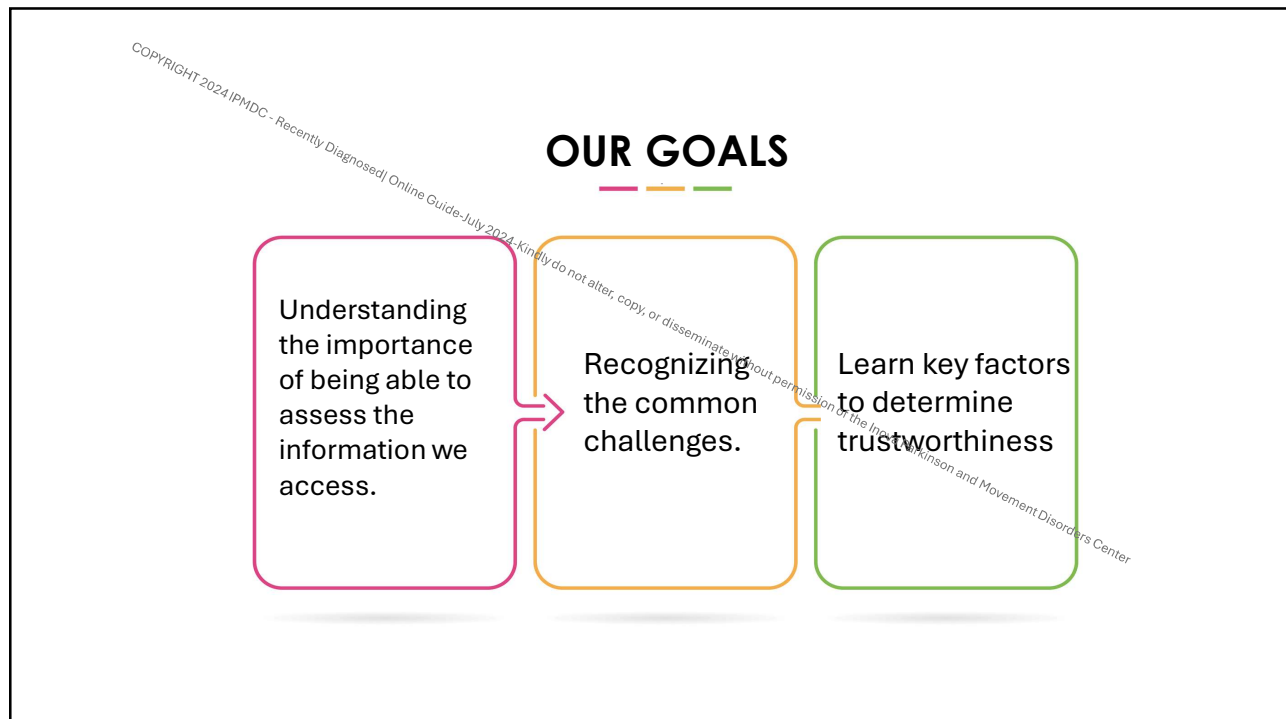




1



2

Why is it important to be able to evaluate the information we access?

- Information is valid and safe
- Not a scam, misinformation, or unhelpful resource.



3

Copyrights for Health & Social Care
Informatics, September 2009; 34(3): 136–148

informa
healthcare

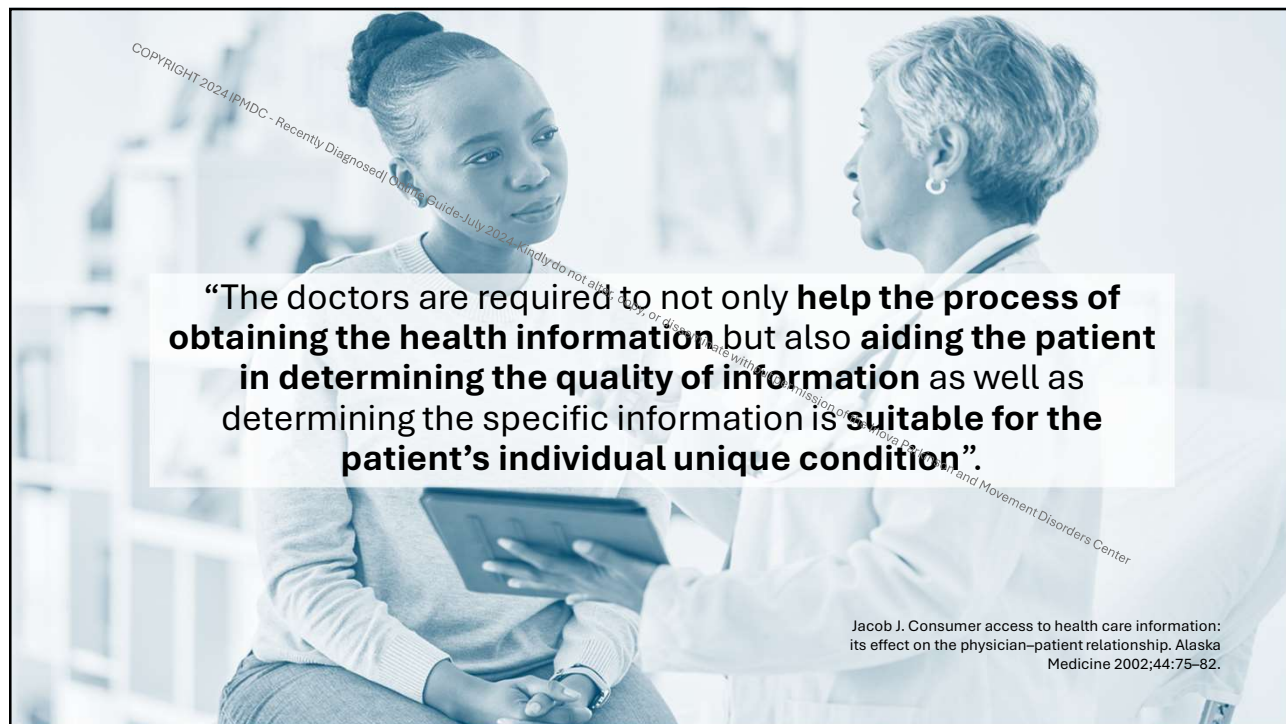
Physicians' perception of the effects of internet health information on the doctor-patient relationship

JEONGEUN KIM¹ & SUKWAH KIM²

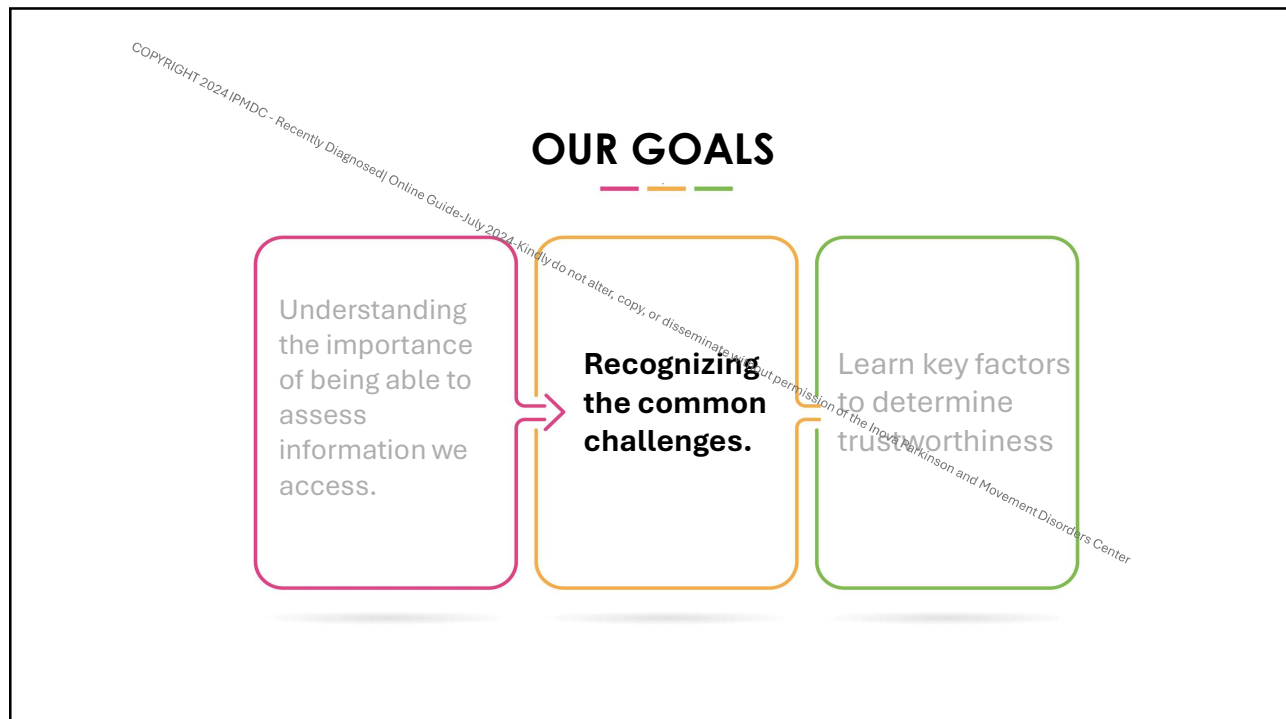
¹College of Nursing, Research Institute of Nursing Science and ²College of Medicine, Seoul National University, Seoul, Korea

- 81% of physicians have seen patients who made inquiries about information they found on the Internet.
- ++ Internet Health information may enhance the patient's knowledge about their health.
- -- Drs perceived that it may also have a variety of negative effects such as:
 - heightening the cost of health care by adopting inappropriate health service utilization (56.2%)
 - making the patients over-concerned about their health (74.5%)
 - damaging the time efficiency of the visit (60.9%).

