

General guidance for Medhome Portal Authors

Keep in mind that enough is enough and that, often, less is more. The online environment can be layered, allowing users to 'go deeper' as they see fit. Our primary users are busy – we should aim to minimize both scrolling and unnecessary clicking. The goal is to provide primary care physicians with sufficient information, resources, and tools to improve their ability to care for kids with chronic conditions. But we also want to offer the interested/motivated user access to additional detail or more in depth information.

Diagnosis Modules

The primary aim of the **Diagnosis Modules** is to serve as useful guides and resources for busy primary care physicians who need to find information about and services for their patients with chronic, often uncommon, conditions. To meet this aim, the Modules should

- be organized in a way that fits with the clinical encounter and care process;
- be organized in a way that users can easily and reliably find the information they seek or quickly learn it is not there to be found;
- be consistent with the organization and formatting of other modules, but deviate from or add to that as needed for the particular diagnosis/condition;
- focus on management (as opposed to diagnosis) of the condition, with an emphasis on collaboration with the patient, family, community services, and sub-specialists;
- present information sufficiently succinctly to minimize the barriers to its access by busy practitioners and completely enough to enable enhanced care at the primary care level;
- offer access to more detailed or complete information for those seeking more;
- annotate all citations and links to inform the user's decision to pursue them;
- provide tools to improve practice efficiency and efficacy (may involve converting available guidelines, information, or opinion into checklists, forms, or charts);
- include patient education to aid families in being effective partners in the care of their children;
- list local/regional services that complement the primary care of patients and specific information to guide the decision to use those services;
- avoid information, explanations, links, services, etc. that are of minimal or questionable value.

And remember that we expect and encourage parents to access the site. But we expect that a parent of a child with a chronic condition should be able to understand most of what we write if we focus on writing for the primary care doc.

Diagnosis Module Name Here

Diagnosis Module Format (updated 8/06)

Though none are complete, good examples of existing modules are Down syndrome, Asthma, Autism, and Neurofibromatosis.

Know that the module doesn't need to be perfect or complete to be put up on the site. As long as there's value to what you've written and we're all comfortable with its accuracy, we can feel comfortable calling it good enough and provide our standard caveat that the "site is still in development". We can then continue to improve it.

Please provide a **reference(s)** for any statement that a user might want to verify or learn more about. Indicate the statement to which the reference applies (as is usually done in a medical manuscript). If the reference is a journal article, all we need is the PubMed ID number (given at the end of every citation in PubMed). If you have not looked it up in PubMed, then we need at least the first author's name, title of the article, the journal name, and the year. And **provide a brief annotation** for any article/book/web page/etc. that you are citing (could pass if it's just a citation to back up a fact) to tell the user why they would want to pursue the reference. If you use EndNote, please feel free to use it for your bibliographic citations and put your annotation for each article in the Notes field in the EndNote listings and send a copy of the EndNote library files. Also know that all we really need for citations is the PubMed ID number (at the end of each citation in PubMed) – so don't type them out, just give us the number.

For any link you want to use, provide the URL, by what text you want the link displayed (display text), and an annotation (why would the user want to click on this?).

For graphics, downloadable files, etc., please indicate where they (or the link to them) should go in the text, and provide them as separate files, indicating the file name in the text.

Note: all links, citations, downloadable files, etc. should be accompanied by a short (1-3 sentence) annotation to inform the user as to the utility, value, focus, ease of use, etc. of the item. Annotate anything that requires the user to leave the page they're on so they know whether it's worth the click/time.

Also, whenever a term or reference in the text deserves some explanation or will likely raise a question or the desire to know more, consider linking it to a definition (we'll be creating a glossary database for this purpose - just provide us with the definition), another page with explanation or detail or more info (existing or to-be-created), or a link to somewhere else that would provide more information. There are a number of medical dictionaries out there that could be useful (and we can create the link for you):

<http://www.nlm.nih.gov/medlineplus/mplusdictionary.html>, <http://cancerweb.ncl.ac.uk/omd/>,
<http://www.genetests.org/servlet/access?qry=ALLTERMS&db=genestar&fcn=term>report2=true&id=8888891&key=Ua6vCjdlFxAAdv>,
<http://www.pharma-lexicon.com/medicalabbreviations.php>,
<http://ghr.nlm.nih.gov/ghr/glossary/Glossary>

Each of the following pages represents a separate section of the module. In *dark red italics* are some explanations or instructions that you can delete when you no longer need them. Feel free to use this document as your working file.

