

DOUBLE CLICK ON HEALTH: INTERNET INTERVENTIONS FOR INDIVIDUALS WITH CHRONIC PAIN

Jennifer Stinson, RN, PhD, CPNP

Scientist and NP, Chronic Pain Program

The Hospital for Sick Children

**Assistant Professor, Lawrence S. Bloomberg Faculty
of Nursing, University of Toronto**

Objectives

- ❑ To understand what e-health technologies are and how they can be used in the delivery of cognitive-behavioral interventions for management of chronic pain
- ❑ To describe the evidence regarding the effectiveness of Internet-based interventions for management of chronic pain
- ❑ To summarize the challenges and opportunities of Internet interventions in chronic pain

Chronic Pain

- Pain that persists beyond the point where normal healing should have taken place
- Varies depending on the injury, but for most injuries if pain persists for 3 months or longer this is chronic pain, by 6 months this is established chronic pain
- Some forms of neuropathic chronic pain may be identified at much less than 3 months duration

Prevalence

- Studies confirm 1 in 5 Canadians suffer with chronic pain (*Moulin et al, 2002*)
- More than one in four children and adolescents have recurrent or chronic pain (*Perquin et al 2000*), and 5-8% suffer severe pain-related disability (*Huguet & Miro, 2008*)

Impact of Chronic Pain

- ❑ Chronic pain is among the most disabling and costly afflictions in North America
- ❑ Negatively impacts all aspects of QOL
 - ❑ Work (loss of work, loss of income, reduction in responsibilities due to pain) and school
 - ❑ Impaired sleep
 - ❑ Mood/anxiety disturbances
 - ❑ Affects relationships with family and friends
 - ❑ Activity impairments/restrictions
- ❑ Chronic pain sufferers report the lowest health related quality of life when compared to others with chronic illnesses such as emphysema, kidney failure and heart disease

Chronic Pain Treatment: The Reality

- ❑ Vast majority of individuals with chronic/recurrent pain do not consult a health professional
- ❑ Many are treating their own pain (may be using harmful strategies)
- ❑ Pharmacological agents alone are effective with only a minority individuals with chronic pain
- ❑ Multidisciplinary multi-modal (3 Ps) treatment approach is recommended (**P**harmacological, **P**sychological and **P**hysical therapies)
- ❑ Growing recognition of need to promote patient self-management

Access to Care

- Expertise is often unavailable in treating pain patients in the community
- Wait times for treatment at publicly funded pain clinics across Canada exceed six month benchmarks with wait times of more than one year at over 30 percent of clinics, ranging up to five years with large areas of Canada having no access to service (*Peng et al., 2007*)
- Only 7 dedicate treat centres in Canada for Children (*Peng et al., 2007*); large urban centres

Self-management

“Individual’s ability to manage the symptoms, treatment, physical and psychological consequences and life style changes inherent in living with a chronic illness.”

(Barlow et al., 2002)

Self-management Skills

- Communication
- Assertiveness
- Decision-making
- Problem-solving
- Self-care
- Self-advocacy
- Self-monitoring

Psychological Treatments for Chronic Pain

- Cognitive-behavioural therapies aim to reduce pain, distress and disability
- Focus on helping patients understand how their thoughts, feelings and behaviours affect their pain, coping skills training and cognitive restructuring
- Substantial evidence of their effectiveness
 - Meta-analytic review of RCTs for adults with chronic pain (*Morley et al., 1999*)
 - Meta-analytic review of RCTs for children and adolescents (*Palermo, et al., 2010*)

Need for Alternative Models

- Despite the empirical support for the use of CBTs in promoting better coping and symptom management, the vast majority of individuals do not have access to these treatments because:
 - expense (costs of treatment, time off work, travel costs)
 - inaccessibility due to barriers to treatment (long wait-times, geography) and clinicians (limited availability of trained professionals)
- Enhanced awareness about chronic pain and greater self-management (CBT) may reduce pain and adverse health outcomes (pain-related disability)

Chronic diseases are a greater threat than the pandemic flu

Second Opinion

ANDRÉ PICARD



We spend a lot of time, energy and money worrying about and bracing for pandemic influenza. While this is, in the main, an appropriate concern, the obsession with bird flu and how it may mutate to infect humans seems to be distracting us from a very real and ever-worsening epidemic that is already in our midst — chronic disease.

An estimated 16 million Canadians are already living with a chronic, non-communicable illness such as cardiovascular disease, cancer, diabetes, asthma and arthritis.

Chronic-disease sufferers visit doctors more often, spend more time in hospital and take far more

drugs than patients with acute illnesses, injuries or more joyful medical concerns such as childbirth.

As a result, they are gobbling up the lion's share of health spending: about two-thirds of the \$130-billion we spend annually on health care in this country.

Chronic illnesses are also, by far, the leading killers.

Cancer and heart disease alone account for three in every five deaths.

And while life expectancy continues to creep up, we are often oblivious to the fact that, on average, Canadians now live the last 10 to 12 years of their lives with disabilities, many of them the result of chronic health conditions.

This has broad implications not only for the health system, but for the social welfare system, the priorities of families (considering the growing number of family members serving as caregivers) and the economy in general, particularly as the population ages.

Given this tremendous impact, one could assume that prevention

and management of chronic disease is the foremost concern of policy makers, health administrators and consumer groups. Sadly, it's not — far from it.

We continue, in this country, to focus on illness care and the treatment of symptoms. Prevention remains largely an afterthought even though, by some estimates, up to 70 per cent of chronic illnesses are preventable — or at least "delayable."

In the treatment realm, we also staunchly cling to the outdated approach of treating individual conditions rather than whole people. Treatment is often provided by specialists.

It is not unusual today for older Canadians (and they are singled out here only because most health problems are slow-developing and hence age-related) to have a multiplicity of conditions: heart disease, diabetes, kidney disease, osteoarthritis, vision problems, urinary incontinence, dementia and so on.

What they need, more than treatment of individual conditions, is co-ordination.

That is the puzzle. But it is not a lot has to do with it. We have records that fortify their efficiency. We mean entry and he age pa their goal to prevent as disease. This, in turn, requires changes in the way health professionals are paid and the way community-based practitioners (general practitioners, nurse practitioners, dieticians etc.) are supported and valued.

We also need to rethink how we deliver care to many patients. In many cases, it would be more humane and more efficient to deliver care in the home and in facilities that house multiple clinics, rather than in traditional hospitals and GP practices.

In short, chronic-disease man-

"We need to rethink how we deliver care"...
"It would be more humane and efficient to deliver care in the home"

over chronic-disease strategy that does not play favourites. After all, there are common risk factors for more chronic illnesses, from poverty through to inactivity.

There are some promising chronic-disease management programs that have sprung up around the country in recent years, in part because of an investment from Ottawa. The 2003 health accord between Ottawa and the provinces included an \$800-million Primary Health Care Transition Fund, whose main purpose was to pay for projects related to chronic-disease management.

plan, one that is focused on prevention, lessening disability and death, and mitigating the burden of long-term illness on the health system and the broader economy.

Chronic disease needs to be a priority, medically and politically. The millions of Canadians with chronic illnesses — and the millions more to come — should not have to depend on a system that is unstructured and unfocused, a health system that is not paying sufficient attention to the real threat to their health and wellness.

apicard@globeandmail.com

(Globe and Mail, May 4, 2006)

E-Health: Part of the Solution



- ❑ Use of emerging information and communication technologies (ICT) to improve or enable health and health care
- ❑ Interactive applications (i.e., Internet, interactive TV and voice response systems, kiosks, Smartphones, CD-ROMs, DVDs, telemedicine)

Consumer Health Informatics

Focused on health behavior change and chronic disease prevention and management:

- ❑ Promotion of self-care
- ❑ Patient empowerment (access to information and ability to use it)
- ❑ Facilitate patient-provider communication
- ❑ Partnerships and shared decision-making
- ❑ Peer to peer communication and social support

eHealth Technologies

- ❑ Interactive health communication applications (IHCA) are computer-based (Internet) interventions that provide health information plus (at least one of):
 - social support
 - decision making support
 - behavioral change support
- ❑ Augment information and support provided by health care professionals (*Murray et al., 2007*)

Why the Internet?