4



5



6

How often do you look for Parkinson's-related educational materials?



Results from the questionnaire

7

Types of information you look for...



PD symptoms

25%



Medication

12.5%



Diet & Nutrition

6.3 %



Exercise

37.5%



Emerging evidence

12.5%

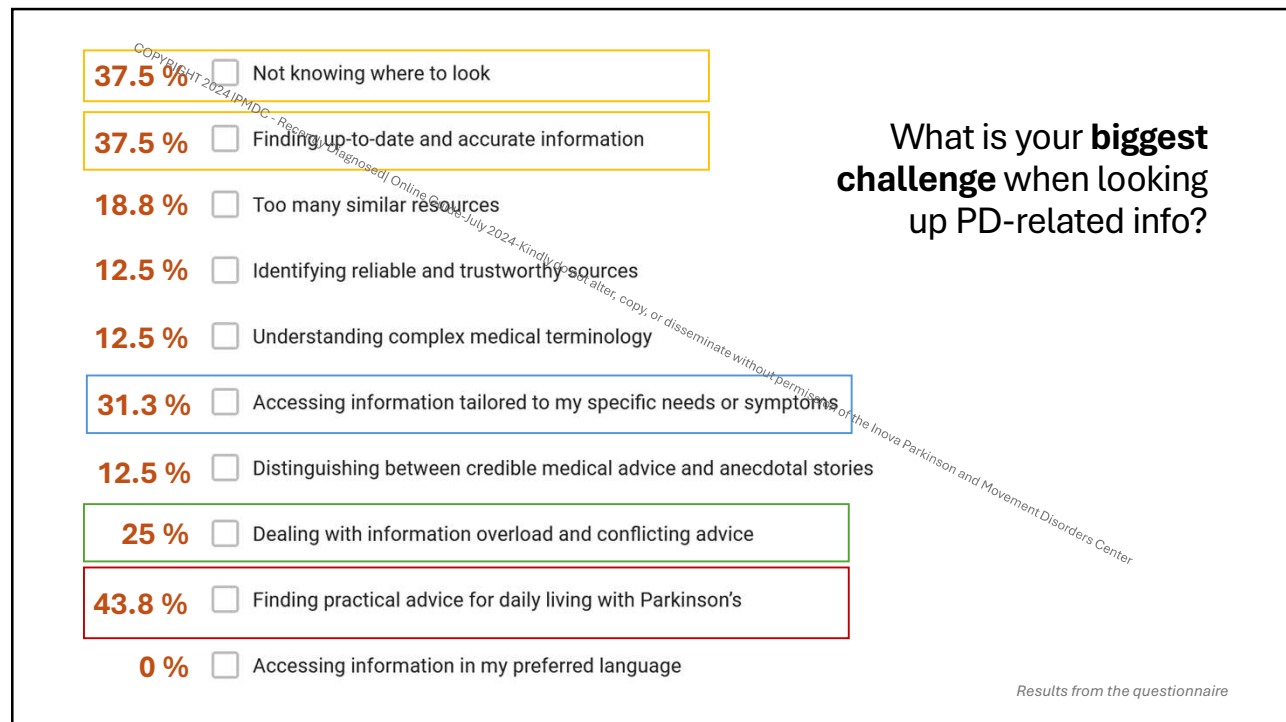


Alternative treatments

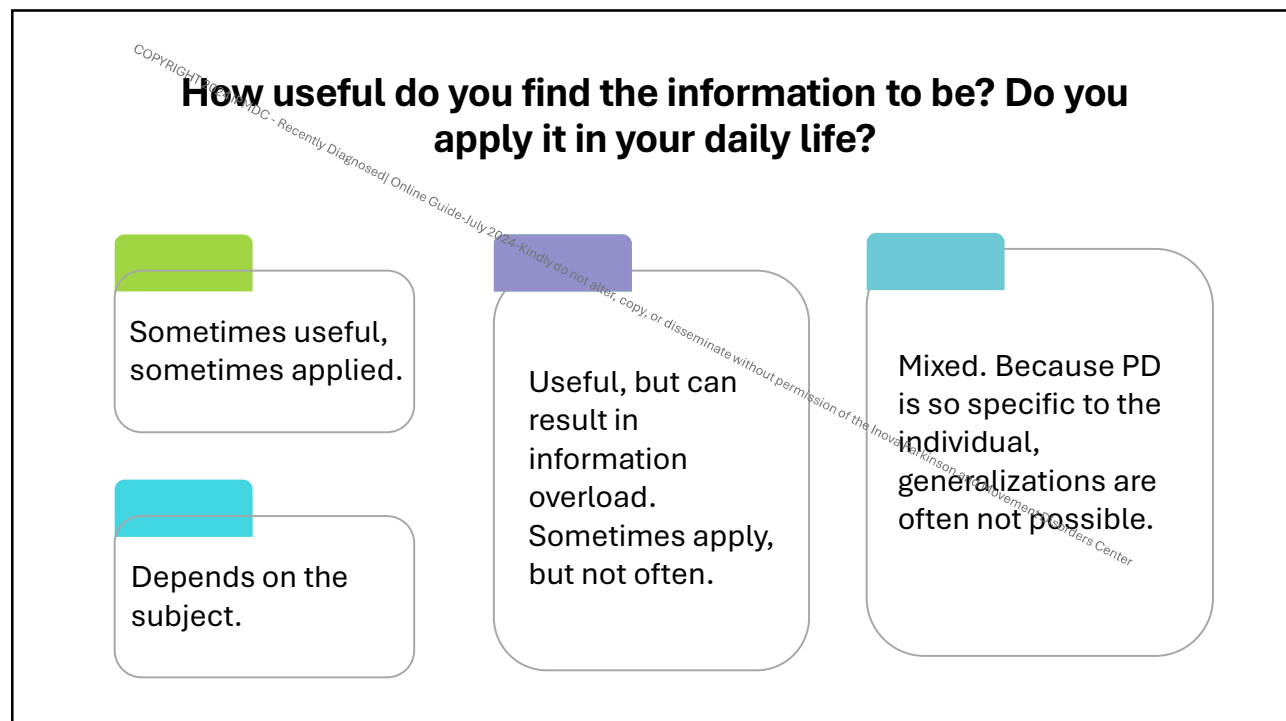
12.5%

Results from the questionnaire

8



9



10

Information mistrust

- Many resources
- Varying quality
- Less pure intentions



11

OUR GOALS

Understanding the importance of being able to assess information we access.

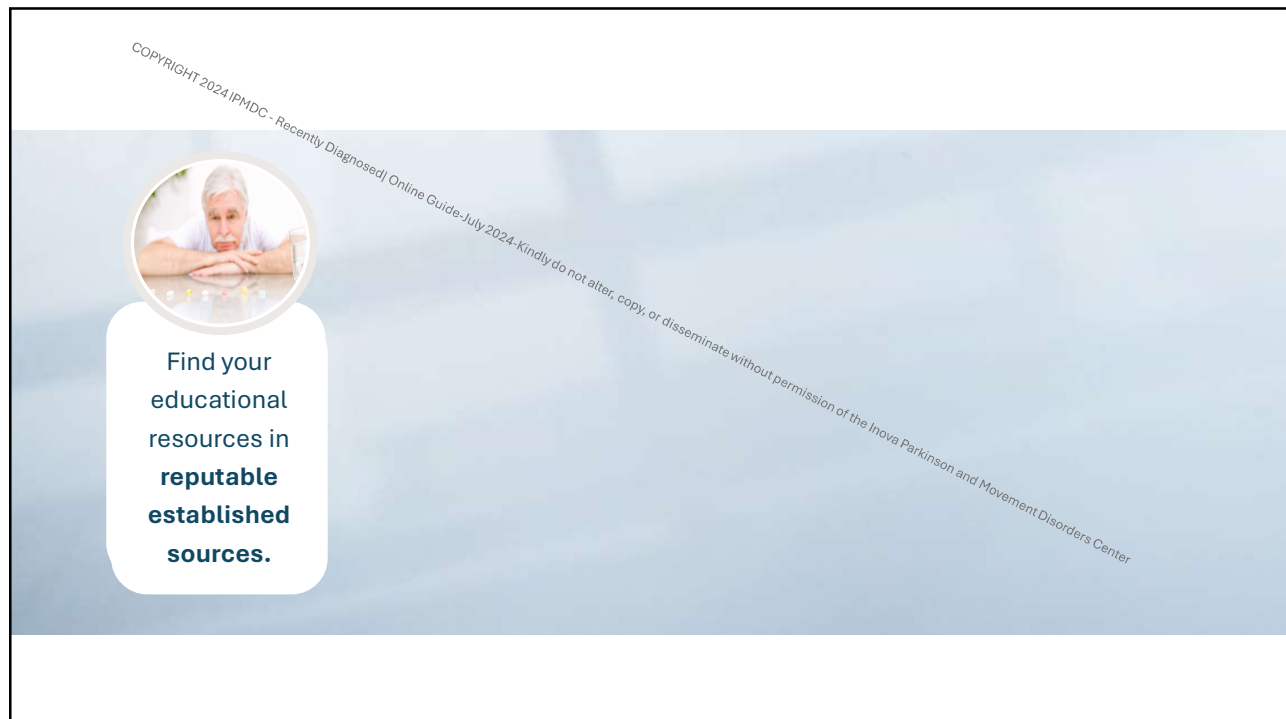
Recognizing the common challenges.

