

# STEP BY STEP PROCESS TO DEVELOP A COMPREHENSIVE SELF-MANAGEMENT TOOL FOR PATIENT WITH CHRONIC DISEASES

Edith Strauss Interactive Day: Engaging Patients as Partners in Knowledge Translation  
(KT)

*How to Workshop: Strategies for designing your own patient education intervention*

***Vanessa Bouchard, pht, MSc, PhD***

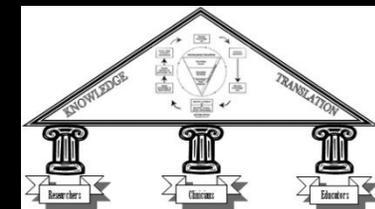
# OBJECTIVES

- Outline the key strategies for designing a patient education intervention
- Define self-management and outline how the theory can be used to design tool
- Illustrate the development of a patient tool using the example of the *Getting On With Your Life With MS* (GETONMS©) workbook

# DISCLAIMER

The work I am presenting today may appear overwhelming at first sight:

- Received substantial funding
  - Edith Strauss KT grant (2010 and 2016)
  - CIHR end of grant KT extension (100k\$)
- Took 7 years and countless hours to develop
- 21 experts involved
- 9 MS patient involved in development



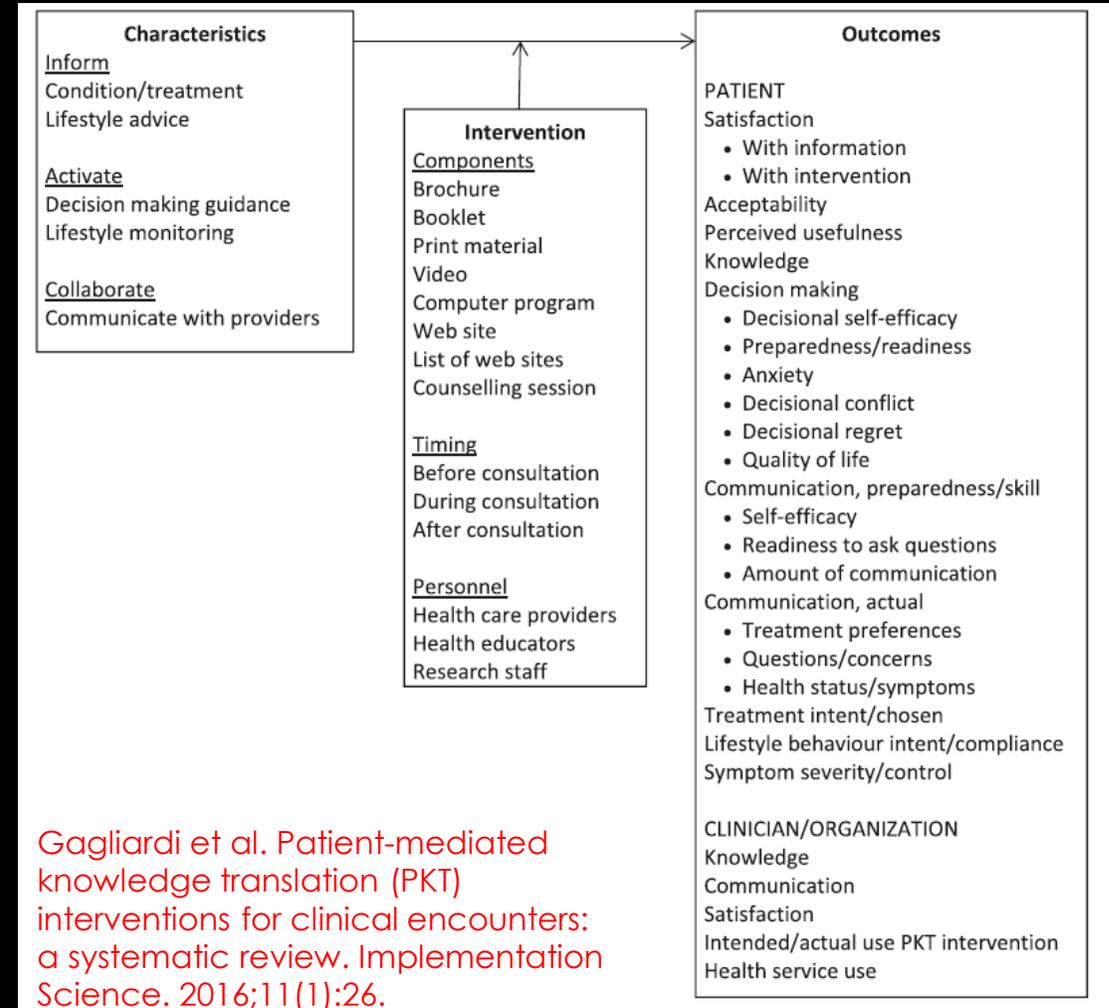
# WHY DO WE CREATE PATIENT EDUCATION MATERIAL?



# CONCEPTUAL FRAMEWORK OF PATIENT-MEDIATED KNOWLEDGE TRANSLATION INTERVENTIONS FOR CLINICAL ENCOUNTERS

## Reasons for patient-mediated KT interventions

- Inform
- Activate
- Collaborate



# SELF-MANAGEMENT DEFINITION

A person's ability to manage **symptoms**, **treatment**, physical and psychological **consequences** as well as **cop**ing with **lifestyle changes** associated with living with a chronic disease.

