Specialty Growth Curves

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Specialty Growth Charts

We often get questions from our users (and OP Support often receives requests we cannot fulfill) about why OP doesn't have additional growth curves for conditions or syndromes like Klinefelter, Turner, or Prader-Willi. There are two fundamental barriers keeping us from incorporating many of these specialty growth curves into OP:

- Copyright restrictions

- Format of available data

Many of the specialty growth curves were created based on grant-funded research. The academic center(s) that performed the research own those growth curves. EHR vendors and others are prohibited, by copyright, from incorporating them into their products without specific relicensing agreements. It is very difficult to find the people in the appropriate organization who "own" this decision. In the cases where those contacts can be identified, the cost is often prohibitive when weighed against the few patients any of us may have for any number of these specialty conditions. Non-profit, patient-advocacy foundations sometimes post specialty growth curves online. However, OP follows all copyright laws, so we cannot incorporate them into OP or redistribute them without specific contractual agreements.

Secondly, large data sets that are in the public domain (such as the growth curves the CDC and WHO offer) come with such large data sets that they can be used to visually "draw" growth curves on the computer for visualization and interpretation of which percentiles are appropriate for our patients. Many of the specialty growth curves have a very limited number of patients, and the paper growth curves were formatted using "hand smoothing" of the curves to make it usable. Plotting a point on a paper graph gives you a rough estimate of which broad categories the patient falls into and whether they are following "anticipated" growth trajectories. For example, measurements from only 78 girls were used to construct the seven female Prader-Willi percentile curves. With large data sets, there is very little "white space" between points, so interpolation is much more consistent and accurate. Most of the special conditions simply do not have enough data points to make interpolation of data be consistent with the author's intent, electronically repeatable, and accurate.

If there is a condition which you feel strongly about, and you can provide the contact where the data exists who has decision-making authority and is willing to sign a contractual agreement with OP, and the data can be provided in a format which OP can process, then our product team can investigate more thoroughly adding it to our system. In the meantime, please join us in advocating for the AAP to push for specialty growth curves being made available in the public domain so that all of our patients can benefit.

For now, you can take the paper forms, scan them into the appropriate patient chart, and annotate them by drawing a dot on the appropriate curve so that you can track those patients over time.