Learn ways to determine trustworthiness


12




13





14

 **Medical societies**


- International Parkinson and Movement Disorder Society (MDS) - <https://www.movementdisorders.org/>
- National Institutes of Health (NIH) - <https://www.nih.gov/>
- American Academy of Neurology (AAN) - <https://www.aan.com/>


International Parkinson and Movement Disorder Society


National Institutes of Health
Turning Discovery Into Health


AMERICAN ACADEMY OF NEUROLOGY®

15

 **Prominent medical centers**

- Muhammad Ali Parkinson's Center (MAPC)
- Mayo Clinic
- Cleveland Clinic
- Any other large center of repute...

16

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Shop local

Your doctor's website

And their newsletter






17


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Non-profits

Esp. if you're looking for a certain voice or perspective

18



European and UK non-profits

Parkinson's Europe*
<https://parkinsonseurope.org/>

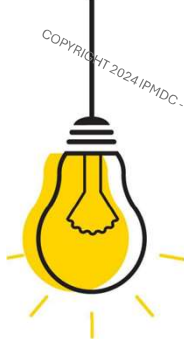
Parkinson's UK
www.parkinsons.org.uk

parkinson's europe

PARKINSON'S UK
 CHANGE ATTITUDES.
 FIND A CURE.
 JOIN US.

*Excellent resource for materials in other languages



19



Support groups

- Optimal for recommendations for local resources
- Better groups will also keep on top of research and breakthroughs
- Recently diagnosed individuals might look for groups geared towards them

20

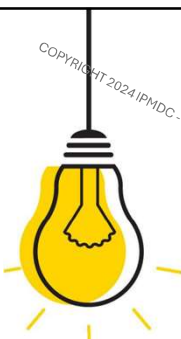
Facebook groups

- Public and private groups on a range of topics
- Ability to post anonymously*

*CAVEAT – All activity is being tracked

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21



Online forums

- Smart Patients
- Health Unlocked
- Parkinson'sdisease.net
- Parkinson's Foundation
- Others....

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22



Community for shared experiences

- Meds
- Supplements
- Rehab
- Procedures
- Others

Prescription drugs

Treatment	Patients
Duloxetine	72,386
Pregabalin	51,672
Gabapentin	50,496
Prednisone	40,414
Sertraline	37,058

See all 2,712 prescription drugs

Over the counter drugs

Treatment	Patients
Ibuprofen	21,833
Naproxen	21,132
Aspirin	13,390
Acetaminophen (Paracetamol)	8,169
Cetirizine	4,596

See all 664 over the counter drugs

Supplements

Treatment	Patients
Vitamin D	15,165
Multivitamins	8,606
Omega 3 Fish Oil	6,793
Vitamin D3 (cholecalciferol)	5,715
Calcium-Vitamin D	5,415

See all 2,643 supplements

Physical therapy

Treatment	Patients
Physical Therapy	10,589
Massage Therapy	2,630
Occupational Therapy	2,249
Speech / Language Therapy	1,941
Pulmonary Rehabilitation	1,721

See all 159 physical therapies

Equipment

Treatment	Patients
Walking Stick/Cane	11,084
Walker	6,187
Therapeutic brace	5,133
Motorized scooter/chair	3,299
Wheelchair (manual)	3,100

See all 600 equipment

Procedures

Treatment	Patients
Radiation Therapy	5,710
MRI (magnetic resonance imaging)	3,229
Neuromuscular Electrical Stimulation	2,165
CT Scan (computerized tomography scan)	2,132
Acupuncture	1,860

See all 729 procedures

23



ChatGPT

Probably not yet...

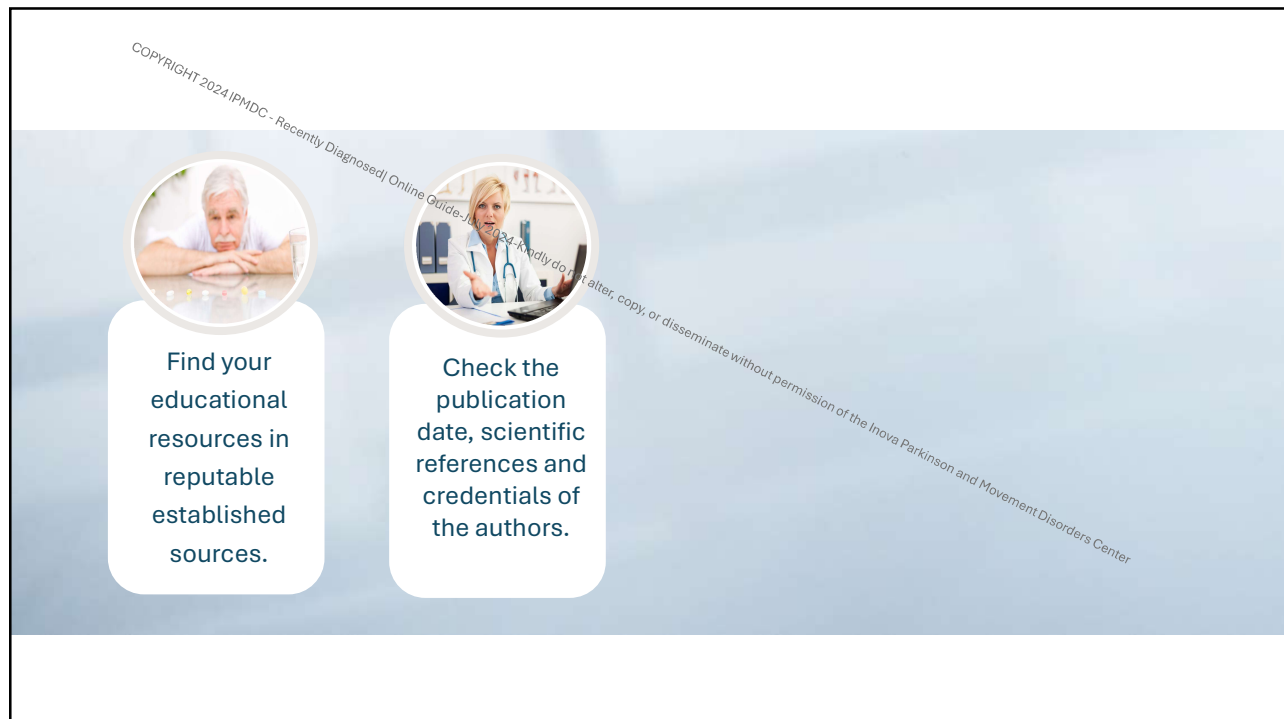
- Trained on a range of resources
 - including unreliable ones
- “Hallucinations” are a known issue