- 75% of U.S. households subscribe to broadband
(*Pew Internet Use Survey, 2007*)
- Health information #1 accessed information online (75-80% of Internet users have searched for health information)
- Opportunities for increased engagement, interactivity, tailoring of interventions, communication with therapists in comparison to other IHCA's

Potential Benefits

- ☐ Reduce inconvenience of scheduling appointments, missing work/school, travel
- ☐ Reduce barrier of distance/proximity to skilled professionals/multidisciplinary treatment programs
- ☐ May increase patient willingness to seek help
- ☐ Quickly disseminate educational and treatment information
- ☐ Reduce time and costs of treatment
- ☐ May improve patient compliance

Other Benefits

- Patient anonymity and free accessibility removes stigma of seeing therapist
- Treatment can be administered at any time and place (enhanced convenience)
- Can be worked through at own pace
- Material can be reviewed as often as desired

Levels of Technology Use

- ❑ **Online counseling/videoconferencing:** technology is used to bring the clinic (or clinician) to the patient
- ❑ **Online bibliotherapy:** technology is used to bring educational material to the patient, usually static web pages (vast majority of all websites)
- ❑ **Interactive health and communication technologies:** technology is used in more complex ways to lead to behavior change; considers human-computer interaction

Ways Technology is Used

- Supplement face to face care
- Replace face to face care
- Stepped care
- Booster or maintenance

Internet Interventions

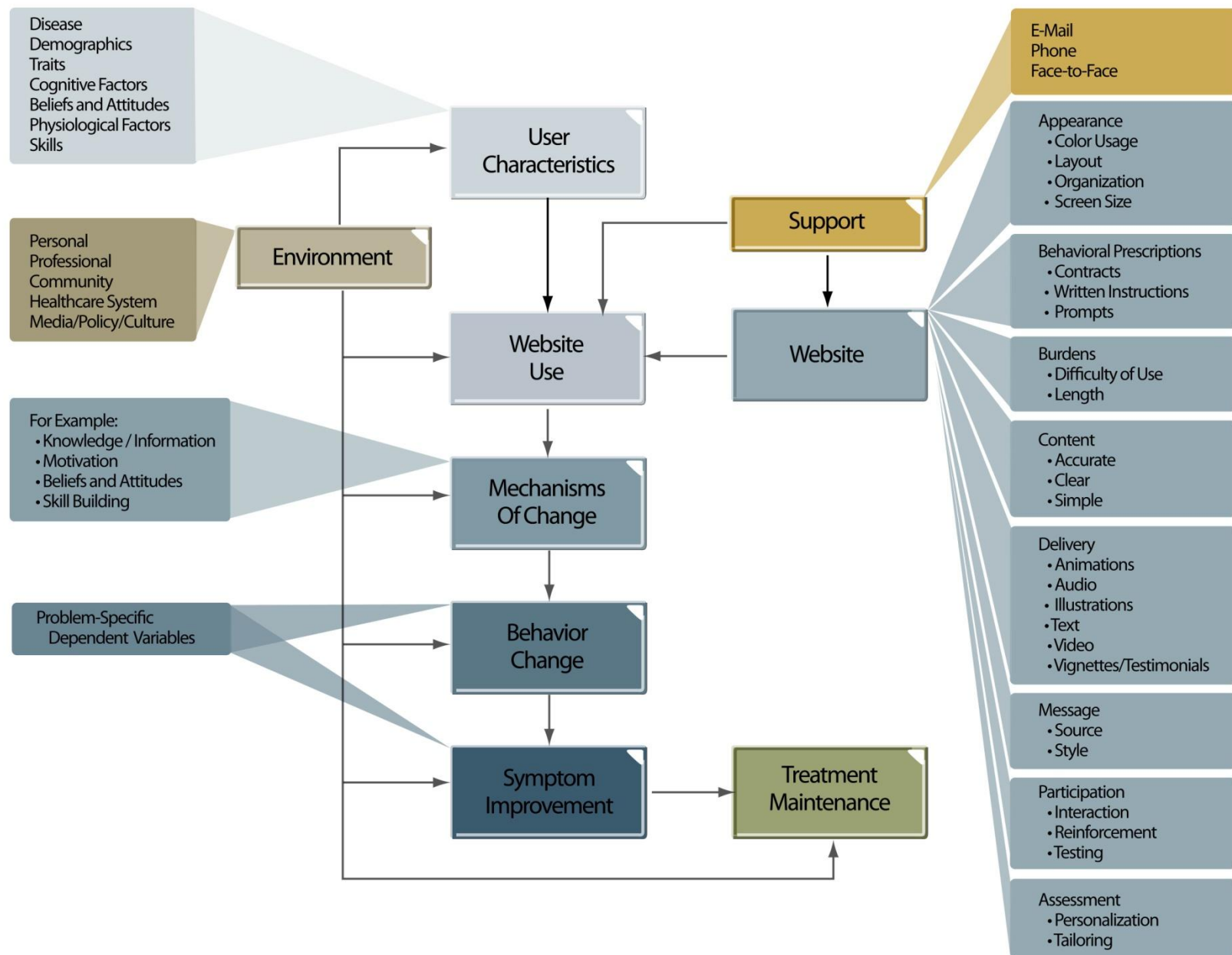
- ❑ Highly structured
- ❑ Self-guided or partially self-guided (coach)
- ❑ Based on effective face-to-face interventions (CBT)
- ❑ Personalized and tailored to user
- ❑ Interactive
- ❑ Makes extensive use of graphics, animations, audio or video clips
- ❑ Provides follow-up and feedback (e.g., decision-making support through emails/telephone)

(Ritterband et al., 2003)

Theory about Behavior Change in Internet Interventions

- Behavior change and symptom improvement may be achieved through different processes than in face-to-face treatment
- User characteristics affect use of the web site
- Website use is affected by website characteristics and type of support (e.g., computer automated, human counseling)

(Ritterband, et al., 2010, Ann Behav Med)



Systematic Reviews & Meta-analyses

- ❑ Internet interventions in behavioral medicine (including studies of chronic pain)
 - Cuijpers, et al., 2008 (pain and HA)
 - Stinson, et al., 2009 (HA and RAP)
- ❑ Internet interventions for chronic pain
 - Macea et al., 2010 (J of Pain)