# SELF-MANAGEMENT SKILLS

Goal  
setting

Decision-  
making

Use of  
existing  
resources

Achievable  
actions  
plans

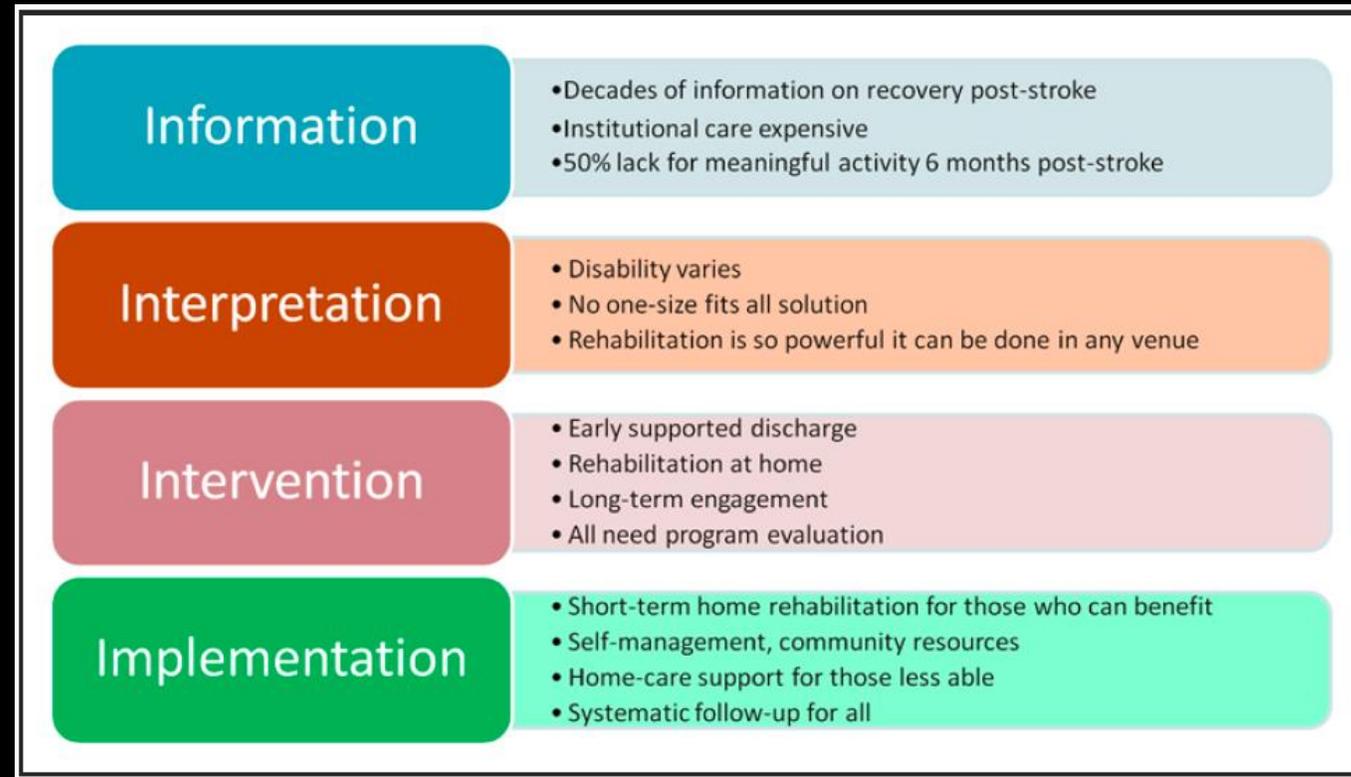
Self-  
evaluation

Problem  
solving

Partnering  
with your  
health care  
team



# SELF-MANAGEMENT MOVES PATIENTS FROM INFORMATION TO IMPLEMENTATION

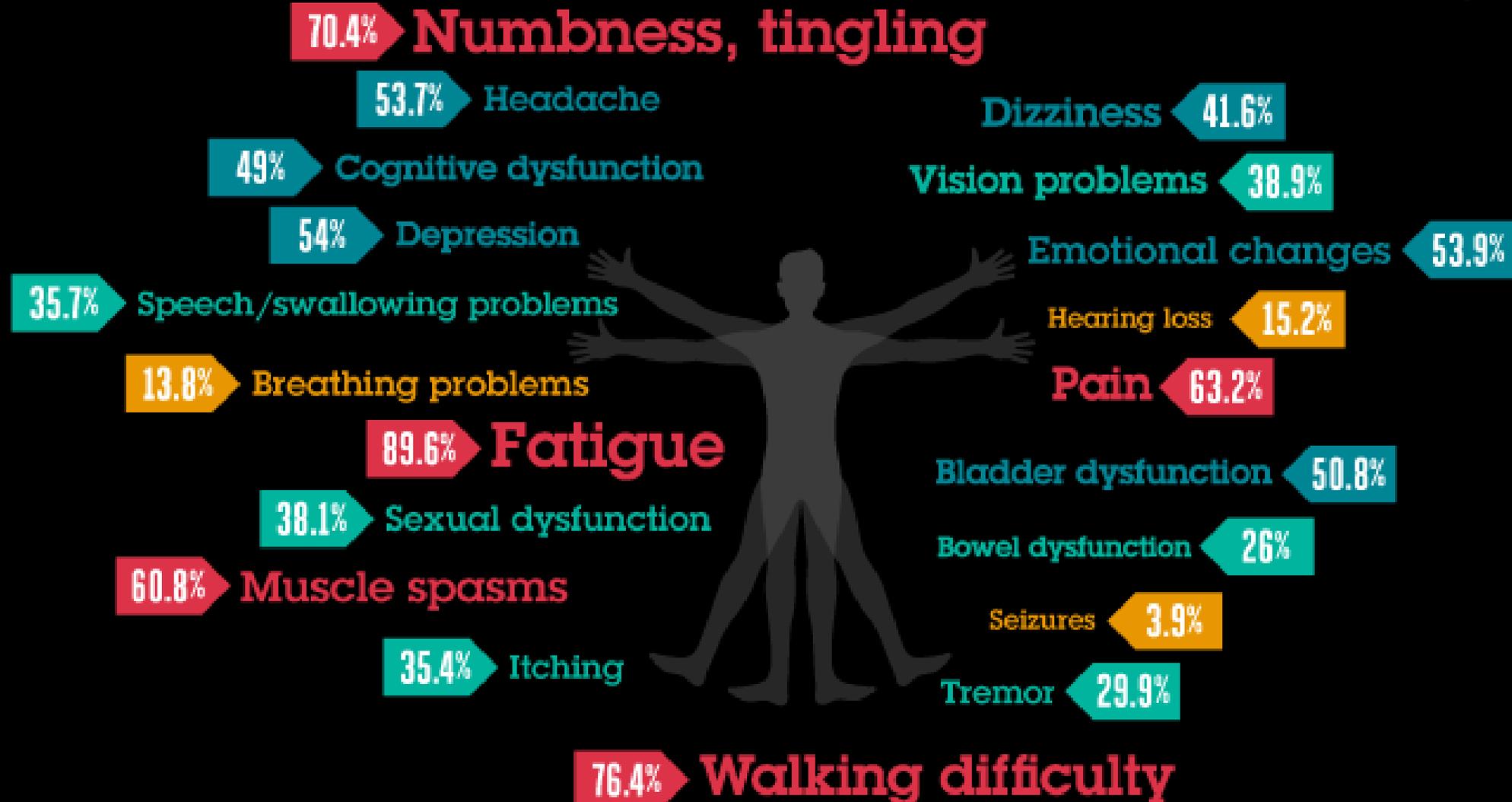




# WHY CREATE A BOOK?

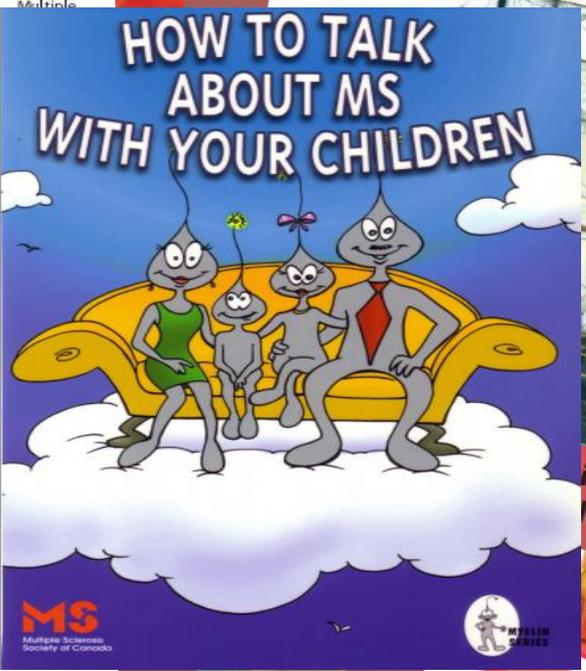
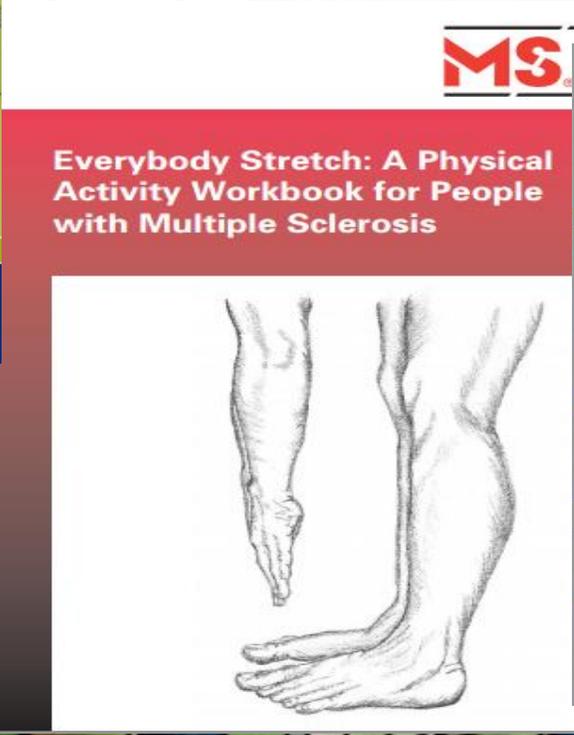
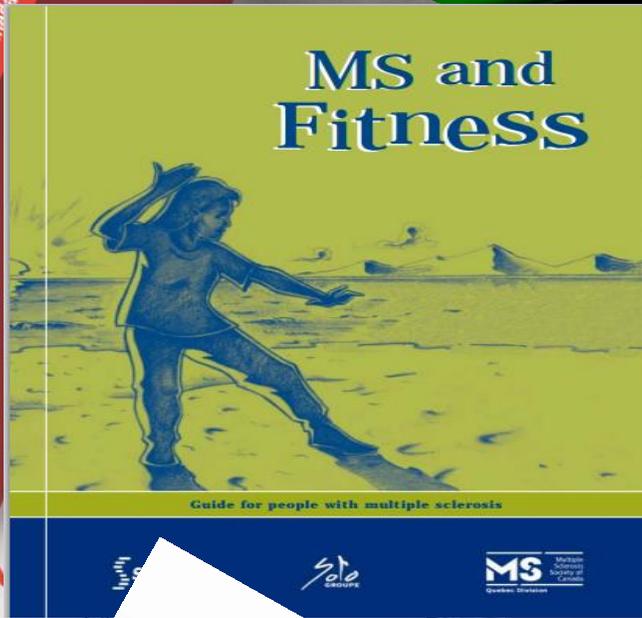
People with Multiple Sclerosis asked  
for it!

# MULTIPLE SCLEROSIS (MS)





PEOPLE WITH MS CAN LIVE!



MS Society of Canada Educational Series

MS Society of Canada Educational Series

# MODEL

  
CANADIAN  
**STROKE NETWORK**  
REDUCING THE IMPACT OF STROKE  
VOLUME 9 NUMBER 1