24

Don't neglect books for inspiration

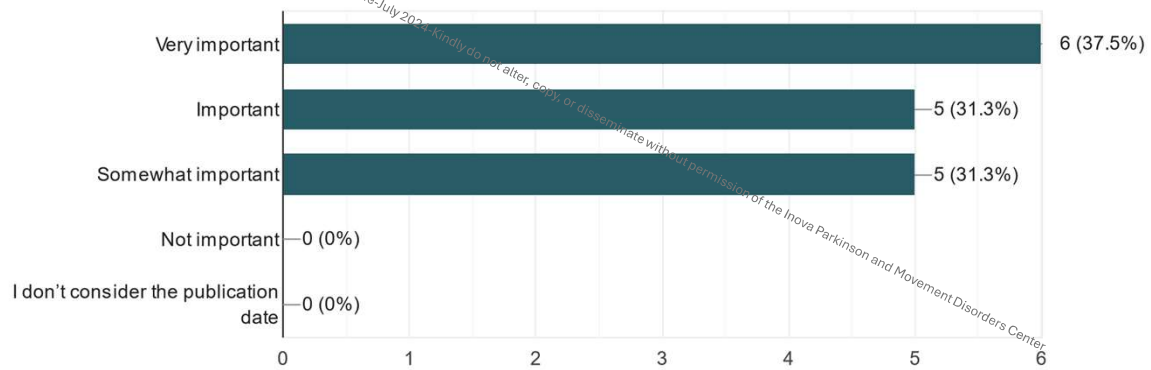


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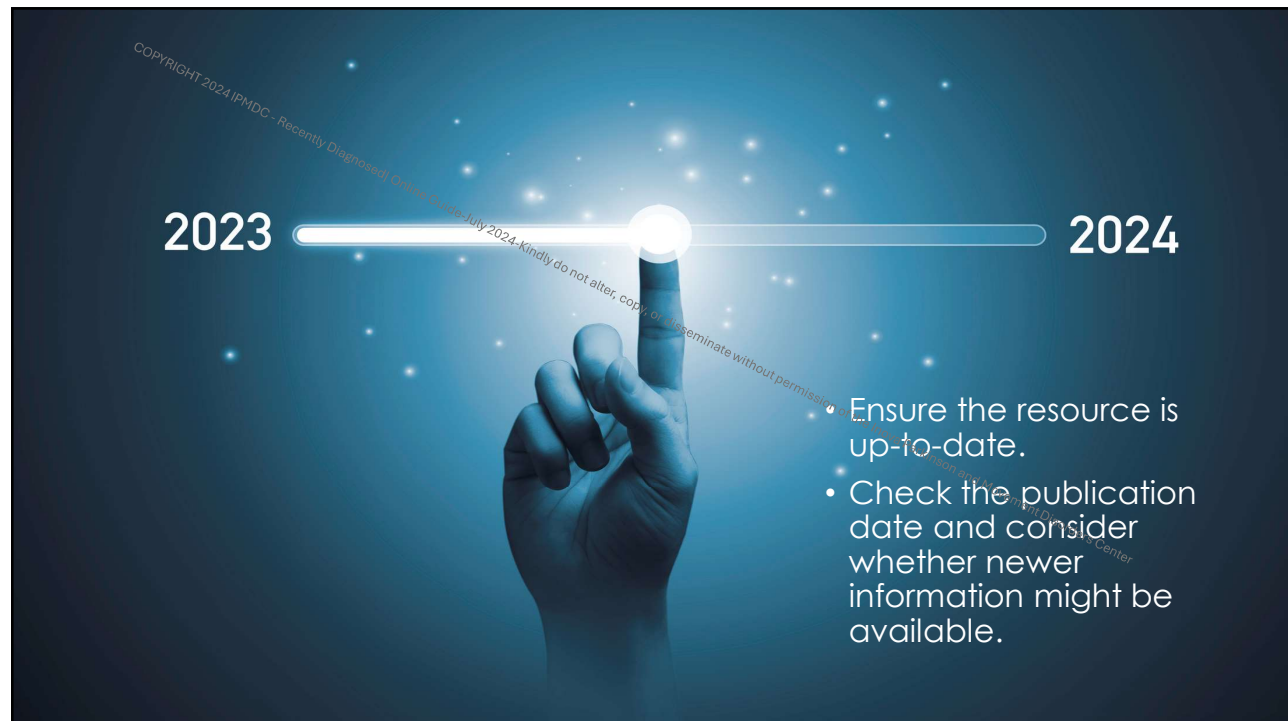
26

How important is the **publication date** of the educational resources you use?



Results from the questionnaire

27



28

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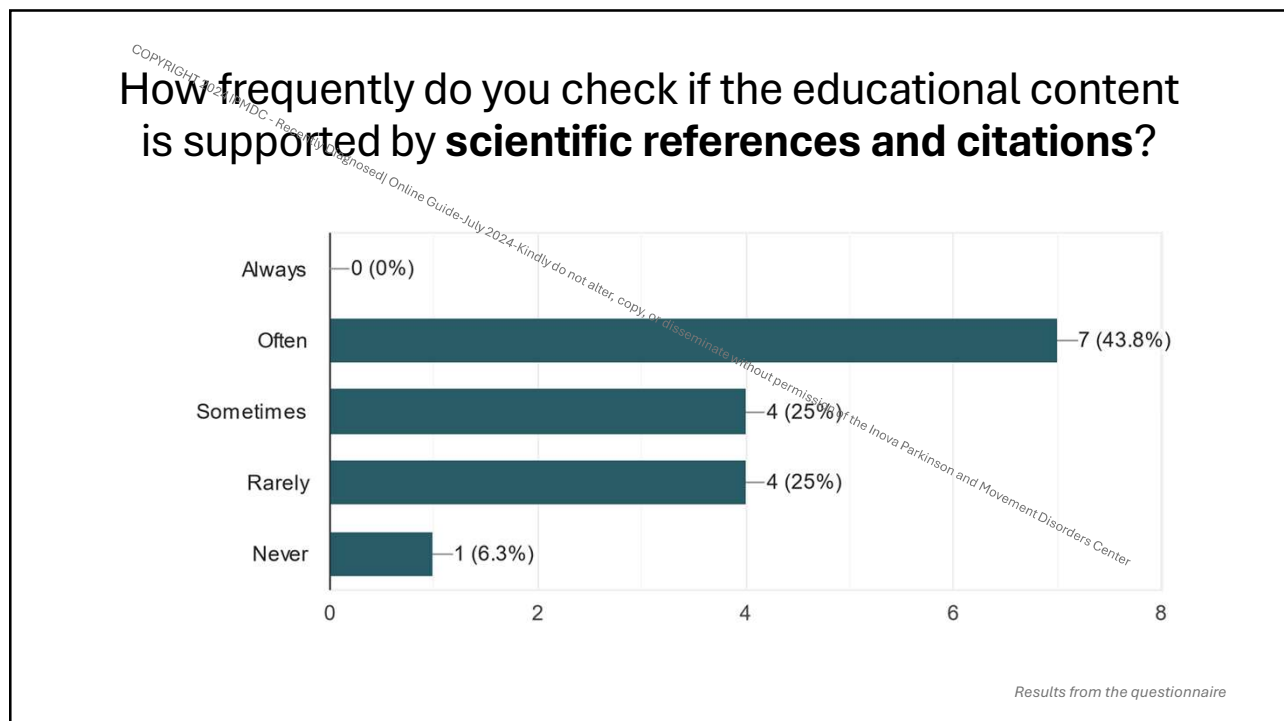
Content has a shelf life

Depending on the topic

- <3 years is best
- <5 is OK
- >5 may potentially be problematic

BEST BEFORE

29

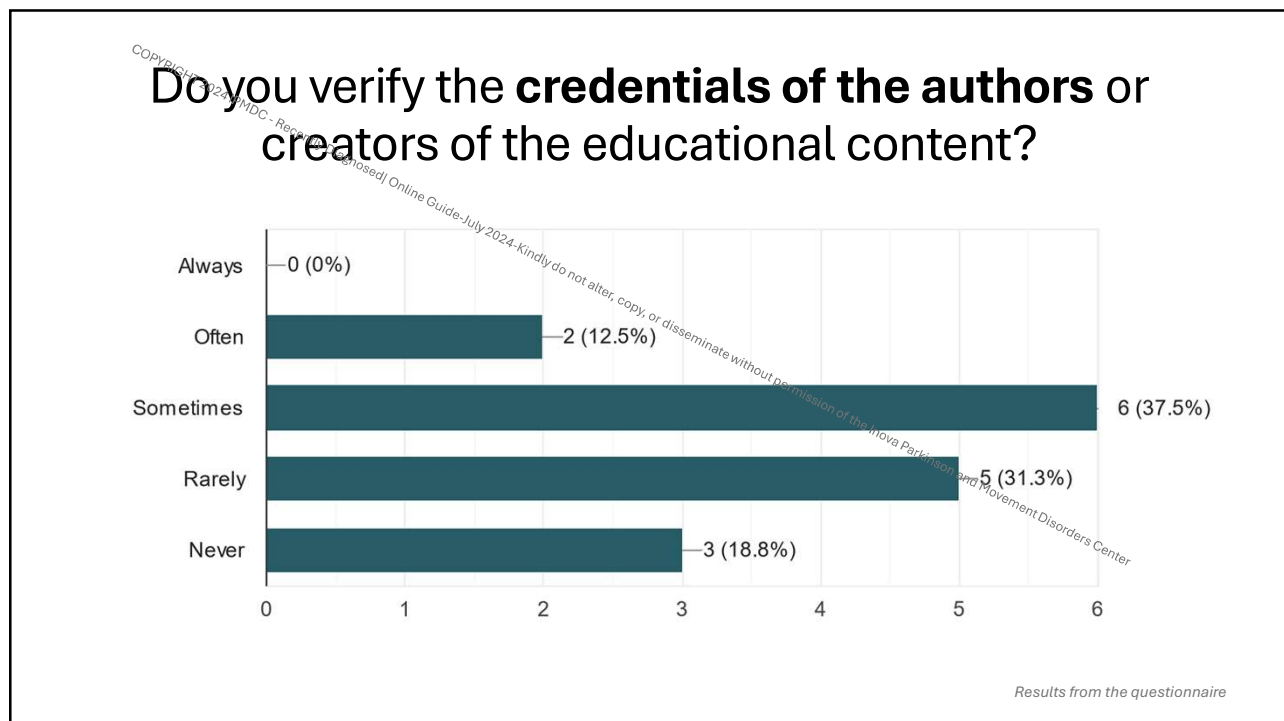


30

Reliable educational resources cite their sources.

- Check the bibliography or reference list to see if the resource references credible and relevant sources.
- The presence of citations indicates thorough research and adds legitimacy to the content.

31



32

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Key questions:

- Are they experts in the field?
- Do they have relevant qualifications and experience?

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CLASSES | TRAINING | RESOURCES

LSVTBIG®

THINK LOUD
www.LSVTGlobal.com
"Empower your life...SPEAK LOUD!"