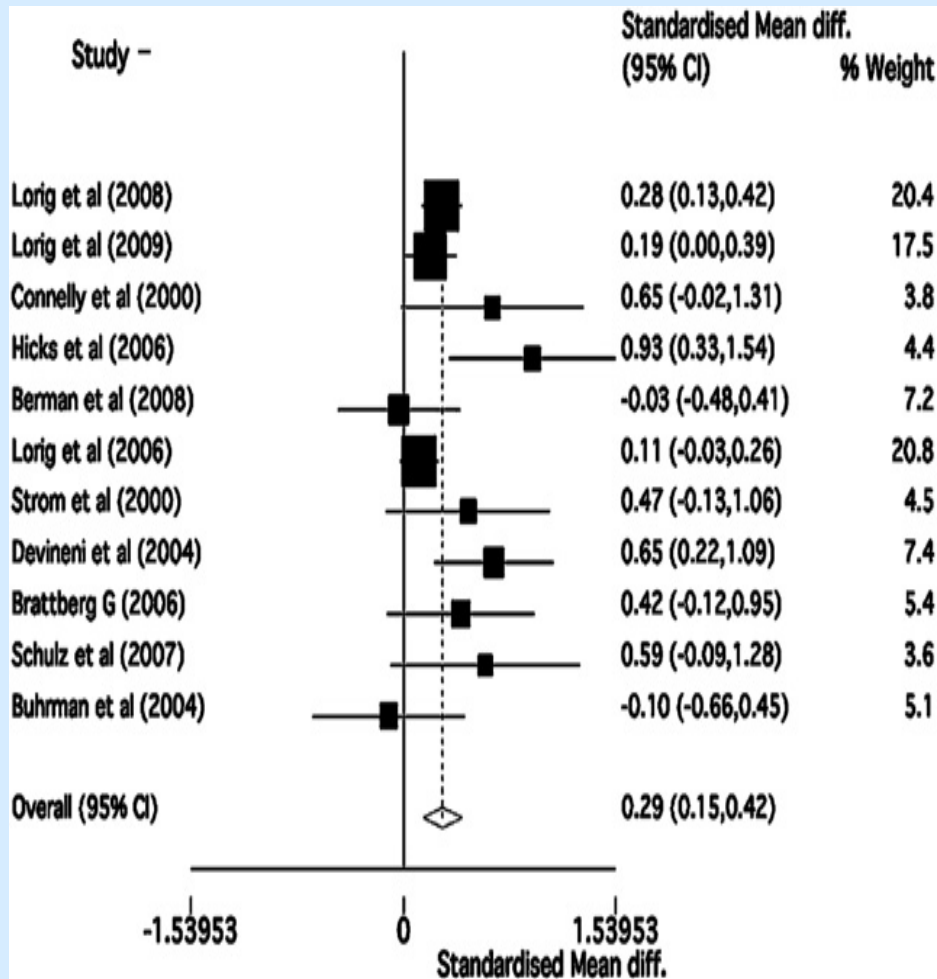
Meta-analysis Findings

- 11 studies that evaluated the effects of web-based interventions on chronic pain using specific pain intensity scales
- N= 2953 (67.5% female; mean age = 41.32; age range 7-91 years)
- Types of pain: arthritis, fibro, whiplash, HA, RAP, LBP, chronic pain syndrome, neuralgia
- Variability in treatment components and duration of interventions (range 6 to 20 weeks)

Common Components

- ❑ Self-pain behaviour management
- ❑ Relaxation strategies
- ❑ Coping with pain
- ❑ Thought changing
- ❑ Problem solving
- ❑ Exercise
- ❑ Controlling emotions (depression/anxiety)

Pooled Effect Size



- Small ES
- Pooled ES was .285 (95% confidence interval: .145–.424), favoring the web-based intervention compared with the waiting-list group

More about Findings...

- Average drop-out rate 26.6% (40% Internet; 64% in control groups) vs 14% for traditional face-to-face therapies
- Predictors of drop-outs: longer duration of pain; less severe pain at baseline; limited knowledge in computing; young age; higher levels of health distress and limitations of activity; and male gender

More about Findings...

- Despite the minor effects and high dropout rates, the decreased costs and minor risk of adverse effects compared with pharmacological treatments support additional studies in chronic pain patients using web-based interventions
- Further studies are needed to confirm the effects and determine the best responders to this intervention (using attention controls, and larger samples)

Teens Taking Charge: Managing Arthritis Online



**Stinson, McGrath, Hodnett, Feldman,
Duffy, Huber, Tucker, Yeung, Hetherington,
Tse, Spiegel, Campillo**

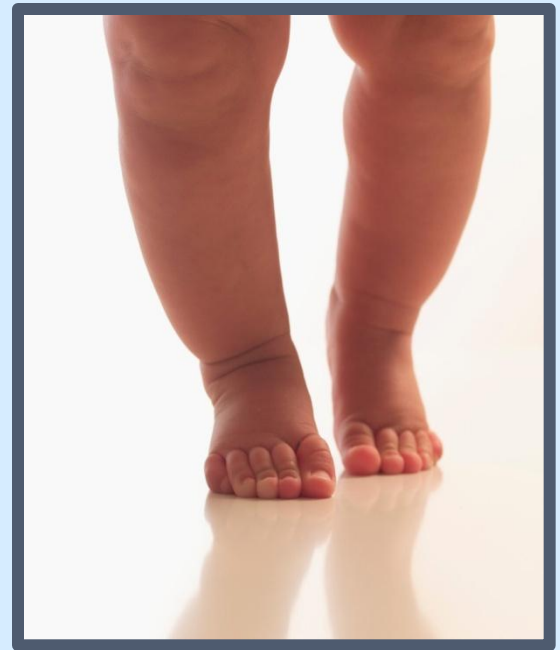
The Steps...

Phase 1: Needs assessment
(Asking the experts)

Phase 2: Development and
usability testing

Phase 3: Feasibility testing
(pilot RCT)

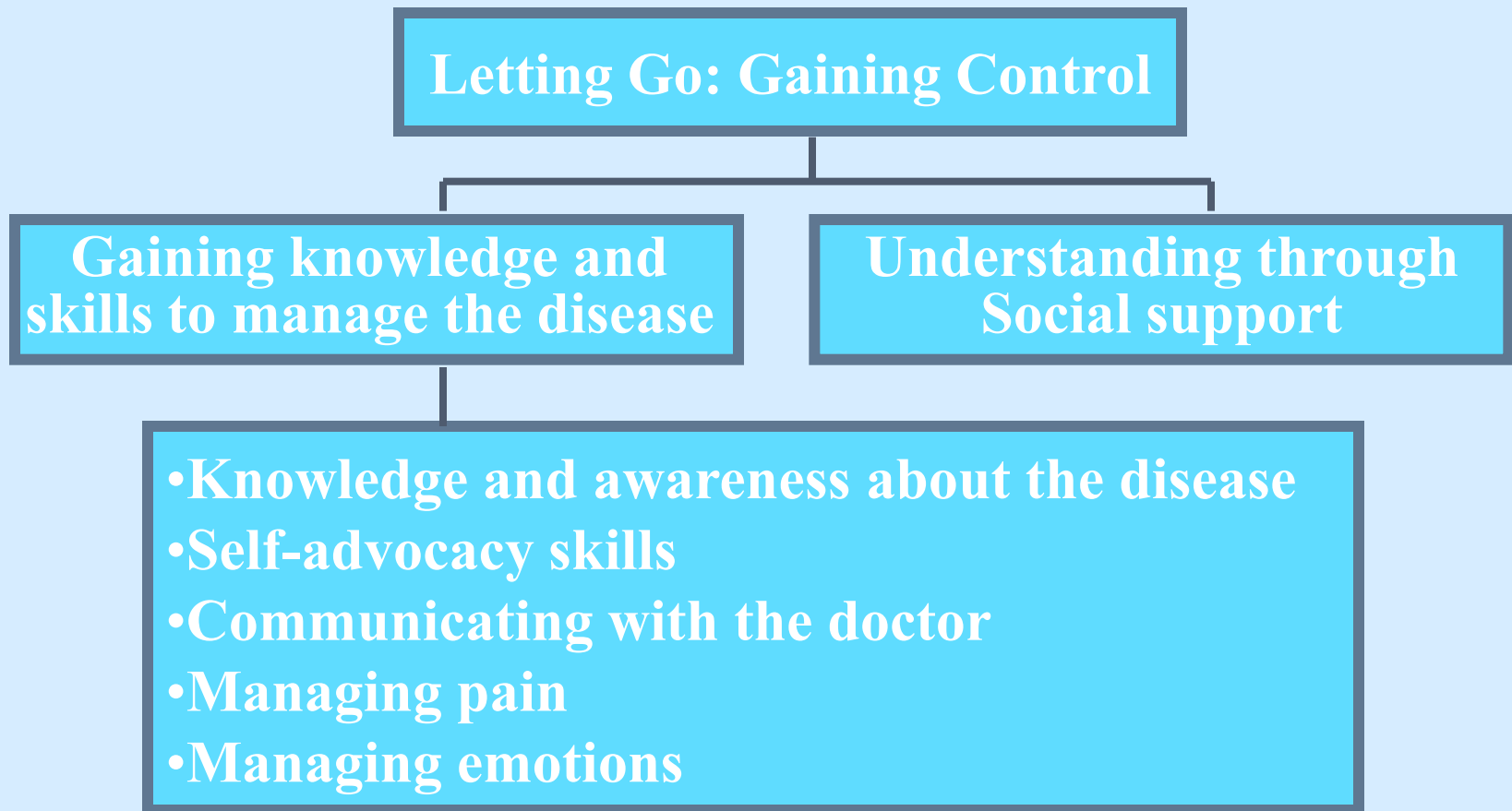
Phase 4: Multi-centred RCT





Phase 1: Needs Assessment

Self-management needs of adolescents with arthritis: Asking the experts





Program Development

Teens Taking Charge Program



- ❑ Multi-component, multi-media interactive program
 - Disease-related information
 - Self-management skills
 - Social support (discussion board, stories of hope, video clips)
- ❑ English and French
- ❑ 12 modules for teens (12-18 years)
- ❑ 2 modules for parents (facilitate 'letting go')



Teens Taking Charge

Managing Arthritis Treatment Program

Logout

Juvenile Arthritis

Juvenile Arthritis

Introduction for Teens

Welcome navreetg

1. About Arthritis

2. Understanding Diagnosis

3. Managing Your Symptoms

What Is Pain?

