptoms, or history suggestive of specific disorder or disease state?
        - **YES**
          - Advanced Laboratory Assessment
            - Insulin-like growth factor 1 (IGF-1)
            - Insulin-like growth factor binding protein 3 (IGFBP-3)
            - Follicle-Stimulating Hormone (FSH)
            - Luteinizing Hormone (LH)
            - Testosterone
            - Estradiol
            - Karyotype
            - Genetic Probes/FISH studies
          - Advanced Imaging Assessment Tools
            - Brain Magnetic Resonance Imaging (MRI)
            - Pelvic Ultrasound
            - Skeletal Survey