PWR!®
Parkinson Wellness Recovery

SPEAK OUT!
Live with Intent
Parkinson and Movement Disorders Center

DUAL TASK FOR PARKINSON'S
Exercise to improve Movement, Voice & Cognition

OHIOHEALTH DELAY THE DISEASE™

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International Parkinson and Movement Disorder Society

International Parkinson and movement disorder Society (MDS) -
<https://mds.movementdisorders.org/specialist-finder>



34

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Red Flags

- Lacking/non-relevant professional credentials
- Not PD-specific or has multiple foci
- Selling supplements or cures and other unrelated products



35

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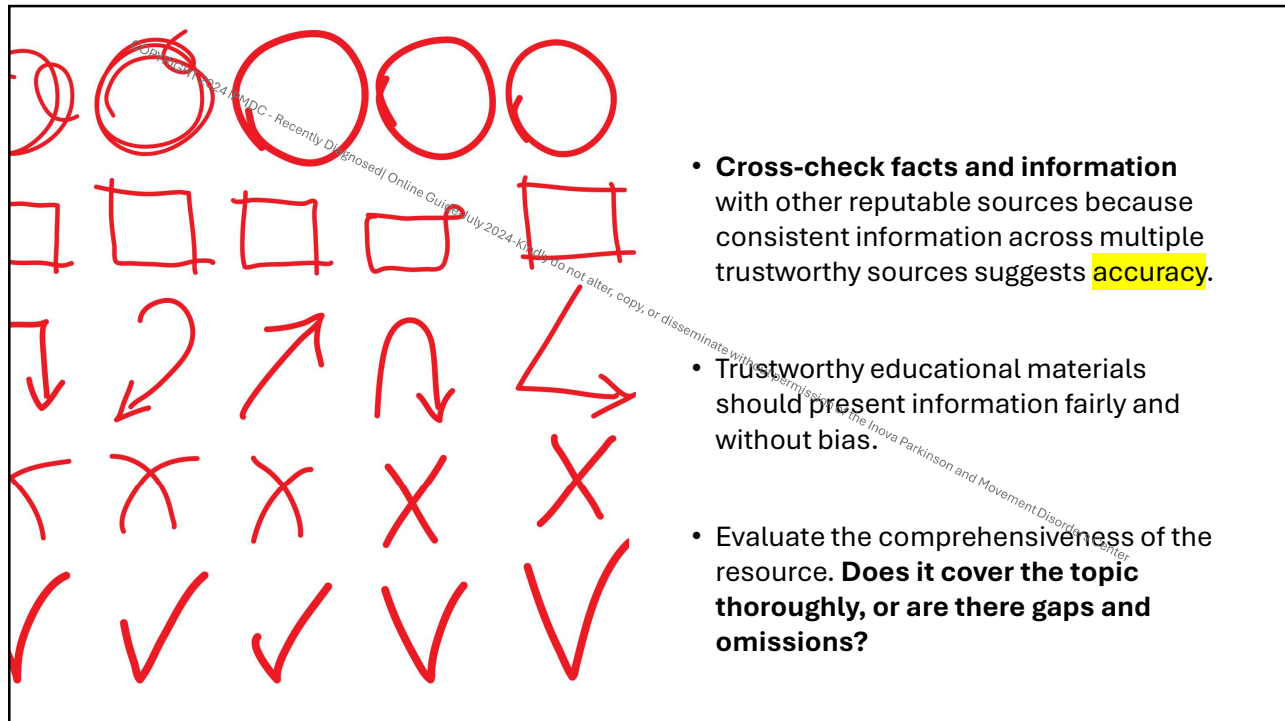


Find your educational resources in reputable established sources.

Check the publication date, scientific references and credentials of the authors.

Cross-check facts and information with other reputable sources

36

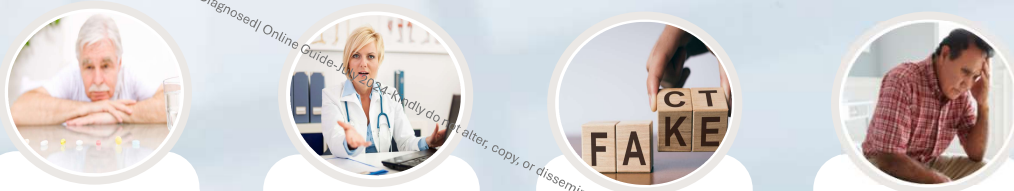


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38

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Find your educational resources in reputable established sources.

Check the publication date, scientific references and credentials of the authors.

Cross-check facts and information with other reputable sources

Assess the intention and if there is another or hidden agenda.

39

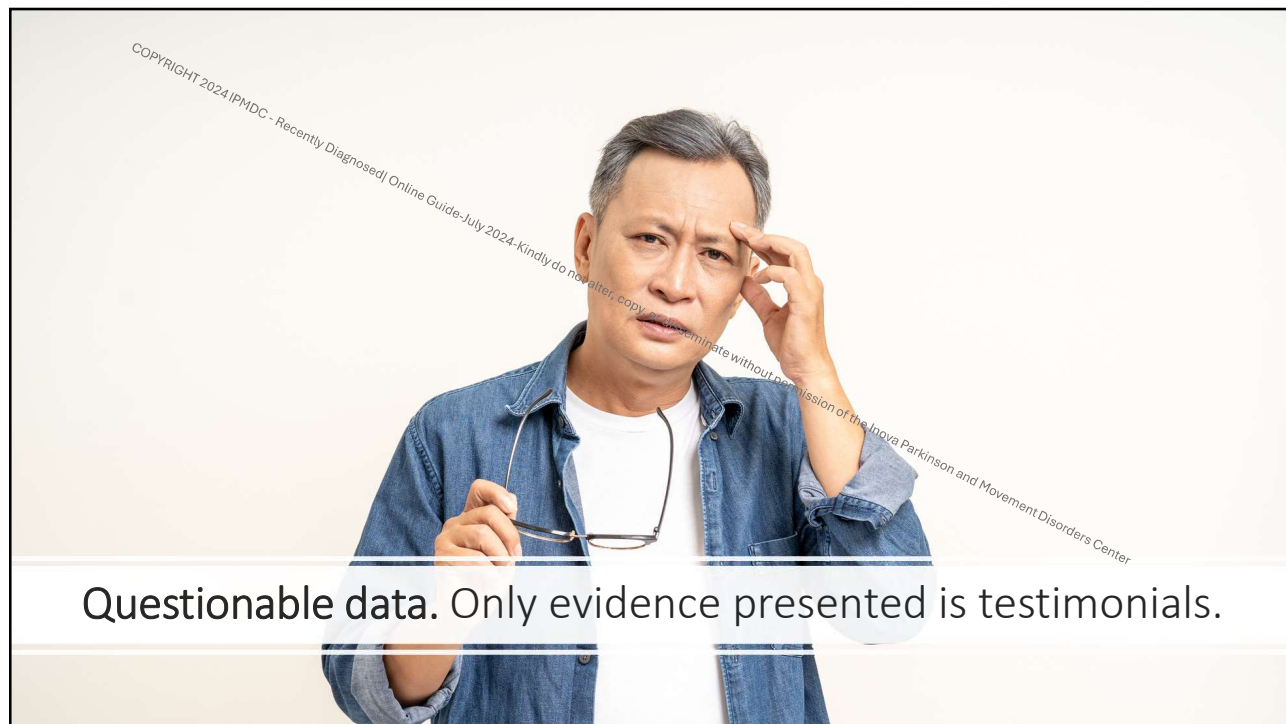
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How to spot Parkinson's Baloney?

Is it intended for educational use, or does it have another agenda, such as selling a product or promoting a particular viewpoint?