Managing Your Pain

Medications for Pain

Physical Methods to Treat Pain

Coping Strategies for Pain

What Is Fatigue?

Managing Your Fatigue

What Is Stiffness?

Managing Your Stiffness

Your Plan for Managing Symptoms

What You Have Learned

4. Managing Stress

Managing Your Pain

Your pain can be changed

Pain can be changed by stopping pain signals from reaching your brain. These pain signals can be reduced or blocked anywhere along the pain pathway. This can be done using medications and non-drug methods including physical methods and coping strategies. It may not be possible to eliminate all pain due to your arthritis. However, there are things you can do to reduce pain to levels that will let you do the things you want to.

Pain can be changed using:

- Medications
- Physical methods such as heat, cold, massage, and exercise
- Pain coping strategies such as relaxation, distraction, and changing the way you think



Click through animation: How we feel pain

How We Feel Pain



HOW WE FEEL PAIN
A step-by-step guide.

CLICK TO START

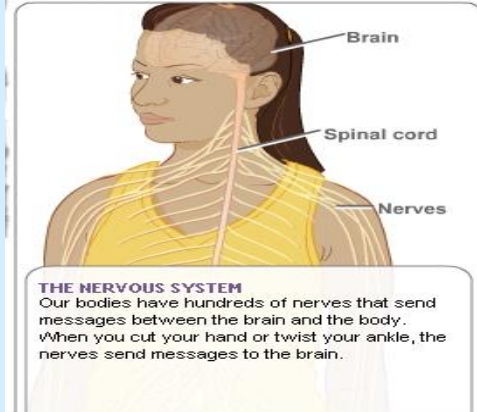
How We Feel Pain



THERE IS NO CORRECT AMOUNT OF PAIN
Each person feels pain differently. For example stubbing your toe may hurt a lot while getting a needle doesn't hurt at all. Maybe your best friend thinks needles hurt worse than anything. Pain also feels different at different times.

◀ BACK NEXT ▶

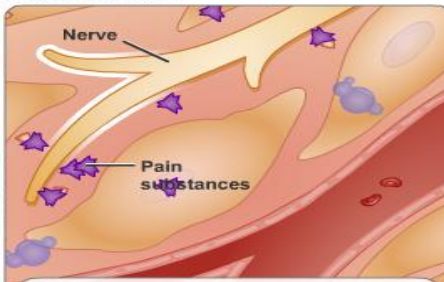
How We Feel Pain



THE NERVOUS SYSTEM
Our bodies have hundreds of nerves that send messages between the brain and the body. When you cut your hand or twist your ankle, the nerves send messages to the brain.

◀ BACK NEXT ▶

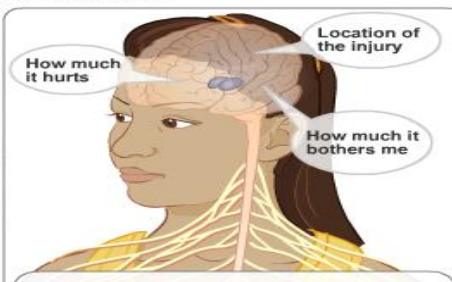
How We Feel Pain



ACTIVATION
When your body is injured, special chemicals are released from the damaged cells. These chemicals cause inflammation (redness and swelling), and make the nerves send messages about the injury to your brain.

◀ BACK NEXT ▶

How We Feel Pain



PAIN EXPERIENCE
The pain messages are processed in the brain, where all the information such as previous pain experiences, feelings, and memories are put together.

◀ BACK NEXT ▶

How We Feel Pain



MODULATION
The brain controls the incoming and outgoing signals. These signals can reduce or increase the pain messages. That means that there are things you can do to reduce pain.

◀ BACK NEXT ▶



Teens Taking Charge

Managing Arthritis Treatment Program

Logout

Juvenile Arthritis

Juvenile Arthritis

Introduction for Teens

1. About Arthritis

2. Understanding Diagnosis

3. Managing Your Symptoms

What Is Pain?

Managing Your Pain

Medications for Pain

Physical Methods to Treat Pain

Coping Strategies for Pain

What Is Fatigue?

Managing Your Fatigue

What Is Stiffness?

Managing Your Stiffness

Your Plan for Managing Symptoms

What You Have Learned

4. Managing Stress

Welcome navreetg

Medications for Pain

Arthritis medications can help reduce your pain and inflammation. You might be taking medications now to help control your arthritis including:

- Non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen
- Disease modifying anti-rheumatic drugs (DMARDs) such as methotrexate
- Corticosteroids such as dexamethasone, methylprednisolone, prednisolone, or prednisone
- Biologic drugs, such as etanercept and infliximab. Biologics are sometimes used in young people who do not respond to the other medications.

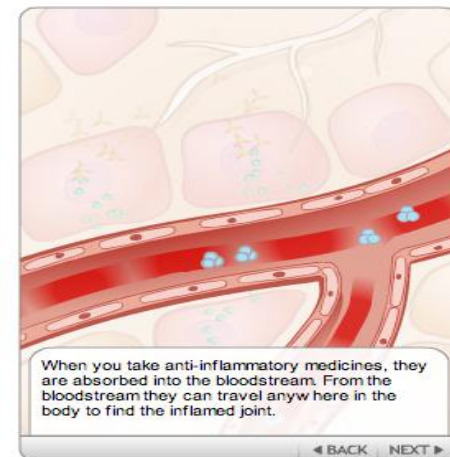
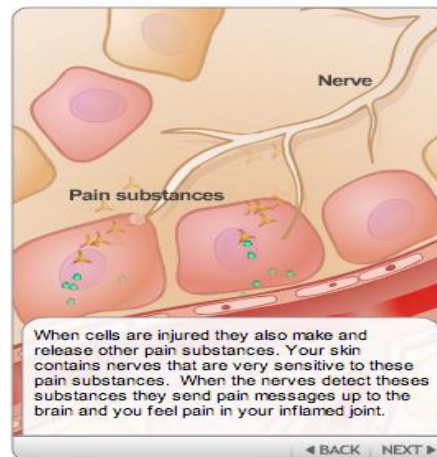
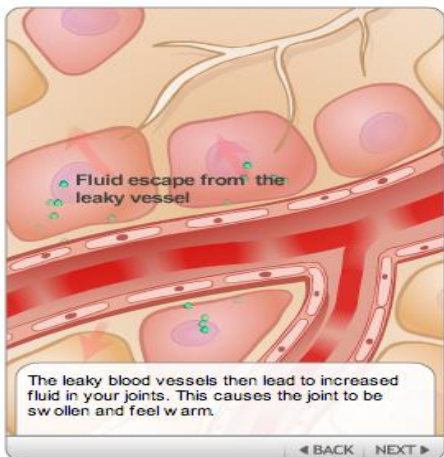
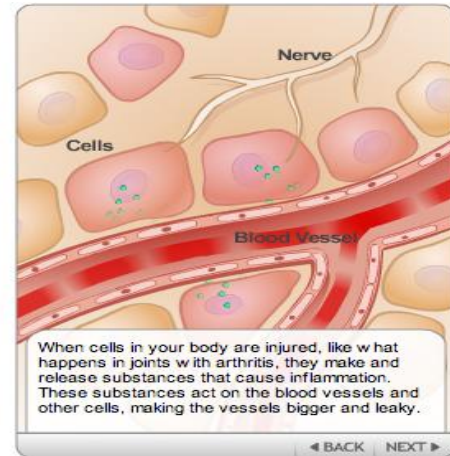
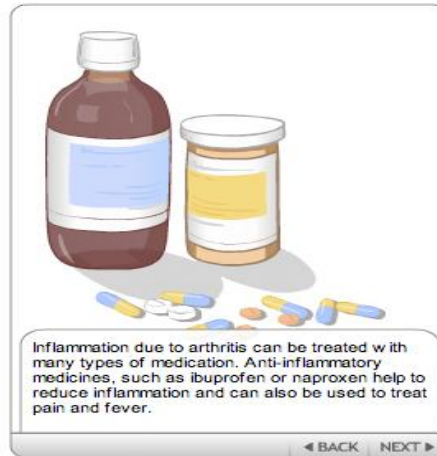
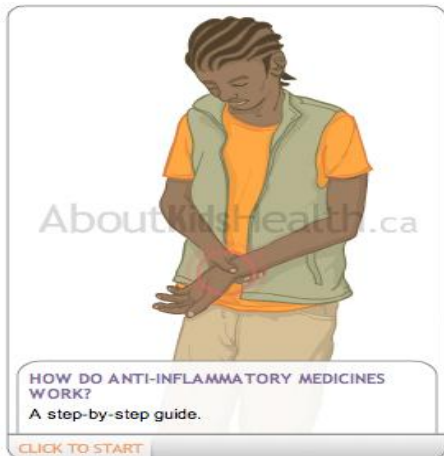
These medications can also help to reduce your arthritis pain. In this page, you will learn about other common pain medicines that can help control pain.