Diagnosis Module Name Here

Brief Description *or definition of diagnosis/condition (brief, focused on summary/clarification)*

Prevalence(s) *with short explanation as needed and supply the reference source(s), identify denominator (births, kids, population, etc.)*

Module Authors *(be sure to complete a author bio for each – format at the end of this file)*

Primary Author – *author link, date of original, date last updated*

Contributing Author(s) – *author link(s), date last contributions*

Reviewer(s) – *author link(s), date last reviewed*

Diagnosis Module Name Here

Clinical Assessment - *outline and discussion, with pictures and sound as needed, of the H&P and examination of patients with the diagnosis (focused on the condition, not so much a diagnostic or differential diagnosis emphasis, except as important for confirmation and /or ongoing reevaluation of the diagnosis) and the basics of therapy, as appropriate. For each subsection, include relevant and pertinent positives and negatives, perhaps brief discussion of importance, or not. In each section, when relevant, offer a listing of services, links, and references.*

Screening *(only if relevant)*

Initial Evaluation /Diagnostic criteria *(if relevant; if criteria are not succinct could link to an Issue page; purpose is not to guide making a diagnosis, but rather to allow confirmation that diagnosis was made correctly or still applies and to aid in ongoing evaluation or of recurrent acute presentations.)*

Pregnancy/Perinatal history

Family History

Current and Past Medical History

Developmental Evaluation

Physical Exam

Sensory Testing *(e.g., hearing, vision)*

Laboratory Testing

Genetic Testing

Imaging/EEG

Subspecialist Evaluations *(include what the purpose is and what the patient/PCP should expect)*

Differential Diagnosis *(if relevant)*

Prognosis

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Diagnosis Module Name Here

Treatment - *discussion should be focused on what the primary care doc needs to know about the therapeutic management of the primary condition. There may be none for the primary diagnosis (as with Down syndrome) or a definitive one (as with repair of a coarctation) or something in between. There may be a fair amount about management of related problems, sequelae, complications, etc. These should be discussed in the Related Problems & Issues sections, but the treatment section could outline these and then link to the relevant Issues pages.*

Types of Repair or Treatment *(with brief description, including preparation, recovery, recuperation, rehabilitation as appropriate)*

- **Residua** *(provide some detail about frequency, duration, etc.)*
- **Sequela** *(provide some detail about frequency, duration, etc.)*
- **Complications** *(provide some detail about frequency, duration, etc.) (provide some detail about frequency, duration, etc.)*
- **Outcomes** *(provide some detail about life span, quality of life, disability, etc.)*
- **Specialty Follow-up**

History *(focused on aspects relevant to post-treatment issues)*

Exam *(focused on aspects relevant to post-treatment issues)*

Imaging/Lab *(focused on aspects relevant to post-treatment issues)*

Subspecialist Collaboration

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Diagnosis Module Name Here

Related Problems & Issues – Categories - see below for a generic list and see the Down syndrome or Cerebral Palsy modules as examples; and know that we can add categories when needed and, within them, **Issues** linking to "Issues pages", each with:

- Discussion of the "Issue", with pictures, graphics, etc., to include, when appropriate, mimicking the module format:
 - > Frequently Asked Questions, if relevant
 - > Tools – items such as checklists, graphs, techniques, forms, etc. useful in the care of children with this Issue and Diagnosis
 - > Patient Education
 - > Links to other web sources, etc.
 - > Services
 - > Bibliography
- canned PubMed search if applicable, references with link to abstract or full text references, with links to abstract/full text (we'll create the links and the search with your parameters).