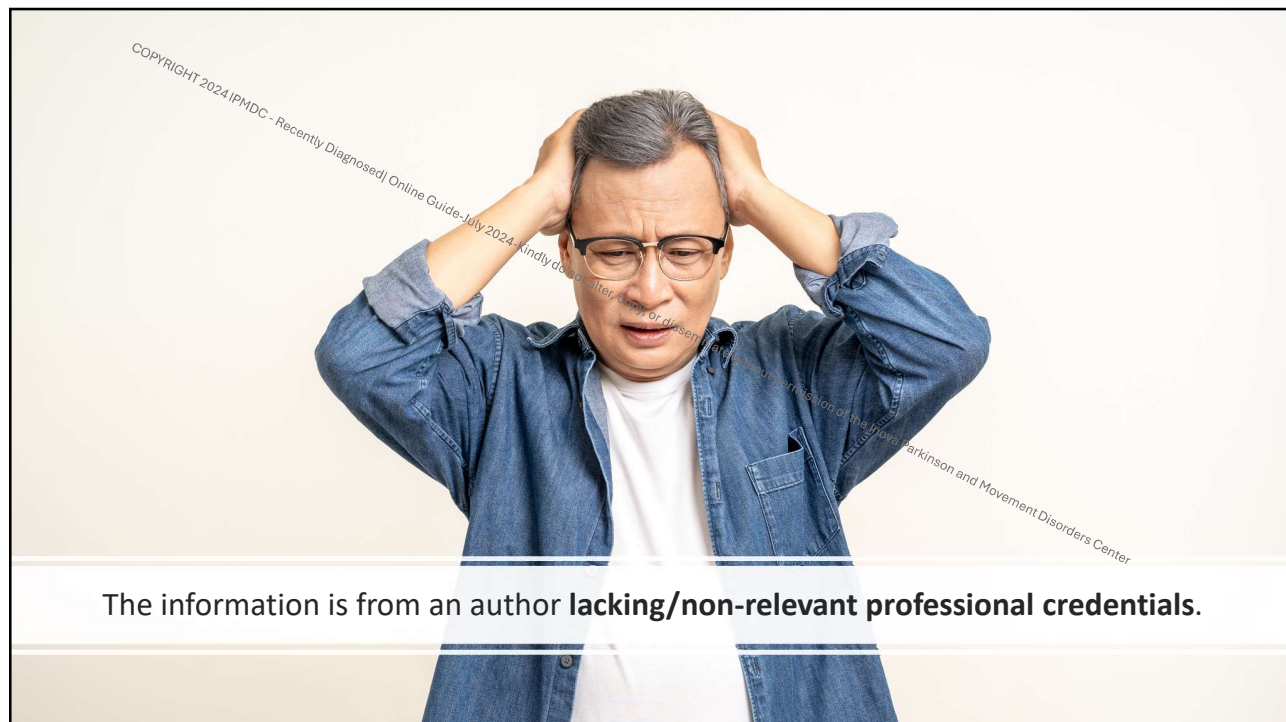
40



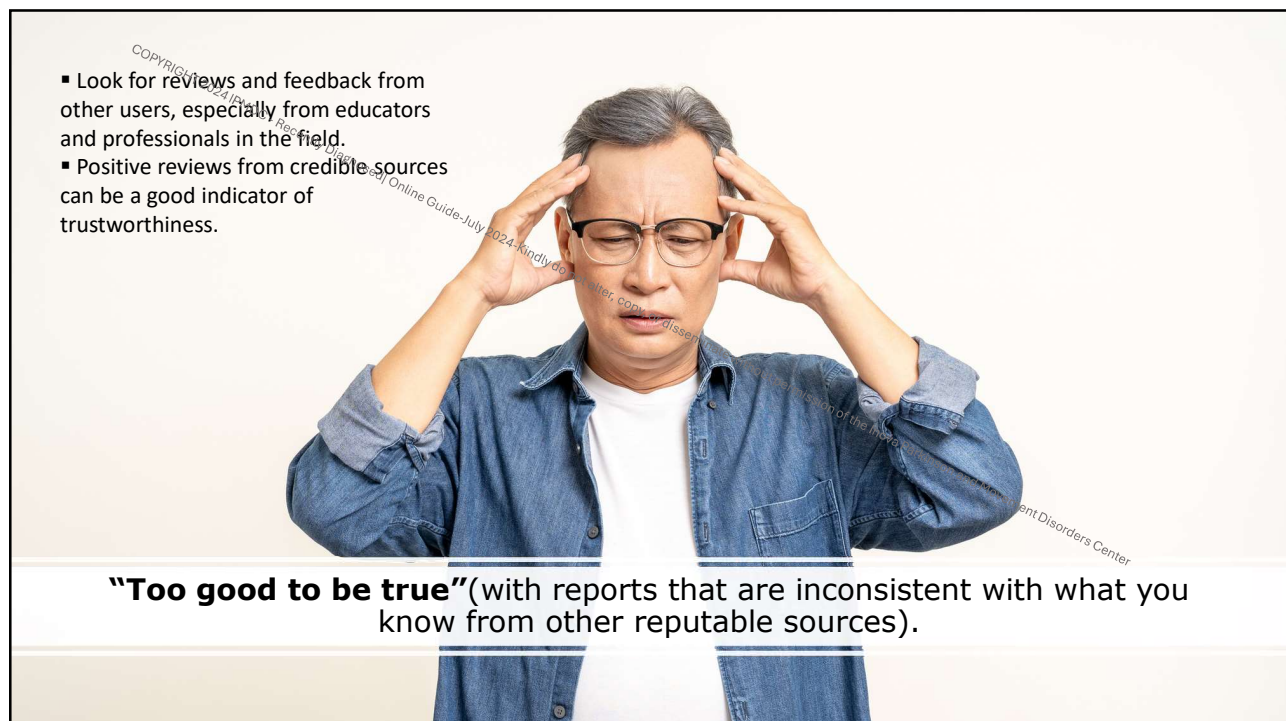
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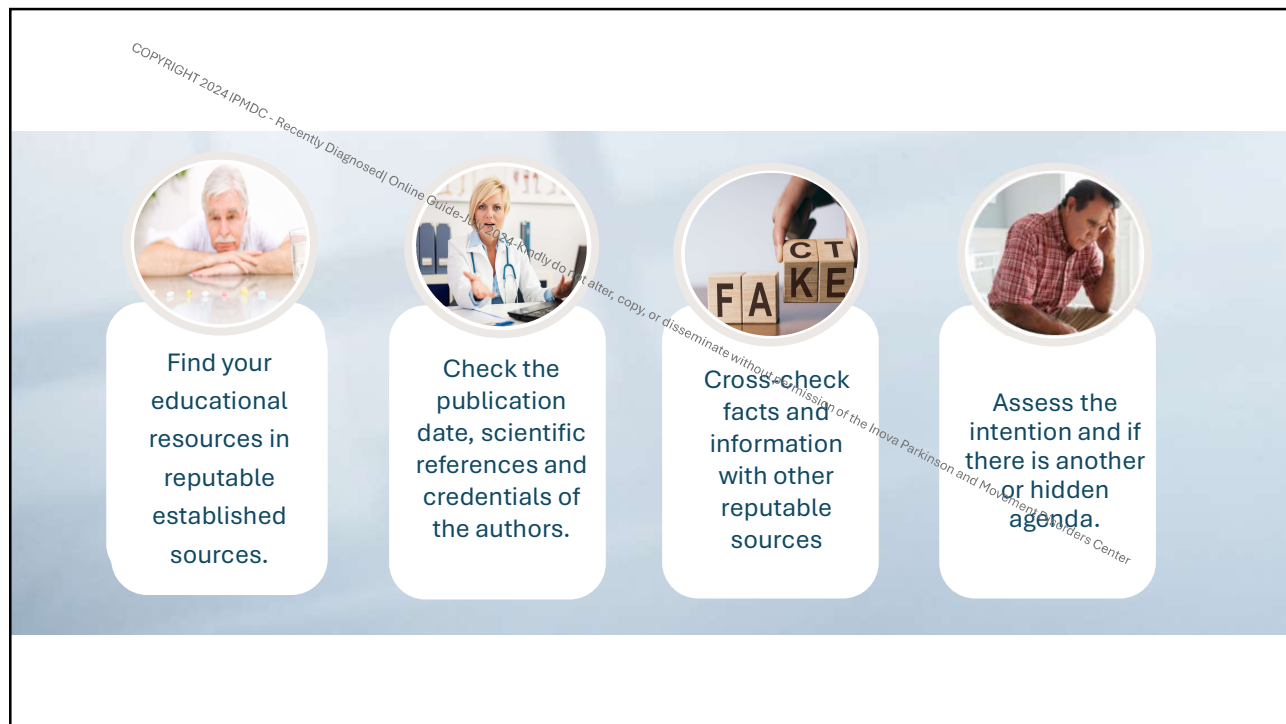
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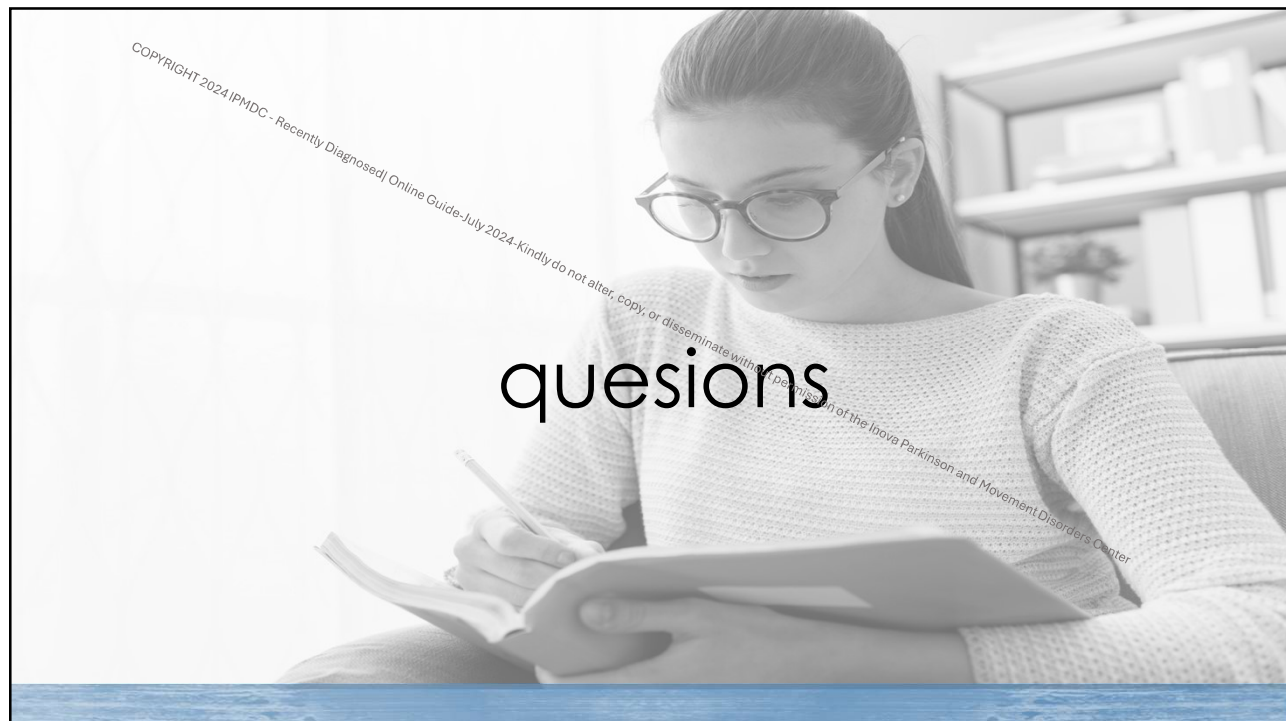
43