Pain meds
are also called
analgesics or
painkillers

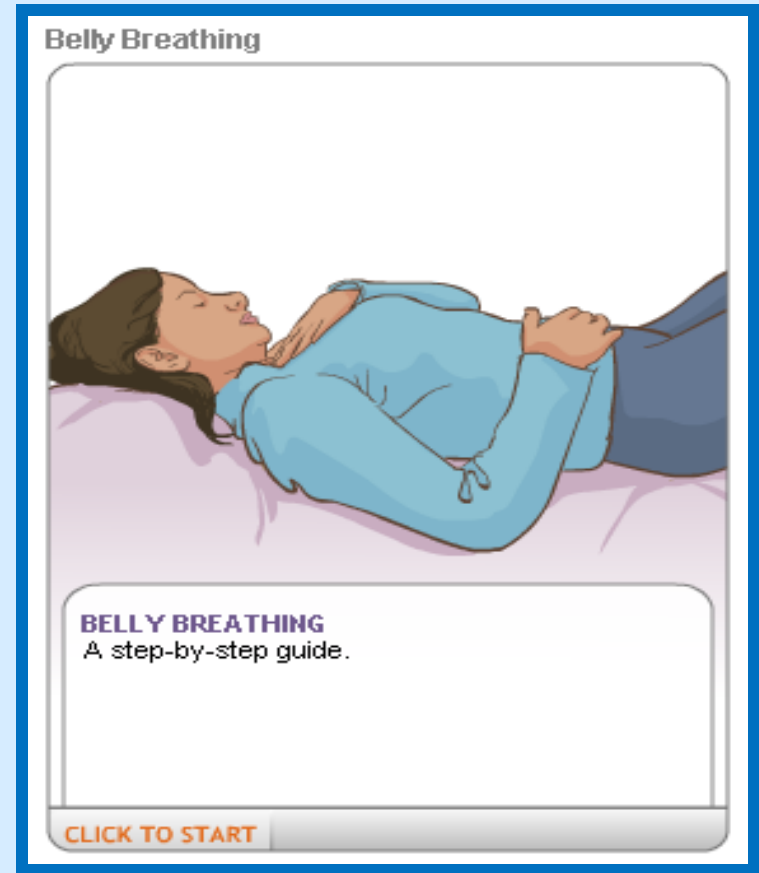


The Teens Taking

Click-through Animation: How Anti-inflammatories Work



Learning to Relax

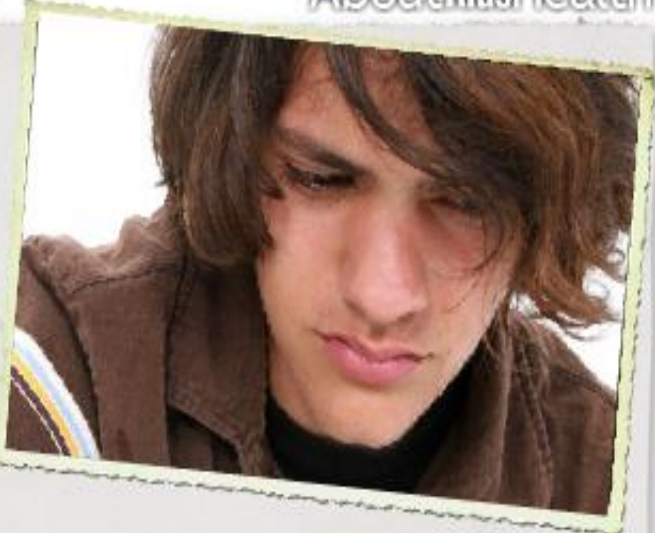


Managing Stress and Negative Thinking

STRESS * THINKING About Kids Health

THE MIND * BODY CONNECTION

Stress can affect every area of your health.

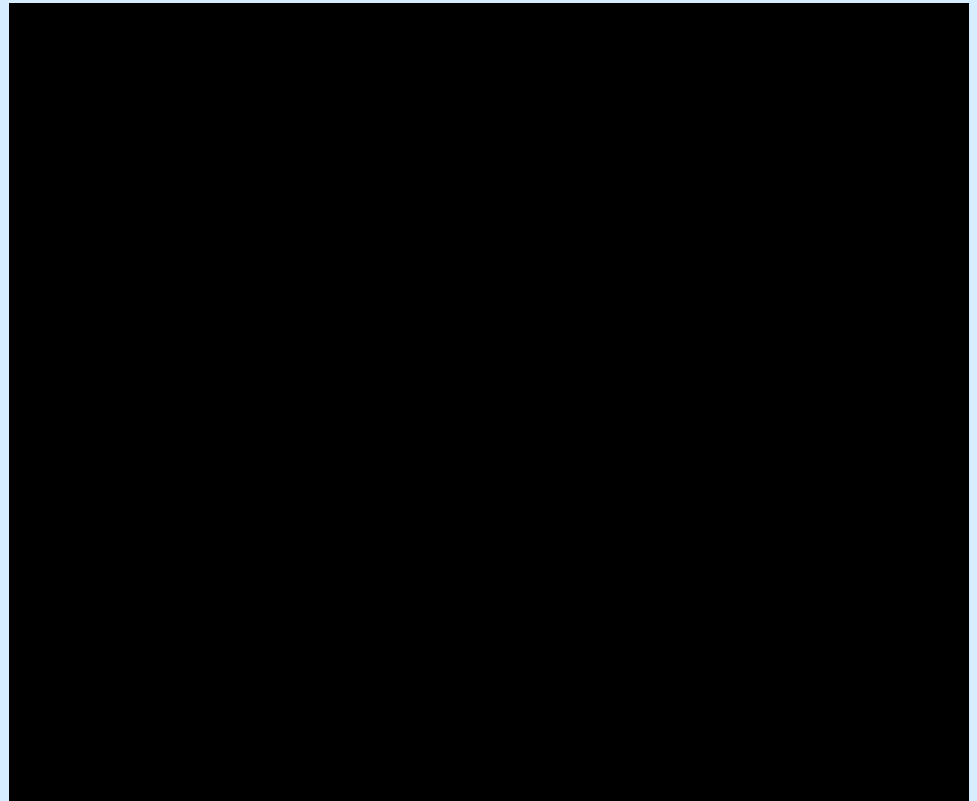


... Use the buttons to go forward or back.

stress causes effects emotions symptoms coping

START →

Social Support



Peer Support – Discussion Board

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 FORUMS

AboutKidsHealth FORUMS

Forums Home | Forums | Help in Reporting Forums (forum) Search


// FORUMS :: AKH GENERAL FORUMS :: GENERAL TOPIC #1

AKH Diabetes Forum

Last post a few seconds ago by stever. 1 replies.

