AboutKidsHealth: A unique initiative in paediatric consumer health informatics

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AboutKidsHealth: Mission statement

We will work to improve child and youth health and quality of life for families around the world. We will accomplish this working within a determinants of health model, using state-of-the-art information design and communication strategies to ensure effective transfer of evidence-based information and tools.

"Quality of health information sites on the Internet; however, has less to do with whether the sites meet a list of static criteria. Rather, quality can be understood as the degree to which Web health information positively affects a user's health outcomes, quality of life, or disease-specific clinical endpoints."

Risk & Patterson, *Journal of the American Medical Association, 2002*

Initial qualitative research: methods

- Unstructured interviews with clinicians
- Observations in clinic and unstructured interviews with families
- Initial proof-of-concept, semi-structured interviews with site schematics
- Second set of semi-structured interviews with schematics of resource centres for brain tumour, diabetes, and heart conditions
  - Clinicians (2 from each of 3 programs)
  - Families (3 from each of 3 programs)

Patient family comments and questions: Diabetes as an example

- "A central place to go and look up information [would be] great."
- "Tell me in plain English what's going to happen."
- "When you're upset, you don't retain it all. It's good to have a place to go to get all the information after the diagnosis."

Common questions included:

What is insulin?
How does the pancreas function?
What are the long term effects of the condition?
What lifestyle changes will be required?

- Despite oral instruction in clinic, parents needed to know:

What signs and symptoms should we watch for?
How do you treat high and low blood sugar?
What are appropriate insulin doses and injection techniques?
What are insulin pumps and how do we use them?

Resource centres: information architecture

The Family Journey

Pre-diagnosis	Diagnosis is confirmed	Consent Treatment begins	Short-term effects Home and school issues	Long-term outcome Managing the condition
About *An overview*	**Understanding Diagnosis**	**Treatment**	**At Home** *Post-Intensive Treatment*	**Looking Ahead** *Adult Outcomes Late Effects*

What can I tell my child? What can I do for my child?

- Signs & symptoms
- Description of condition
- Etiology, if known
- Diagnostic tests and procedures
- Coping with diagnosis

- Detailed description of diagnosed condition
- Understanding treatment or options (hospital and global)
- Risks & complications associated with treatment
- Consent and assent

- Undergoing treatment
- Specific treatments (surgery, medication)
- Understanding drugs
- Condition management
- Compliance

- Practical aspects of home care
- Continuing treatment
- Special considerations (e.g., diet)
- Back to school
- Managing problems
- Compliance
- Complications

- Long-term outcome & prognosis
- Late effects
- Psychosocial needs
- Cognitive effects
- Research
- Resources

Resource centre: content characteristics

- Level I content
  - less than Grade 10 reading level (accuracy *vs* readability), Browsealoud enabled
  - supported with glossary and illustrations
  - secondary and tertiary sources
  - process: consult -> write -> review -> revise -> review -> revise -> QA
- Level II content
  - plain language treatment of current research from primary sources
  - 600 – 1200 words each
  - review and comment on relevance by clinician

Content and features: Resource Centres

- Seven Resource Centres: Brain Tumour, Diabetes, Epilepsy, Heart Conditions, Pain, Pregnancy & Babies, Premature Babies
- 45,000 to 325,000 words of Level I content
- 5000 to 15,000 words of Level II content
- Over 160 original medical illustrations, animations, and other images
- Comprehensive, interactive, family focused

Content and features: A-Z Health Library

- **A-Z Health library**
  - 575 everyday health topics
  - less than Grade 7 reading level
  - Syndicated content but reviewed and revised by SickKids staff — original illustrations added
  - Complete rewrite currently underway
- **Online magazine**
  - Publish ~10,000 words/month
  - Series, feature articles, news items, and columns

Content and features: How the body works

AboutKidsHealth April 21, 2006

trusted answers from SickKids

Sign In | Register Search

HOME RESOURCE CENTRES HEALTH A-Z NEWS HOW THE BODY WORKS JUST FOR KIDS

Choose an organ or system

- Brain home
- Brain anatomy
  - Left side view
  - Right side view
  - Coronal view
  - Sagittal view
  - Ventral view
- CSF circulation
- Cranial nerves
- Blood supply

HOW THE BODY WORKS: The Brain

//BRAIN ANATOMY :: VIEW LEFT SIDE

Print Email Glossary Off

Wernicke's

Wernicke's area is responsible for understanding language. Damage to this area results in Wernicke's aphasia, which is an inability to understand the meaning of words. The ability to speak is not impaired, but the person speaks gibberish.

Put brain parts here...

DRAW PAINT ERASE MOVE RESET TOOL HELP

ZOOM IN SHOW HEAD OUTLINE PRINT THIS IMAGE

Roll your mouse over the image to see the name and function of the parts. Use the tools to remove parts to see internal anatomy, draw on the image, or enlarge it for a closer look.

NEXT

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Content and features: Just for Kids

- Over 150 minutes of original narrated animations for children and youth
- Downloadable material: desktops, games
- Supports all Resource Centres with condition management information and tools
- General health and safety information as well
- Just for Kids was recently re-designed, 3 new modules launched

Usability testing

- Parents of 12 children with complex conditions
- 1.5 hour, task-based, think-aloud protocol
  - "Can you please find information on how to adjust the insulin dose?"
  - Semi-structured interview sought qualitative information on content and design during testing
- Post-test site evaluation questionnaire — 24 questions, seven point Likert scale from 1 (strongly disagree) to 7 (strongly agree)
- Overall response was 6.1

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