**GETTING ON WITH  
THE REST OF YOUR LIFE  
AFTER STROKE**

**Bonus**  
A patient's guide  
to stroke care

**SET GOALS**  
Check out our  
goal-setting guide.

**GET ACTIVE**  
Add a pedometer. You won't  
realize how far you've come.

**BE CREATIVE**  
Creativity improves  
brain recovery.

[WWW.CANADIANSTROKENETWORK.CA](http://WWW.CANADIANSTROKENETWORK.CA)

  
CANADIAN  
**STROKE NETWORK**  
REDUCING THE IMPACT OF STROKE  
VOLUME 9 NUMBER 2

**GETTING ON WITH  
THE REST OF  
YOUR LIFE  
AFTER  
STROKE**

**Bonus**  
A patient's guide  
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**SET GOALS**  
Check out our  
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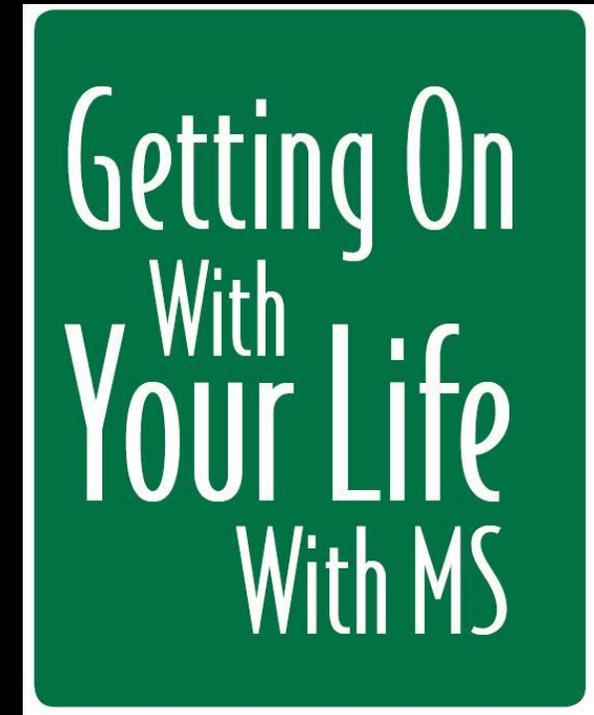
**GET ACTIVE**  
Buy a pedometer, then walk  
and track your progress.