☆☆☆☆☆ Enable Email Subscription Change View Sort Posts: Oldest to newest Previous Next

2 minutes ago 3

 **stever**

Joined on 10-18-2006
Posts 0

Hypoglycemia Resource


[Reply](#) [Quote](#) [Delete](#) [Edit](#)

[Favorites](#) [Contact](#) [Moderate](#)

Do you know where i can locate a good resource where I can learn all about hypoglycemia and hyperglycemia with regards to my child's diabetes?

[Report abuse](#) [Quick Reply](#)

a few seconds ago 4 in reply to 3

 **Dr. Know**

Joined on 10-18-2006
Posts 0

Re: Hypoglycemia Resource

[Reply](#) [Quote](#) [Delete](#) [Edit](#)

[Favorites](#) [Contact](#) [Moderate](#)


Sure there is a great amount of information right on the AboutKidsHealth site:
<http://www.aboutkidshealth.ca/clinicalAreas.asp?pageContent=DB-nh3-03d>

[Report abuse](#) [Quick Reply](#)

Ask the Expert



Weekly Quiz

1. About Arthritis	<h2>Managing Your Symptoms: What You Have Learned</h2> <p>In this session, you have:</p> <ul style="list-style-type: none">■ Learned what causes pain, stiffness, and fatigue■ Discovered medicines, physical methods, and coping strategies to manage your pain, stiffness, and fatigue■ Learned five tips to improve your sleep■ Learned how to develop and evaluate a plan to manage your symptoms <p>Quiz: Managing your symptoms</p> <p>Click here to review what you have learned</p> <p>Your health coach will review your answers with you.</p> 
2. Understanding Diagnosis	
3. Managing Your Symptoms	
What Is Pain?	
Managing Your Pain	
What Is Fatigue?	
Managing Your Fatigue	
What Is Stiffness?	
Managing Your Stiffness	
Your Plan for Managing Symptoms	
What You Have Learned	
4. Managing Stress	
5. Relaxation	
6. Arthritis Medication	
7. Distraction	
8. Other Types of Arthritis	
9. Managing Your Thoughts	
10. Therapies, Self-monitoring, Supports	
11. Your Lifestyle	
12. Looking Ahead	

Quiz: About Arthritis

There is no way possible to change pain signals once you have hurt yourself. ☐ T ☐ F required

Thinking positive can help with managing pain, stiffness, and fatigue. ☐ T ☐ F required

If you have arthritis, you should never exercise because it will further damage your joints. ☐ T ☐ F required

[Close box](#)

Parent Modules

- ❑ Arthritis: Impact on you and your family
- ❑ Letting go: Enabling your child to take control





Phase 2: Usability Testing

(Stinson et al., J Med Internet Res, 2010)

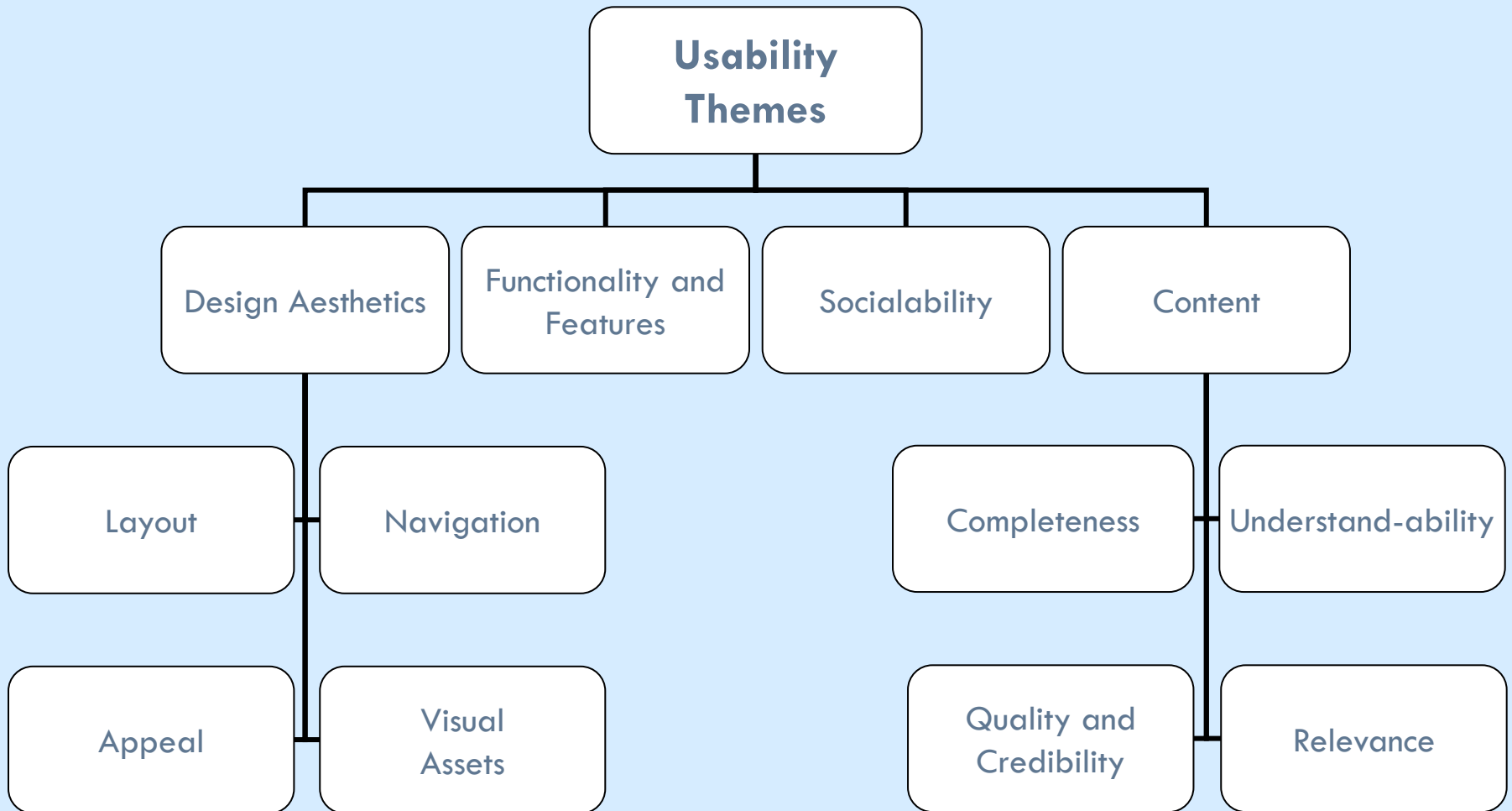
Study Design

- A qualitative study design with semi-structured, audio taped interviews and observation by a trained observer was undertaken with two iterative cycles (English and French) to determine the usability and intuitiveness of the user interface of the Internet intervention with the goal of further refining the prototype
- Usability objectives:
 - **Ease of use**
 - **Efficiency**
 - **Errors**
 - **Participants' satisfaction**

Sample Characteristics

Characteristic	English (n=11)	French (n=8)
Female (%)	73	73
Age (mean, SD)	15.45 (1.71)	16 (1.23)
Duration of illness (years)	7.85	6.66
PGA disease severity (VAS)	0.90 (0.87)	0.84 (1,72
Disease subtype (% Poly -)	45	38

Views on Usability



Design Aesthetics

□ Layout

- Teens liked material chunked and broken up with graphics; parents were willing to scroll through information
- Put most important information at top of each page

□ Navigation – “intuitive” and “user-friendly”

- Changes made to medication section

□ Visual assets (illustrations, graphics, animations)

- Important aspect of site that helped to make written information clearer, enhanced interactivity and engagement

□ Visual appeal (look and feel of site)

- Visually appealing: “friendly” and “approachable”
- Doesn't look too “scientific”; its easy to read



Juvenile Arthritis

Introduction for Teens

1. About Arthritis

What Is Arthritis?