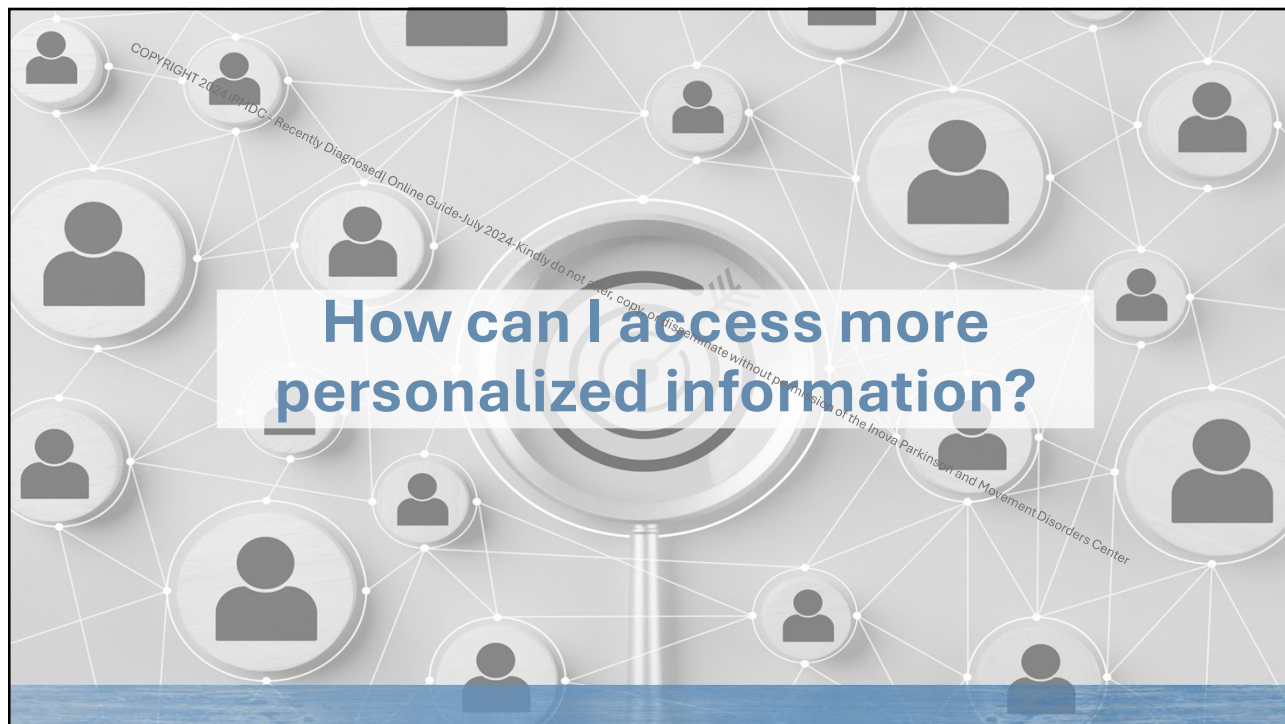
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45



46



47

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Look for live programs so you can ask more personalized questions

For example, IPMDC programs like **“Let’s Chat About Thinking”** series

« All Events

Event Series: Let's Chat About Thinking

Let's Chat About Thinking series

July 19 from 2:30 pm - 3:30 pm EDT

with Dr. Jenn Pauldursi, Cognitive and Behavioral Neurologist

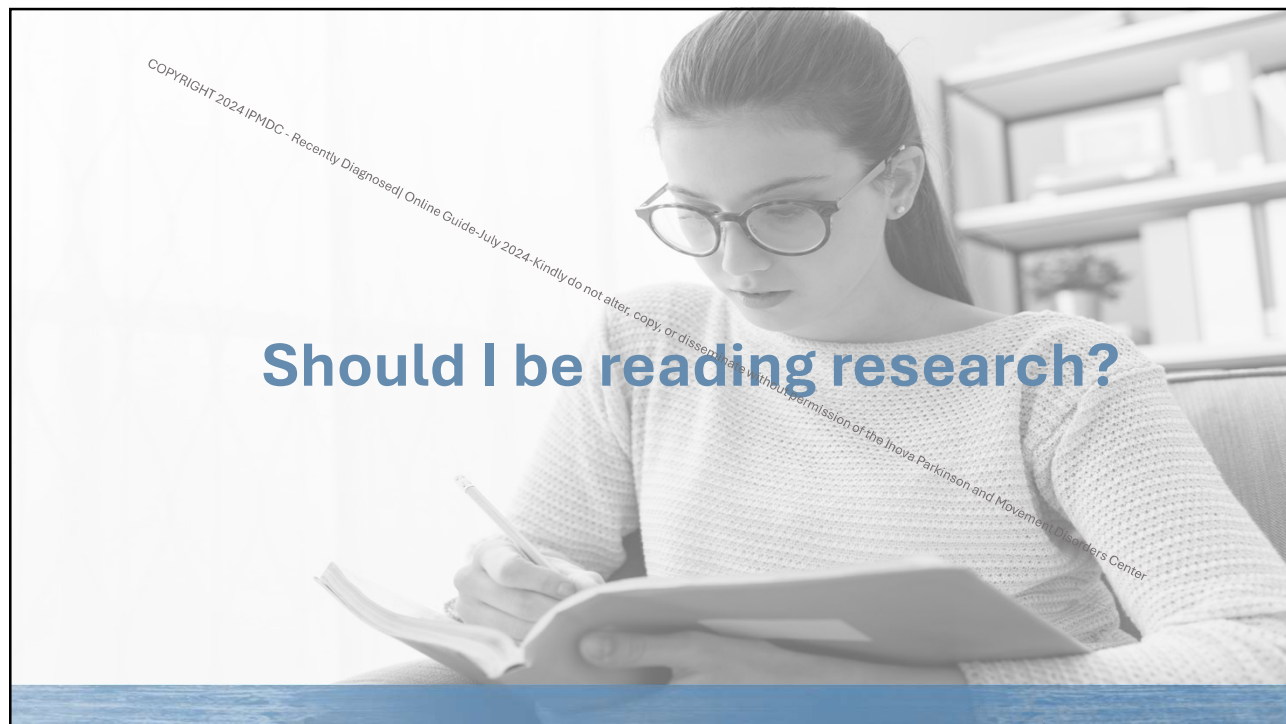
This month's topic:
“I Don't Have Any Memory Problems Anyway, Right, Honey?”

Anosognosia is a phenomenon when the brain is unaware of the problems or challenges that it may be having. Other people may notice that we are forgetting or making more mistakes, but in our perspective, it seems like we are doing just fine! Why does this happen? Is it subconscious or is it my brain stubbornly denying the truth? Sometimes trying to “prove who’s right” can lead to conflicts and defensiveness—and often this is the most troubling and sensitive part of having brain disease. Let’s talk about this sensitive topic of not knowing what’s wrong and decide if ignorance really is bliss.

Please click here to register and you'll receive your link to join in.