**BE CREATIVE**  
Creativity improves  
brain recovery.

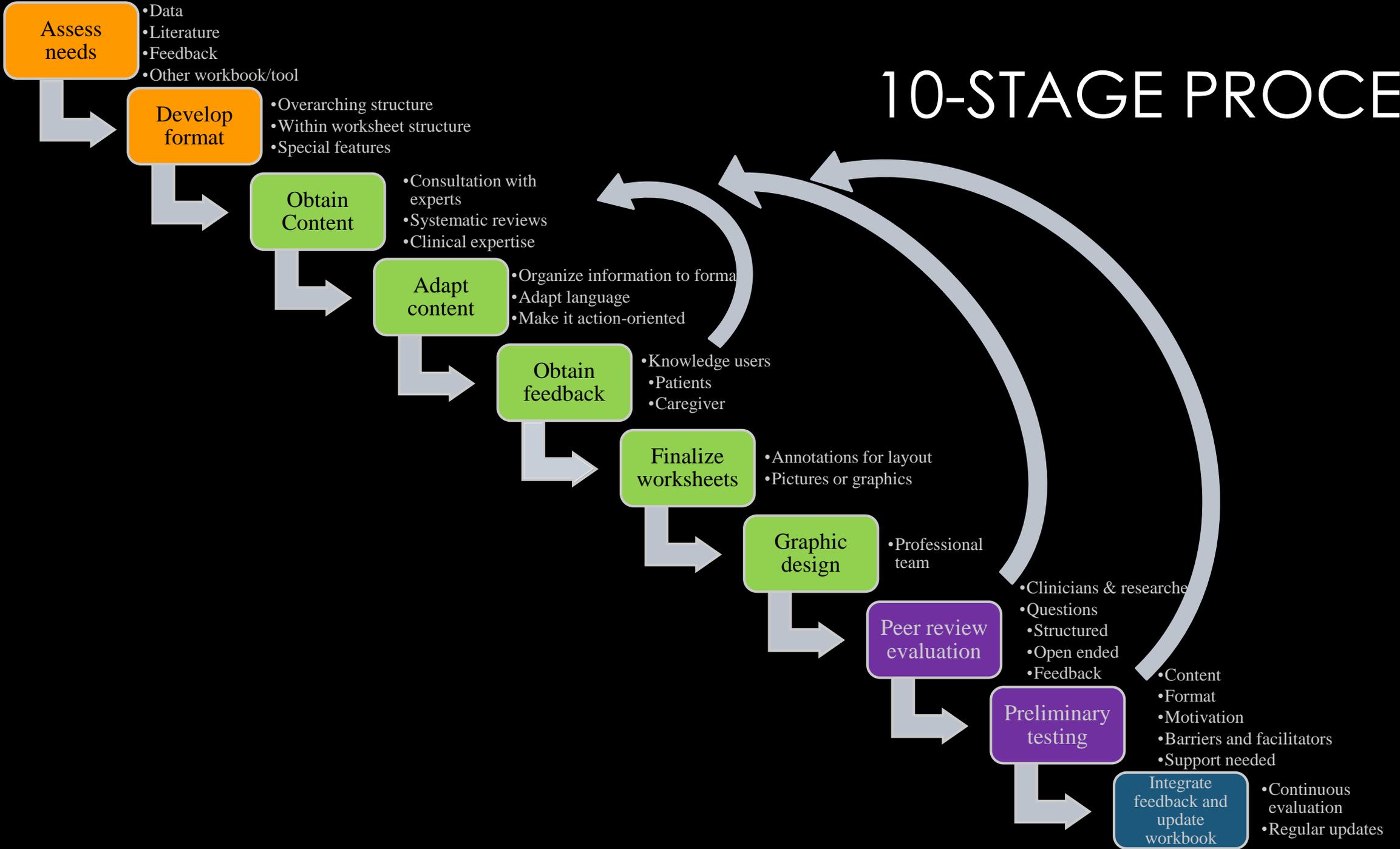
[WWW.CANADIANSTROKENETWORK.CA](http://WWW.CANADIANSTROKENETWORK.CA)

# GETONMS© PHILOSOPHY

- Based on needs
- Evidence-based
  - Expert developed
  - Patient improved
  - Peer reviewed
- Integrates self-management principles and skills
- Targets quality of life
- Individually tailored
  - Choose from menu of topics
- Easy to use
- Visually pleasant

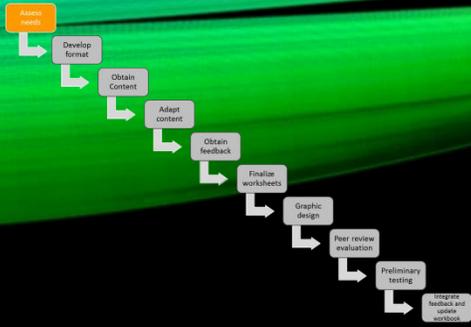


# 10-STAGE PROCESS

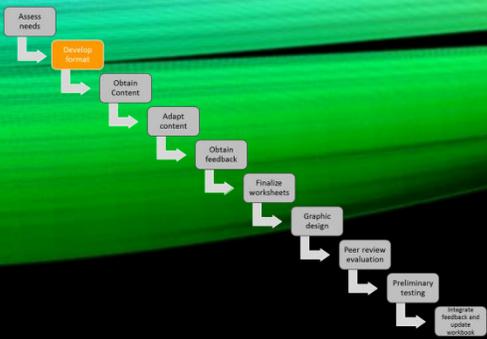




# STAGE 1: ASSESS NEEDS OF THE POPULATION



- Literature
- Data: MS life impact study 2008 – 189 participants nominated 62 areas of their life affected by MS
- Focus group of clinicians and researchers
- Informal discussions with patient-experts
- Topics important to self-management
- What is the problem?
- What do the patients need?
- What is already done?
- Is there literature available on the topic?



# STAGE 2: DEVELOP THE FORMAT

1. Overarching strategy template

- 1
- 2
- 3
- 4
- 5

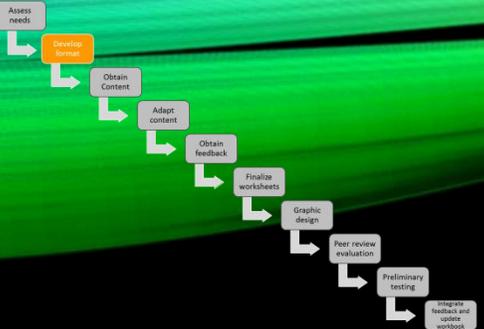
- Getting...
- Health...
- Dealing...
- Pa...
- care team
- Putting it all together...
- plan of action



DECLINING

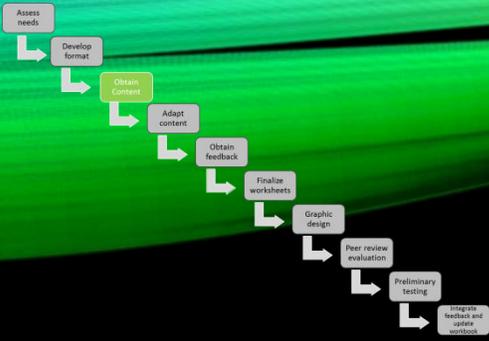
Whenever you see this "evidence icon" you are seeing the latest research evidence on the topic.

This "VIP icon" accentuates a "Very Important Point" being discussed.