What Causes Arthritis?

Types of Arthritis in Young People

Oligoarticular Arthritis

Polyarticular Arthritis

Systemic Arthritis

Enthesitis-related Arthritis

Psoriatic Arthritis

How will Your Arthritis Affect You Now?

How Will Arthritis Affect Your Future?

What You Have Learned

2. Understanding Diagnosis

3. Managing Your Symptoms

4. Managing Stress

5. Relaxation

6. Arthritis Medications

7. Distraction

8. Other Types of Care

9. Managing Your Thoughts

10. Therapies, Self-monitoring, and Supports

11. Your Lifestyle

12. Looking Ahead

Click Here to get back to the JIA Parent Site!

Juvenile Arthritis

Systemic Arthritis

What is systemic arthritis?

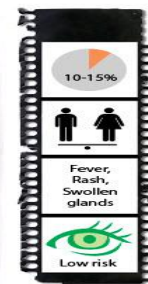
Systemic (say: sis-tem-ik) arthritis is less common and affects only 10% to 15% of young people with arthritis. It is often a more severe form of juvenile idiopathic arthritis. Systemic means it affects many parts of the body, rather than just a few specific places like your joints.

sis-tem-ik

Quick facts about systemic arthritis

If you have systemic arthritis, here are a few things you might want to know:

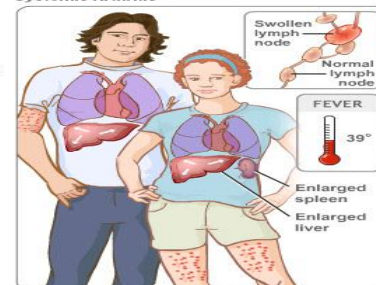
- It occurs in about 10% to 15% of young people who have arthritis.
- It affects boys and girls equally.
- It involves a few to many different joints.
- The disease may range from mild to severe.
- You will usually have a spiking fever. This is a fever that rapidly rises and falls. The fever occurs once or twice every day. The fever lasts for a long time.
- Generally with the fever, you will feel tired and unwell. This happens most often in the late afternoon or evening. When your temperature returns to normal, you will feel better.
- The arthritis symptoms begin within six months after the fever starts. Usually the arthritis symptoms will persist, even after the fever goes away.
- There is also a rash of pale pink-red spots on the chest, upper arms, thighs, and other parts of the body. The rash may come and go with the fever.
- Swollen lymph glands are common.
- Your liver and spleen may become larger than normal.
- If the disease is severe, you may have inflammation around your heart, lungs, or bowels. Also, your immune system may start to destroy blood cells.
- Eye disease such as uveitis is not common.



In the early stages of systemic arthritis, there is sometimes no sign of arthritis, such as joint pain or swelling. This makes it very difficult to diagnose this type of arthritis. After all, there are many other illnesses that also cause a fever and rash in young people. Many tests are often needed to diagnose this type of arthritis. Rarely, the body-system problems that come with this type of arthritis, such as heart and lung inflammation, can be life-threatening.

The duration of systemic arthritis varies from person to person. Some young people have only one episode of the disease, get better and never have a problem again. Usually however, there are flares of disease over time. A small number of young people with systemic arthritis develop very severe arthritis in many joints. They may require aggressive treatment to control it.

Systemic Arthritis



Systemic arthritis affects both males and females equally. It is characterized by presence of fever, swollen lymph glands, and rash. When severe, there may be inflammation of heart, lungs, liver, or spleen.

Last Reviewed

January 26, 2009

Reviewed by

Adam Huber, MSc, MD, FRCPC
 Alex V. Levin, MD, MHS, FAAP, FAOD, FRCSC
 Patrick J. McGrath, PhD
 Laura E. Schanberg, MD
 Lynn Spiegel, MD, FRCPC
 Jennifer Stinson, RN, PhD, CPNP
 Lori B. Tucker, MD



Content

❑ **Completeness**

- Comprehensive “one site can address all the needs”

❑ **Understandability**

- Readability (6-7), use of plain language, and explanation of medical terminology (glossary of terms)

❑ **Quality and credibility**

- Content appeared accurate, representing the best evidence
- High quality information

❑ **Relevance**

- Applicable to needs of youth with JIA and their parents
- Vocalized strong need for such a program

Functionality and Features

- ❑ What user could do on site and extent that site pages and external links loaded without error
- ❑ Adaptive and interactive features of site allowed for increased level of personalization of website content
 - My Journal
 - Goal setting
- ❑ Interactivity enhanced motivation and engagement with program

Socialability

- ❑ Ability of program to support social interactions among participants
- ❑ Liked discussion board and videos of teens with JIA – helped to ease feelings of hopelessness and isolation
- ❑ Most teens commented that they did not know another teen with JIA
- ❑ Most teens felt they would use the discussion board feature but only 1/2 of parents stated they would

Conclusions...

- ❑ Testing uncovered formatting/navigation problems that were corrected
- ❑ Participants suggested addition of exercise/yoga videos
- ❑ All of the participants stated the Internet program was easy to navigate, use, and understand and was satisfying to complete
- ❑ They felt the content was appropriate and geared to meet the unique needs of both adolescents and parents and they liked the look and feel of the web-site
- ❑ All participants stated this would have been especially helpful when they were first diagnosed



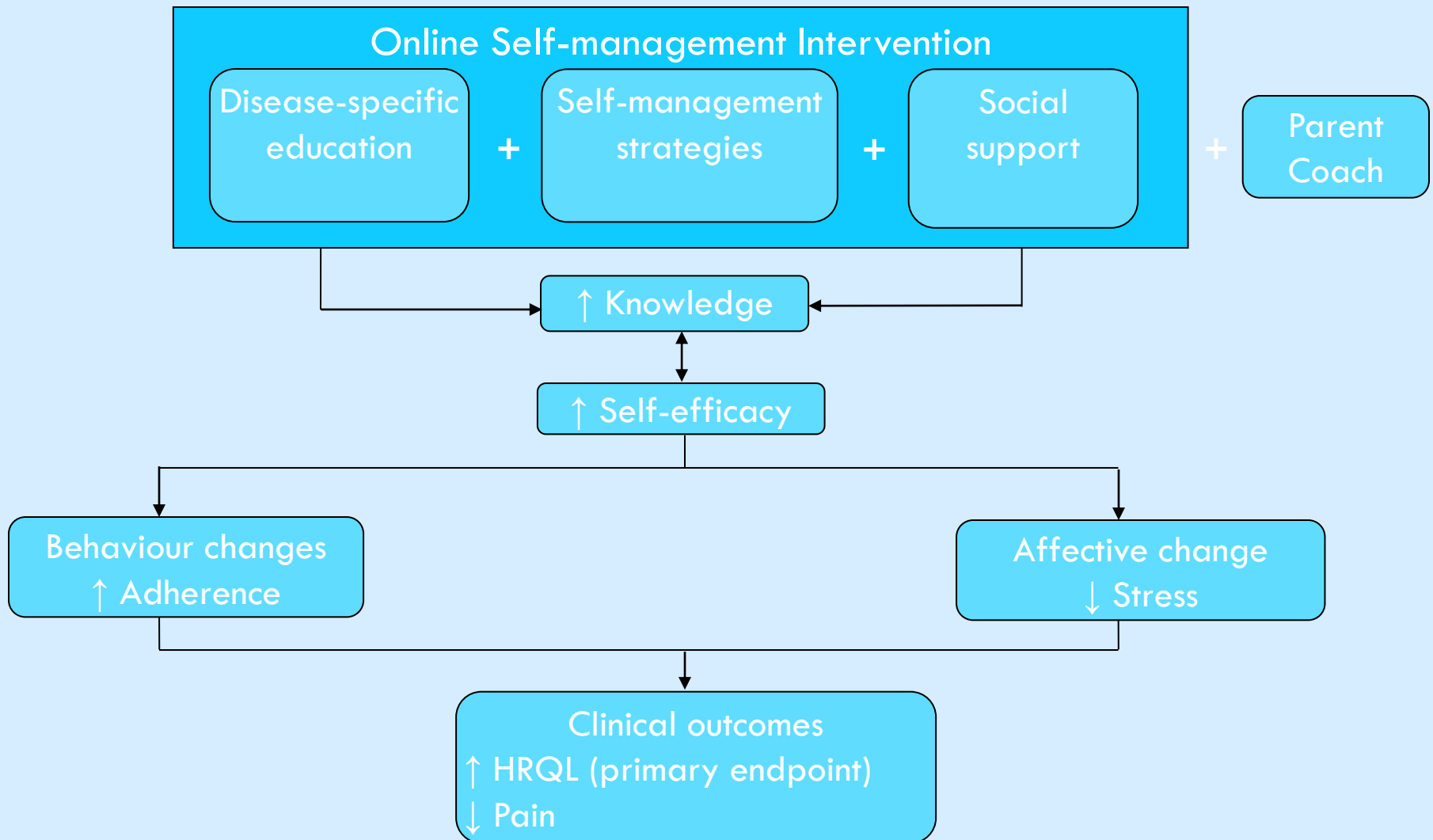
Phase 3: Feasibility Testing

(Stinson et al., J of Rheum, 2010)