Jenn Pauldursi, MD
Cognitive and Behavioral Neurologist

48



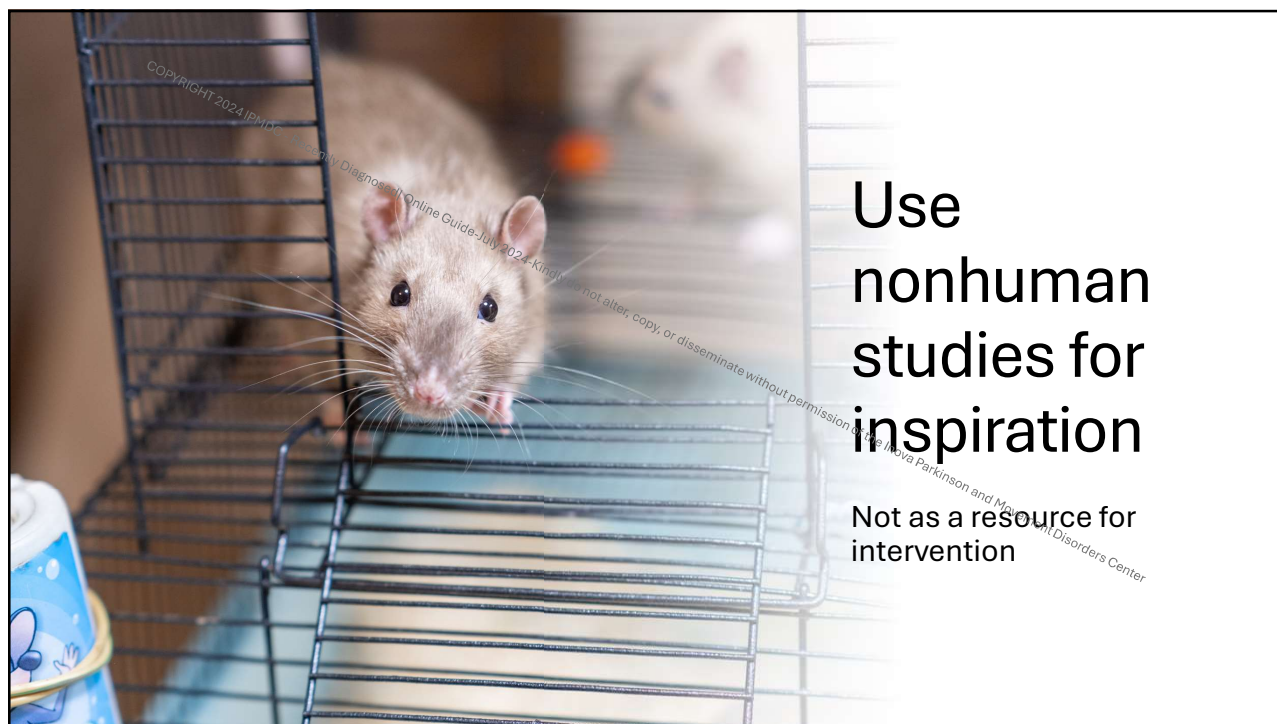
49

If you do just remember not all are created equal

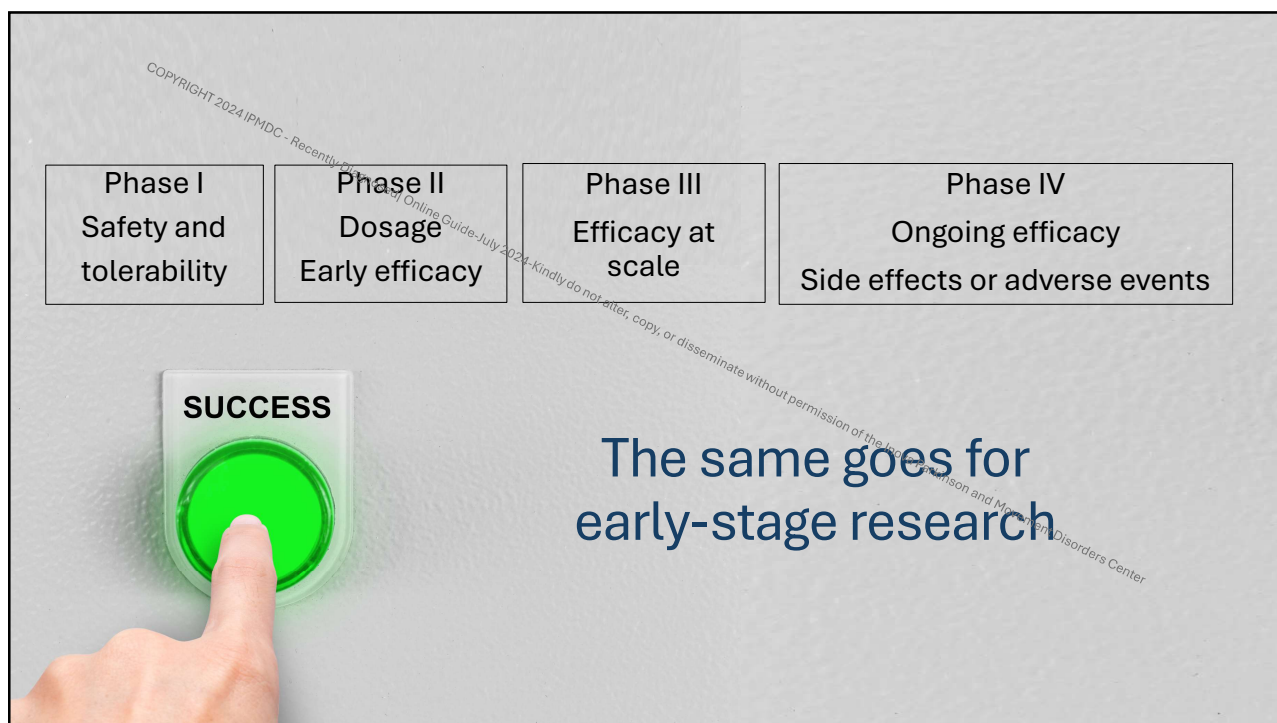
Early studies are often underpowered and may lack key elements, such as blinding of raters, a control group and randomization

- “Pilot”
- “Acceptability”
- “Feasibility”
- “Open label”

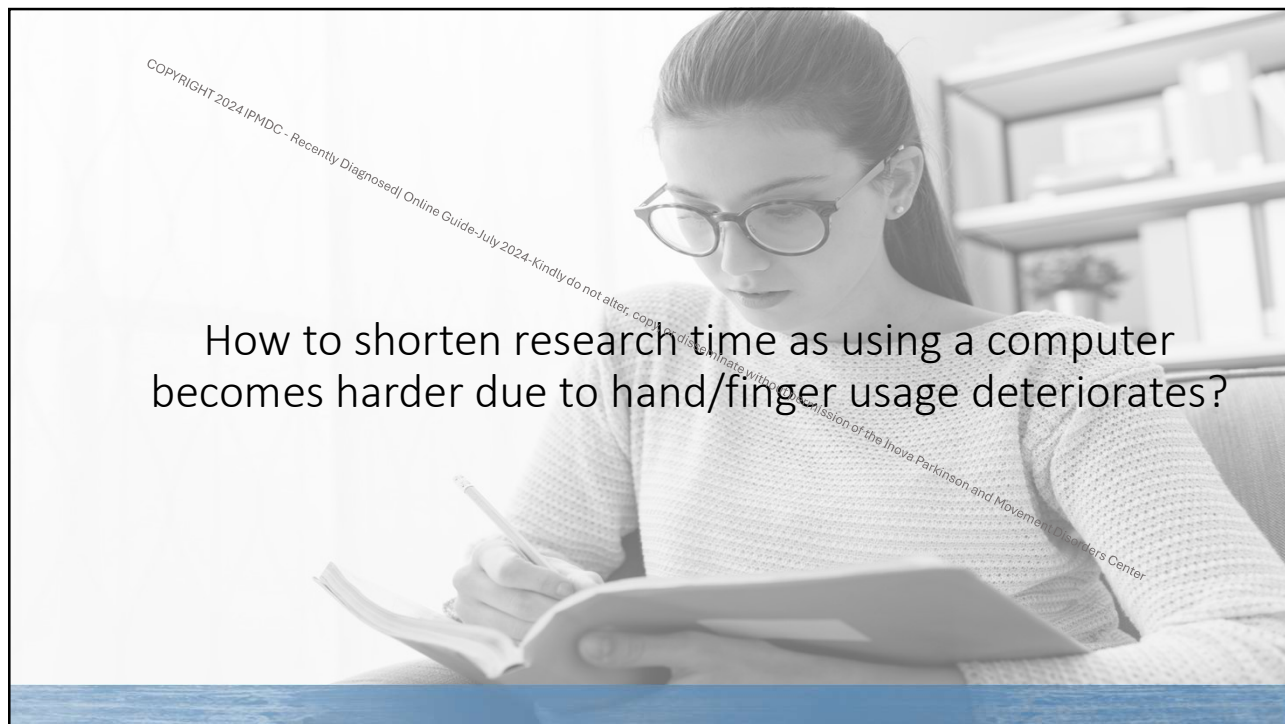
50



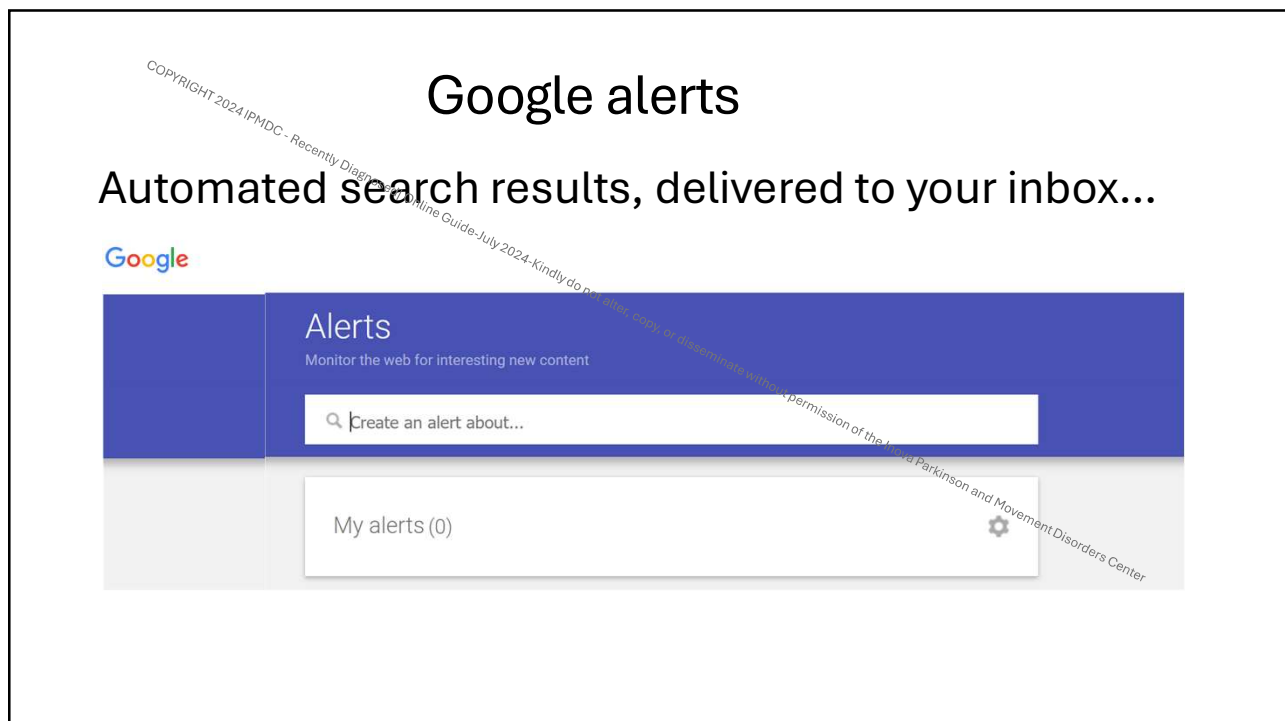
51



52



53



54

Consider “aggregators”

Parkinson's



<https://parkinsonsnewstoday.com>

ScienceDaily®

<https://www.sciencedaily.com>

Medical Xpress

<https://medicalxpress.com>



<https://www.news-medical.net>

NeurologyLive

<https://www.neurologylive.com>

55



Consider consulting a librarian

- Online searching
- Print resources
- Local organizations and groups

56

Summary

Systematically evaluating the educational resources you use for Parkinson's disease allows you to better determine their reliability and trustworthiness so that they can assist you more effectively.

57

Thank you for coming

58