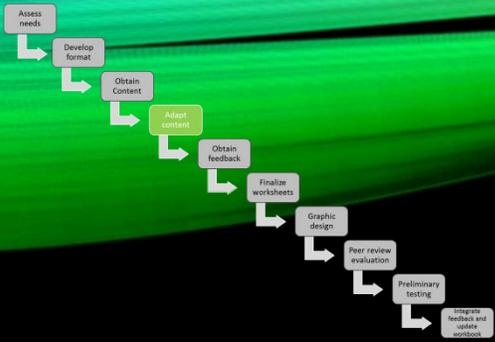
# STAGE 2: DEVELOP THE FORMAT

- What format are you going for?
  - Pamphlet
  - Worksheet
  - Video capsule
  - Web page
- Outline the sections that will need to be filled
- If you work with a graphics department: ask if they already have a template



# STAGE 3: OBTAIN CONTENT FOR THE TOPICS AND WORKSHEETS

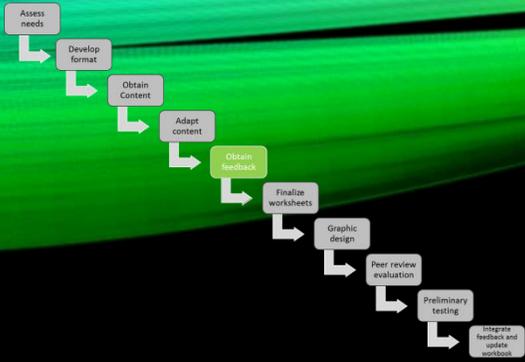
- 21 experts
  - Symposiums
  - Networking activities
  - MS clinics
  - Published literature
- Informed by systematic reviews
  - When none available, literature reviewed systematically
- Create content
  - Use the available literature
  - Use the strength of team members
  - Find images and graphics that help the understanding of the content



# STAGE 4: ADAPT THE CONTENT TO THE FIT THE PURPOSE

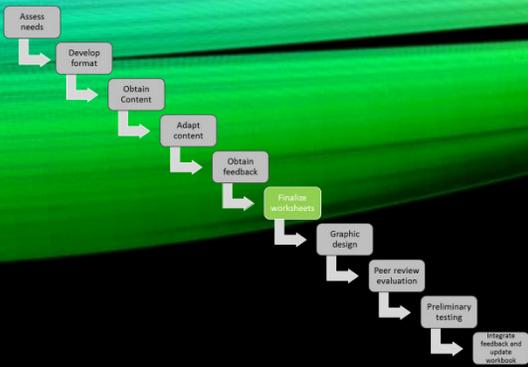
- Simplify the **content**
- Reduce clinical **language**
- Structure content to fit **template**
- Ensure **assessment** and **action plan** were present
- Create vignettes
  - To demonstrate how to use assessment or action plan
- Multiple rounds between authors until agreement
- May not be necessary if the project is simple
- If multiple authors: unify language
- Readability level
  - < Grade 6





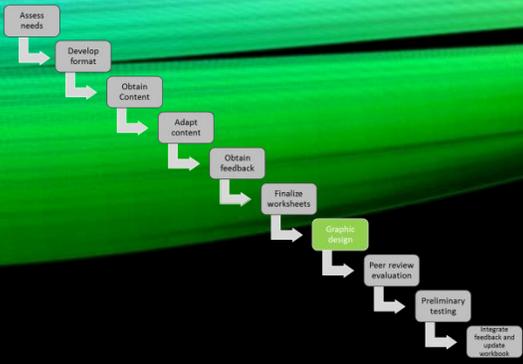
# STAGE 5: OBTAIN FEEDBACK

- 4 Women with MS
- Feedback on:
  - Usefulness
  - Clarity
  - Applicability
  - Relevance of content and format
  - Identifying language issues, grammatical and typographical errors
- One or two potential users should have a look at the content you wish to include.
  - Usefulness
  - Clarity
  - Applicability
  - Relevance of content and format
  - Identifying language issues, grammatical and typographical errors
  - Missing information



# STAGE 6: FINALIZE WORKSHEETS

- Update worksheet based on feedback
- Consensus between authors
- Add **indications** and image **suggestions** for graphics team
- Integrate feedback
- Do necessary corrections
- If you work with a graphics department: include indications on layout and images.

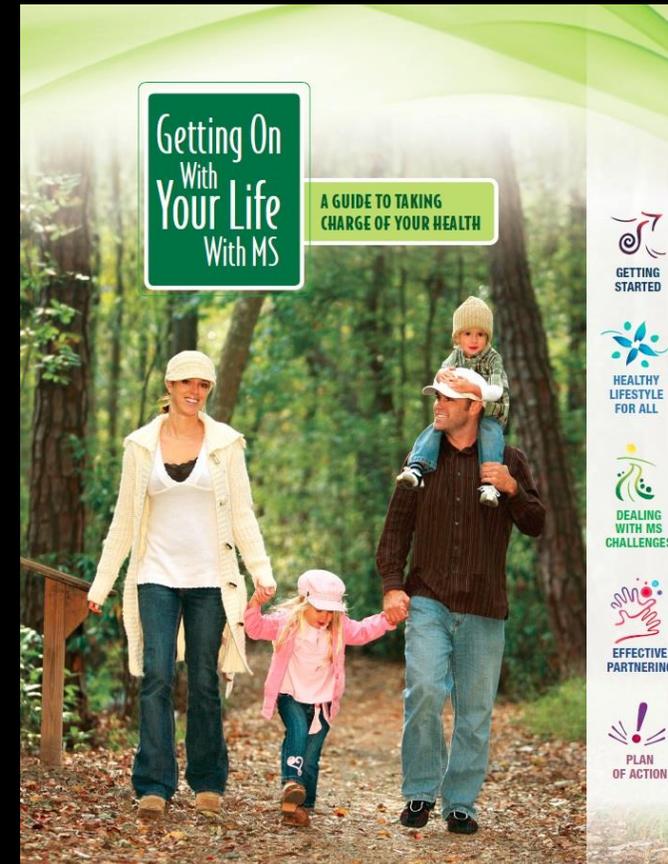


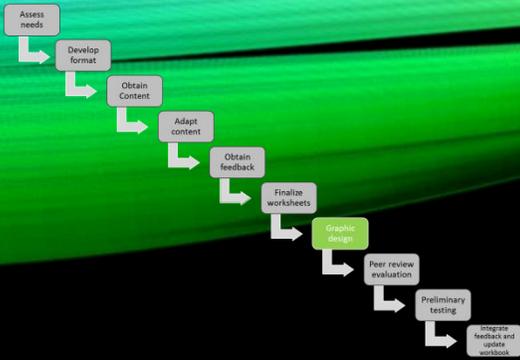
# STAGE 7: GRAPHIC DESIGN

- Earthlore Communications



- Multiple rounds of feedbacks and revision
- Production of a beta- test version of **Getting On With Your Life With MS**