Indicate the names of the Issues and in which Category they go as shown by the Examples below

Behavior

Bowel Movements

Cardiac

Clinical Assessment

CME

Dental

Dermatology, Skin & Appearance

Example 1

Ear / Nose / Throat

Endocrine

Family

Funding and Access to Care

Gastrointestinal

Genetics

Growth

Hearing

Imaging

Immunity

Infectious Disease

Language Development

Learning

Maturation / Puberty

Mental Health

Mobility, Function and ADLs

Motor Development

Example 2

Example 3

Musculoskeletal

Neurologic / Seizures

Nutrition

Other

Pharmacy and Medications

Recreation and Leisure

Renal

Respiratory

Sleep

Social Development

Surgery

Transition to Adulthood

Urologic

Vision

You can add pages here or create additional files for the Issues.

Perhaps we could have a separate module section called "Common Issues for CSHCN" or something like that where we could put all the generic issues. With care and planning, and using metadata, we could substitute a specific issue for the diagnosis for the common issue when appropriate (e.g. substituting a specific page on SSI applications for a child with autism for the generic page on SSI applications).

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Helpful Articles – *a few good review articles with annotations, a “canned” PubMed search, and any links to great review-type sites (e.g., OMIM’s review of Down syndrome) Give us the references (all we really need is the PubMed ID number (at the end of each listing in PubMed. And let us know the parameters you want for the search (terms, how far back to go, etc.) and we can create the search link*

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Diagnosis Module Name Here

Frequently Asked Questions

- *Frequently asked questions by docs, updated periodically with questions from users*
- *Frequently asked questions by patients, updated periodically with questions from users*
- *Include questions about Hot Topics - new, emerging, or controversial issues with up-to-date references and links*

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Diagnosis Module Name Here

ICD9 - *Diagnosis coding – give us a list of all relevant and related diagnosis codes from IDC-9 and DSM-IV
(tell us the codes or the diagnoses and we'll create the pdf file)*

Diagnosis Module Name Here

Practice Guidelines - *the best you can find, with annotation, reference, and links. Give us the references and annotations and we'll create the links. If none exist, let's explain that and offer the next best thing if such a thing exists.*

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Diagnosis Module Name Here

Tools for Your Practice

- *collection of all the tools relevant to the diagnosis, most from Issues pages; will include diagnosis-specific forms for use in data recording (e.g., growth charts) or communications (e.g., referral forms), checklists constructed from practice guidelines, etc.*
- *Patient/Parent Questionnaire - downloadable/printable list of issues relevant to the diagnosis for patients/parents to “check-off” their interests/concerns/priorities; could be used as chart reminder or pre-visit questionnaire (example in CP module)*

We’re happy to help create the tools with your advice and direction.

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Patient Education

Specific patient education materials; most downloadable, customizable, and printable. You can get the stuff to us in any form and we can help convert to pdf or other formats

Links to other resources for patient education

- Patient Handouts*
- Useful Web sites*

Diagnosis Module Name Here

Links - *a list of relevant web links, each with brief annotation. May categorize links for physicians and for patients. Will include a compilation of links from other pages in the module.*

Diagnosis Module Name Here

Services – *give us a list of relevant services with any additional information the users might need or want.*

- *Specialty Services - Physicians, other professionals, and facilities with interest and expertise in children with the diagnosis, contact information, details of interest/focus*
- *Allied Health Services - Listing of allied health services relevant to the diagnosis, contact information.*
- *Community Services and Resources*
- *Community Resources - Listing of additional resources available within communities for patients, families, etc.*
- *any other services you think appropriate*

Diagnosis Module Name Here

Bibliography – *this will automatically compile of all the citations from the module (and those that have been retired from active use). Please list here any other relevant references, books, etc., each with brief annotation.*

Diagnosis Module Name Here

Author Bio format – *please provide us the following information about yourself and all authors working on the module*

Name and title(s)

Academic Rank

Academic position(s) (if any; e.g. Division Chief; new line for each)

Department

Other Positions (e.g., Medical Director of _____, Editor of _____; new line for each)

Institution

Address 1

Address 2 (if any)

City, State Zip

email (optional – will be posted so it will not be findable for spam)

Link (optional; to personal, divisional, or other website)

selected bibliography: (list any of your citations of relevance; please limit to 5, we can also provide a link to a PubMed search for your articles if you'd like)