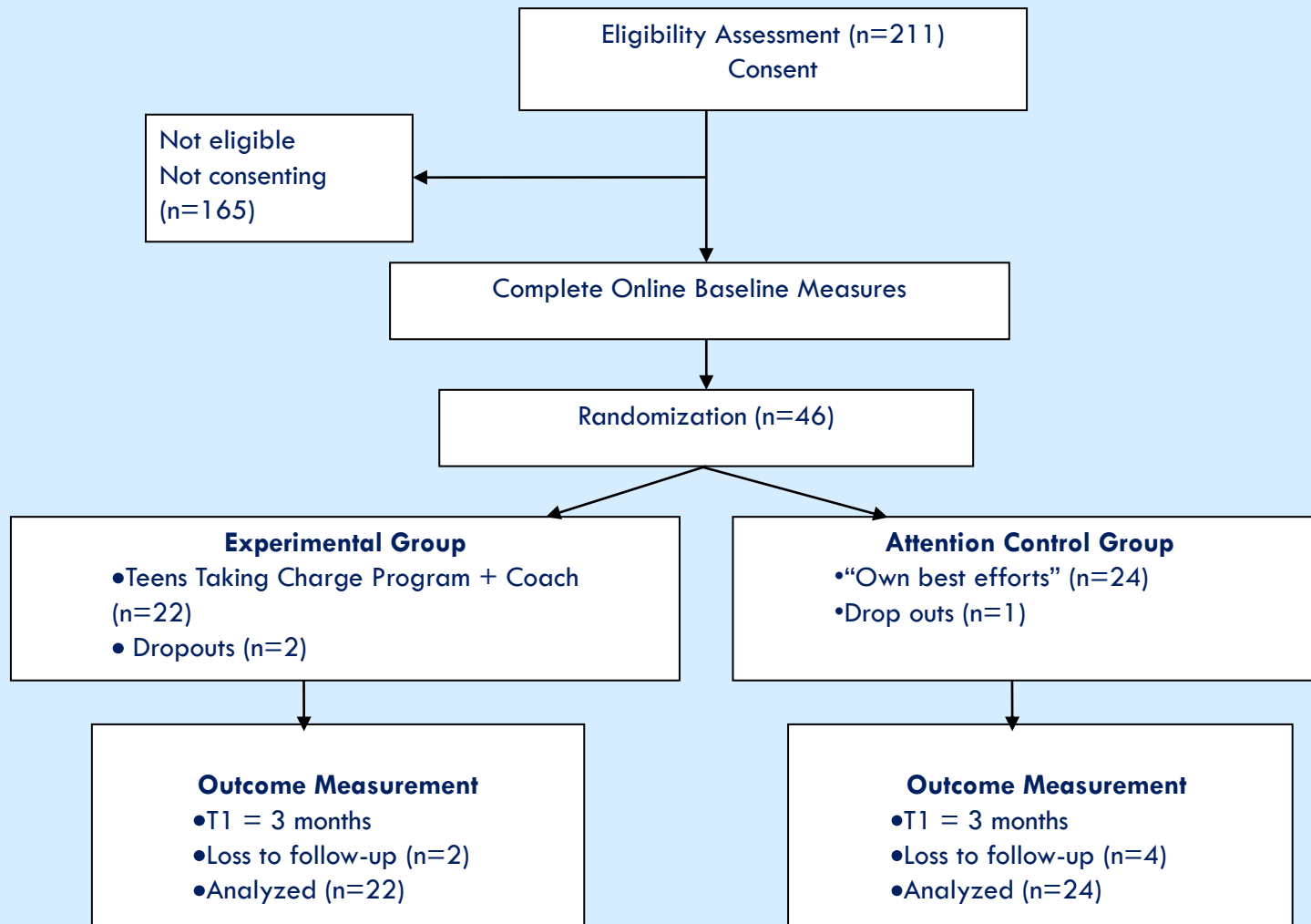
Study Design and Aims

- ❑ A single-blinded RCT was used to test the feasibility of the “Teens Taking Charge” intervention
- ❑ **Feasibility Aims:**
 - Assess adolescents’ willingness to be randomized
 - Pilot the intervention, attention control strategies (e.g., adolescents’ ‘own best efforts’ at managing arthritis), and outcome measures
 - Determine adolescents’ perceptions regarding acceptability of the web-based intervention
 - Obtain estimates of treatment effects in primary (HRQL) and secondary (knowledge, coping, self-efficacy, stress, treatment adherence, pain) outcome measures to inform the calculation of appropriate sample size for the future RCT (Phase 4)

Hypotheses



Study Participant Flow



Sample Characteristics

Characteristic	Experiment (n=22)	Control (n=24)
Female (%)	64.8	66.8
Age (mean, SD)	14.28(1.28)	14.83(1.66)
Duration of illness (mean, SD) in years	6.47(4.13)	6.67(5.05)
PGA disease severity (VAS)	1.87(1.67)	2.5(1.89)

Results...

- ❑ Experimental group had significantly higher disease knowledge ($p < 0.001$, with a large effect size [ES] of 1.32) and lower average weekly pain intensity ratings ($p = 0.03$, with a moderate $ES = 0.78$) compared to the attention control group
- ❑ No differences: HRQL, stress, adherence or self-efficacy
- ❑ Program usage patterns:
 - high compliance with completing weekly modules (91%)
 - utilized communication features
 - actively engaged in the intervention through goal-setting and completing personalized information

Next Steps....

- Phase 4 – multicentred RCT (grant under review) to test JIA program
- Developed JIA resource centre
- Template for development of other interventions (sickle cell disease, cancer, haemophilia)
- Cost-effectiveness studies

Qualitative Results

Teen:

“The program has made me more confident...I’m not as shy...everything seems easier, more sorted out...in all aspects of life.”

Parent:

“I believe it has really given her a lot to think about...it has given her insight into the future and I think that’s a big part of why we’ve been so successful in her taking over being responsible for taking her meds.”

Conclusions

- ❑ Psychological interventions for chronic pain are ideally suited for computer delivery systems
- ❑ Addresses barriers related to access and may boost compliance with practice of cognitive and behavioral skills
- ❑ Emerging treatment outcome data shows clinically significant improvements in individuals receiving interactive health and communication interventions

Challenges

- ❑ Cost (program development; minimal therapist involvement or self-guided)
- ❑ Knowledge and experience (phased approach, standards for development and testing)
- ❑ Sustainability - ongoing web upgrades/maintenance
- ❑ Planning for dissemination (free or fee)

Acknowledgements

Collaborators:

- Jacqueline Lukas-Bretzler (CAPA)
- Laurie Proulx (CAPA)
- Doug Earle (TAS)
- Robert Watts (TAS)
- Dr. Bianca Lang (CAPRI)

Funding:

Research Coordinators:

- Navreet Gill (Project Coordinator)
- Meghan White
- Michele Gibbon
- Aleasha Warner
- America Uribe