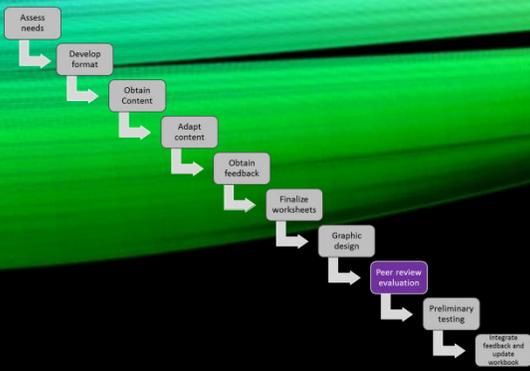
# STAGE 7: GRAPHIC DESIGN

- Earthlore Communications



- Multiple rounds of feedbacks and revision
- Production of a beta- test version of **Getting On With Your Life With MS**

- If you work with graphics department: clearly indicate what you need/want
- If you do it yourself:
  - Use appropriate software and formatting
  - Make sure you have the rights to use pictures and images



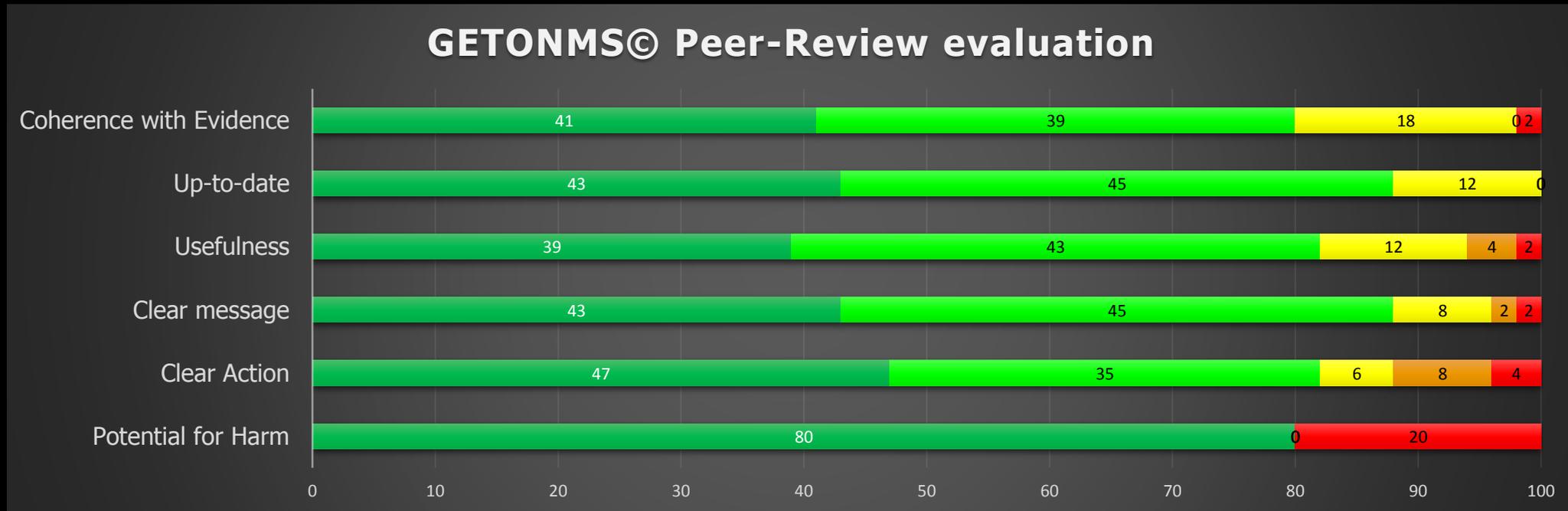
# STAGE 8: PEER-REVIEW EVALUATION

- Email experts with:
  - Selected worksheet(s) in PDF format
  - Link to survey
- Measures
  - Patient Education Material Assessment Tool (PEMAT) (Shoemaker, 2014)
  - Close-ended questions with 5-point Likert scale to test if content is:
    - Coherent with evidence, up-to-date, usefulness, clarity of message, clarity of action, and potential for harm
  - Open ended questions:
    - Potential improvement

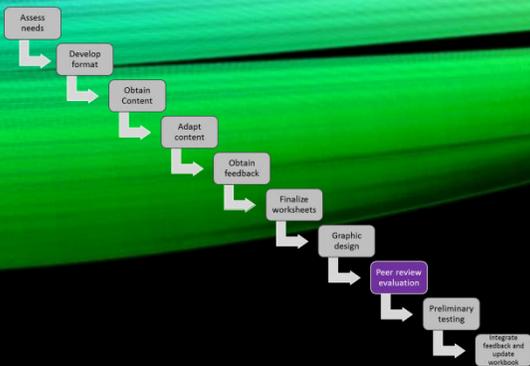


| Item #                                | Item   | Response Options                              | Rating |
|---------------------------------------|--|---|--------|
| <b>Topic: Content</b>                 |  |   |        |
| 1                                     | The material makes its purpose completely evident.   | Disagree=0, Agree=1                           |        |
| 2                                     | The material does not include information or content that distracts from its purpose.  | Disagree=0, Agree=1                           |        |
| <b>Topic: Word Choice &amp; Style</b> |  |   |        |
| 3                                     | The material uses common, everyday language.   | Disagree=0, Agree=1                           |        |
| 4                                     | Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined.                      | Disagree=0, Agree=1                           |        |
| 5                                     | The material uses the active voice.  | Disagree=0, Agree=1                           |        |
| <b>Topic: Use of Numbers</b>          |  |   |        |
| 6                                     | Numbers appearing in the material are clear and easy to understand.  | Disagree=0, Agree=1, No numbers=N/A           |        |
| 7                                     | The material does not expect the user to perform calculations.   | Disagree=0, Agree=1                           |        |
| <b>Topic: Organization</b>            |  |   |        |
| 8                                     | The material breaks or “chunks” information into short sections.   | Disagree=0, Agree=1, Very short material*=N/A |        |
| 9                                     | The material’s sections have informative headers.  | Disagree=0, Agree=1, Very short material*=N/A |        |
| 10                                    | The material presents information in a logical sequence.   | Disagree=0, Agree=1                           |        |
| 11                                    | The material provides a summary.   | Disagree=0, Agree=1, Very short material*=N/A |        |
| <b>Topic: Layout &amp; Design</b>     |  |   |        |
| 12                                    | The material uses visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points. | Disagree=0, Agree=1, Video=N/A                |        |

# RESULTS – PEER-REVIEW EVALUATION

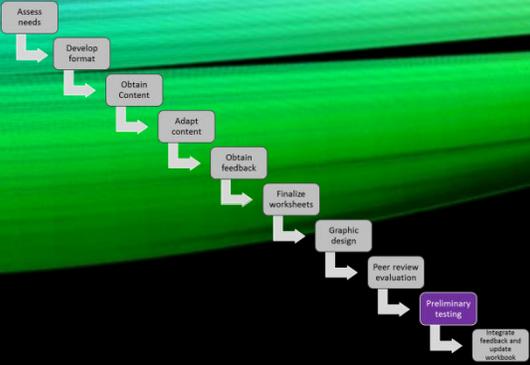


# STAGE 8: PEER-REVIEW EVALUATION



- Have some of your colleagues review your educational tool
  - Same profession working with same clientele
  - Same profession working with different clientele
  - Other profession working with same clientele
  - Team coordinator
- Patient Education Material Assessment Tool (PEMAT) (Shoemaker, 2014)
  - 26 Agree/Disagree questions

| Item #                                | Item   | Response Options                              | Rating |
|---------------------------------------|--|---|--------|
| <b>Topic: Content</b>                 |  |   |        |
| 1                                     | The material makes its purpose completely evident.   | Disagree=0, Agree=1                           |        |
| 2                                     | The material does not include information or content that distracts from its purpose.  | Disagree=0, Agree=1                           |        |
| <b>Topic: Word Choice &amp; Style</b> |  |   |        |
| 3                                     | The material uses common, everyday language.   | Disagree=0, Agree=1                           |        |
| 4                                     | Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined.                      | Disagree=0, Agree=1                           |        |
| 5                                     | The material uses the active voice.  | Disagree=0, Agree=1                           |        |
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| 6                                     | Numbers appearing in the material are clear and easy to understand.  | Disagree=0, Agree=1, No numbers=N/A           |        |
| 7                                     | The material does not expect the user to perform calculations.   | Disagree=0, Agree=1                           |        |
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| 8                                     | The material breaks or "chunks" information into short sections.   | Disagree=0, Agree=1, Very short material*=N/A |        |
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| 12                                    | The material uses visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points. | Disagree=0, Agree=1, Video=N/A                |        |



# STAGE 9: PRELIMINARY TESTING

- Design:
  - Longitudinal qualitative interviews on the use of the GETONMS© workbook
  - 3 interviews over 2 months
  - GETONMS© given after first interview
- Participants:
  - 5 English speaking community dwelling adults with MS with sufficient cognitive ability
- Methods:
  - Cognitive debriefing (content and usability)
  - Questionnaires (support, quality of life)

# QUALITY OF LIFE

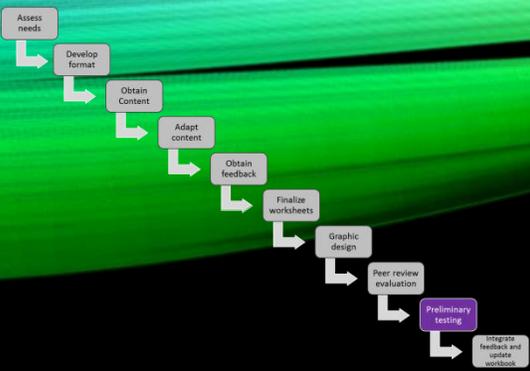


**Expectations**



**Coping**

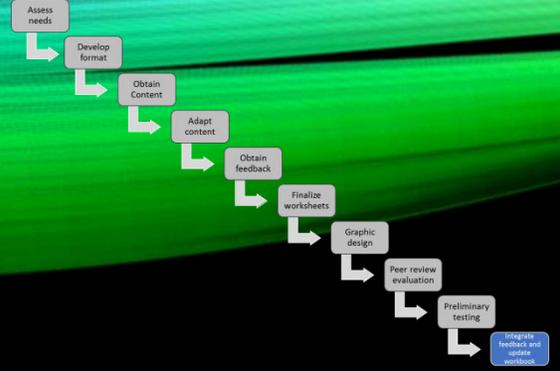




# STAGE 9: PRELIMINARY TESTING

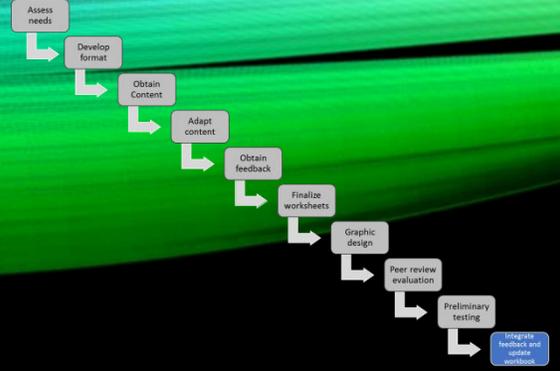
This can be done as continuing improvement!

- Give tool to some patients and their caretakers and follow up after a while:
  - Is it relevant?
  - Did you put it to use?
  - Was it easy to read/ to put into practice?
  - Did it make a change?
  - What would you change or add?



# STAGE 10: INTEGRATE FEEDBACK TO UPDATE WORKBOOK

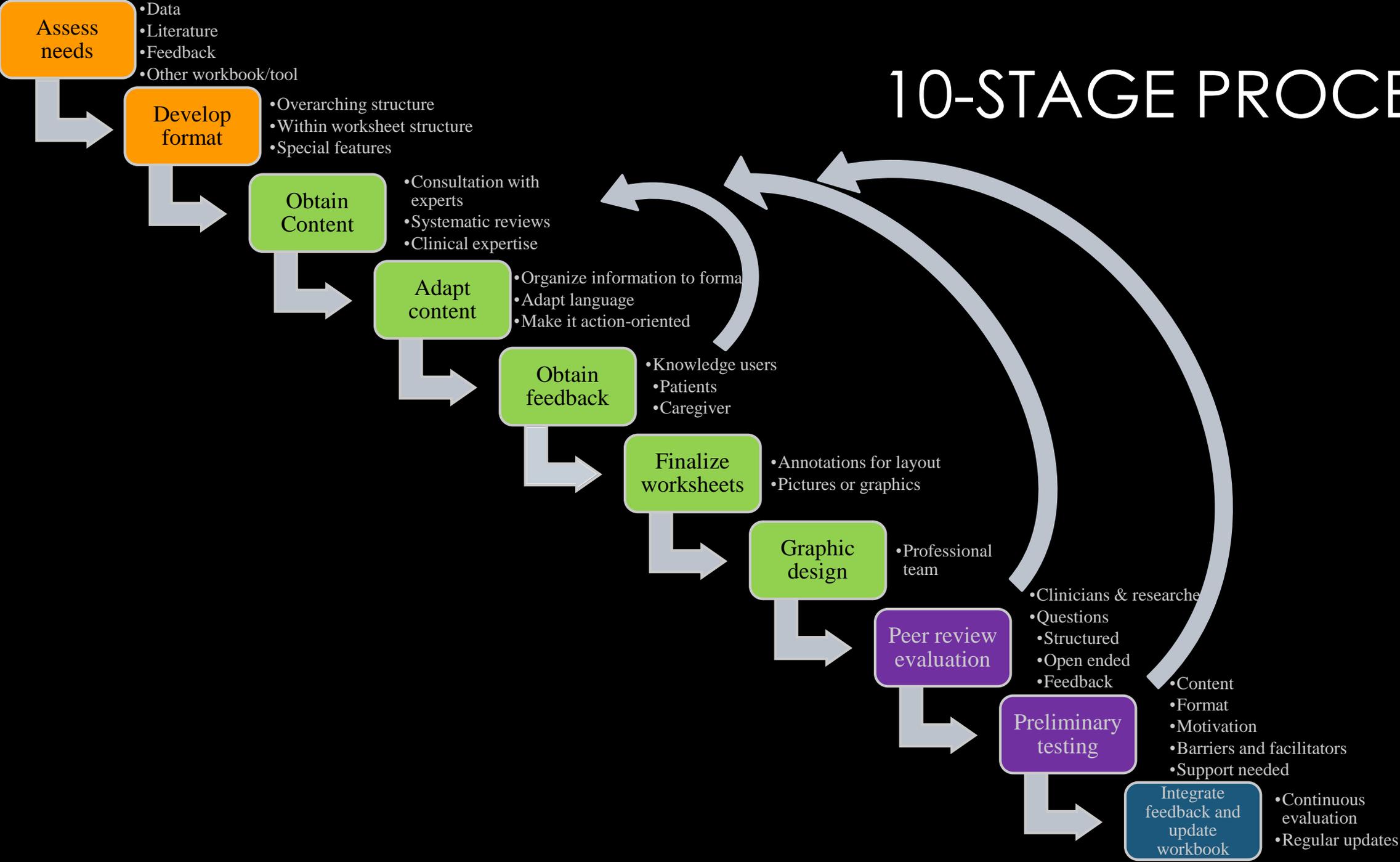
- Put together a list of modifications based on **feedback** from
  - Peer review
  - Preliminary testing
  - Issues identified by the authors
- Modification made by Earthlore Communications
  - Several iteration
- New version of GETONMS© to be tested in a pilot study



# STAGE 10: INTEGRATE FEEDBACK TO UPDATE WORKBOOK

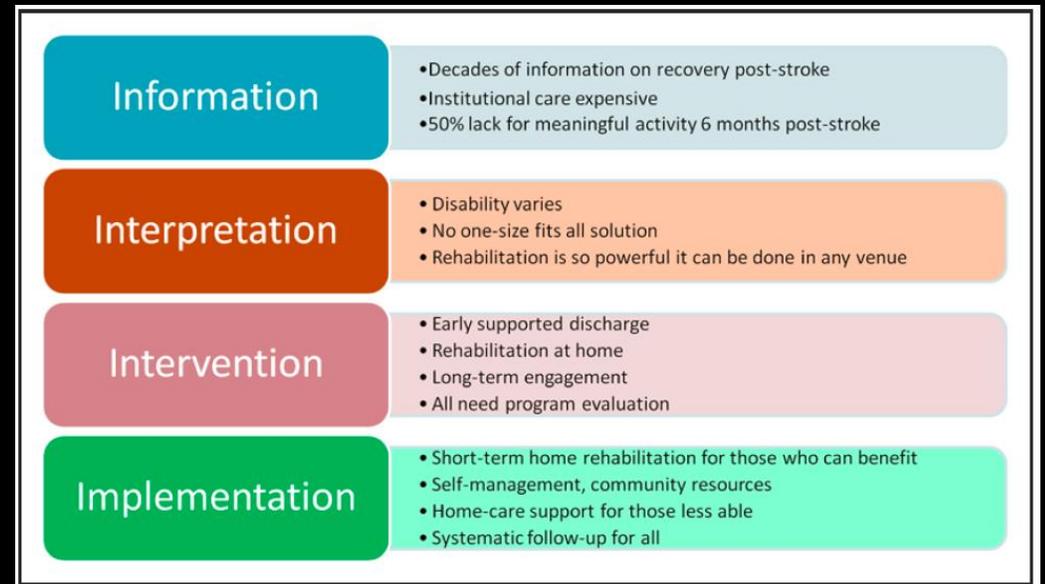
- Use the feedback obtained from users to improve your document.
- Sometimes change in policy, hospital management mean that the reality of the patient experiencing it will be different so always good to review it once in a while to make sure it is :
  - Up-to-date
  - Matches patient needs
  - Appropriate format

# 10-STAGE PROCESS



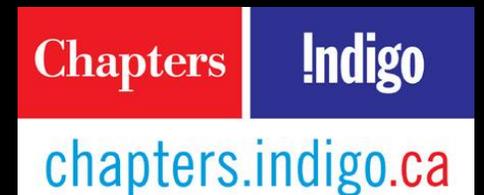
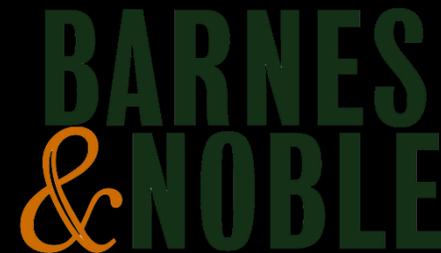
# DISCUSSION

- GETONMS© is **first** self-management program to cover **all** topics important to people with MS
- Consistent with the 4Is principle



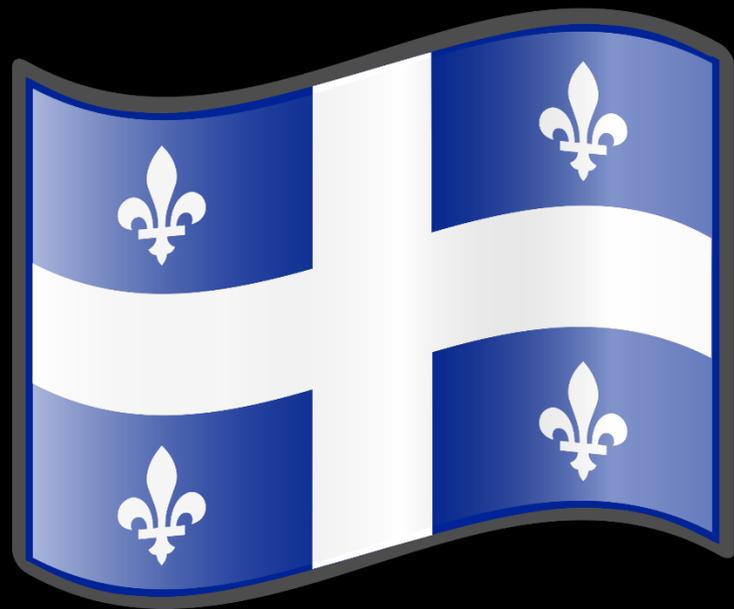
Mayo. Stroke (2016)  
47(6):1685-91

AT THE MOMENT...



45 

IN THE FUTURE...



En Français!



# THANK YOU!

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