

Supporting care partners with health information technology

Catherine DesRoches

Family Caregiving for People with Cancer and Other Serious Illnesses: A Workshop

May 16, 2022



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OpenNotes and Care Partners



Patients Who Share Transparent Visit Notes With Others: Characteristics, Risks, and Benefits

Sara L Jackson ¹ ; Roanne Mejilla ² ; Jonathan D Darer ³ ; Natalia V Oster ¹ ;
James D Ralston ⁴ ; Suzanne G Leveille ^{2, 5} ; Jan Walker ² ; Tom Delbanco ² ;
Joann G Elmore ¹ 

Patients, care partners, and shared access to the patient portal: online practices at an integrated health system

Jennifer L Wolff, Andrea Berger, Deserae Clarke, Jamie A Green, Rebecca Stametz, Christina Yule, Jonathan D Darer

Journal of the American Medical Informatics Association, Volume 23, Issue 6, November 2016, Pages 1150–1158, <https://doi.org/10.1093/jamia/ocw025>

Empowering Informal Caregivers with Health Information: OpenNotes as a Safety Strategy

[Hannah Chimowitz, BA](#)   • [Macda Gerard, BA](#) • [Alan Fossa, MPH](#) • [Fabienne Bourgeois, MD, MPH](#) • [Sigall K. Bell, MD](#)



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Carol



- Retired Harvard University librarian
- Avid New York Times crossword doer
- Traveler, reader, and art museum frequenter
- Diagnosed with dementia in 2016

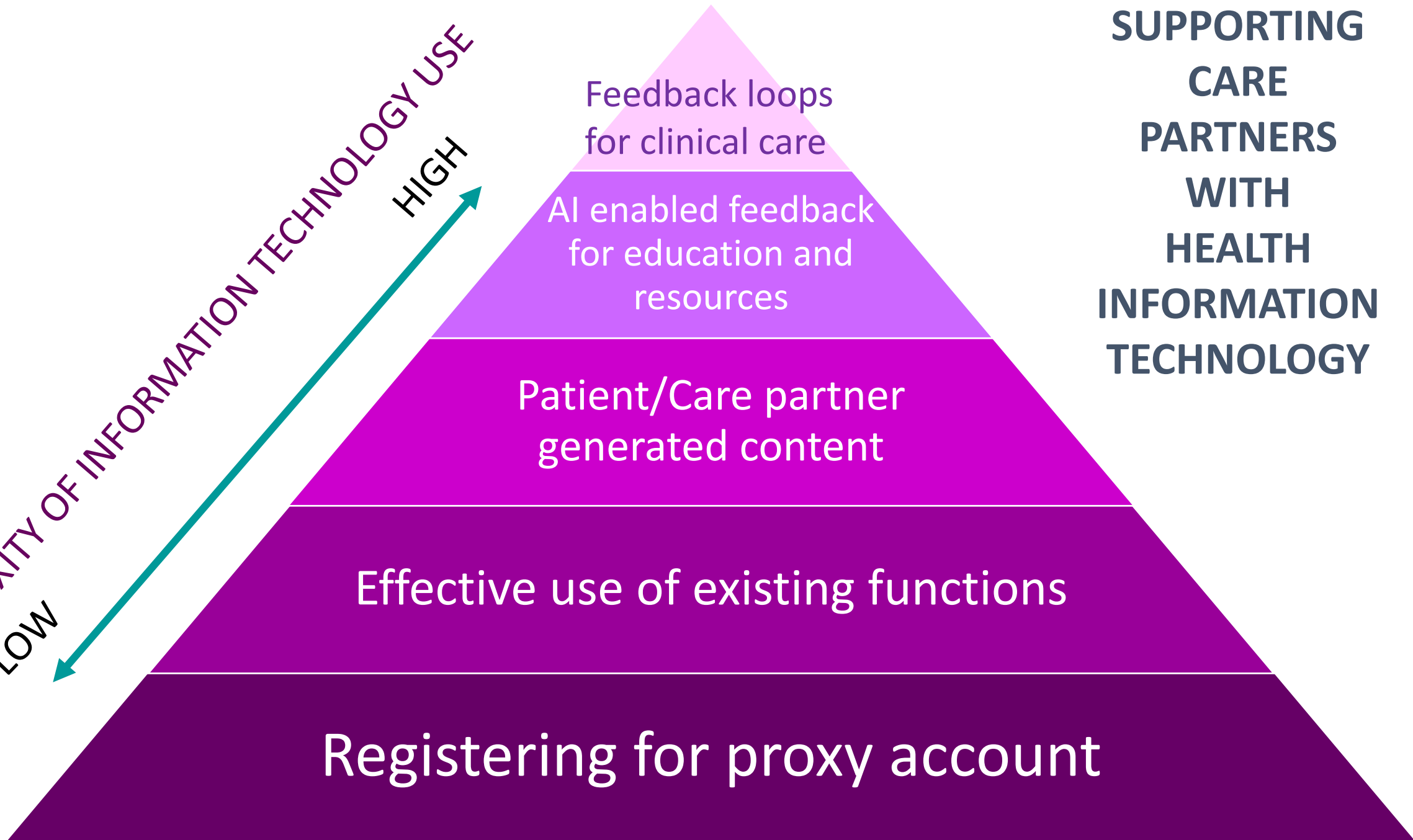


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COMPLEXITY OF INFORMATION TECHNOLOGY USE
LOW
HIGH



**SUPPORTING
CARE
PARTNERS
WITH
HEALTH
INFORMATION
TECHNOLOGY**

Registering for proxy access and using existing functions

- Collaboration between OpenNotes and Johns Hopkins University (Jennifer Wolff)
- Three clinical sites
 - University of Utah
 - University of Rochester Medical Center
 - Providence Health Systems
- Increase registration and use of proxy access to the patient portal
- Funded by the John A. Hartford Foundation



MyChart Proxy

MyChart makes it easy to review details about your medical visits. MyChart Proxy lets you share important information about your health with those you trust most.

Your MyChart Proxy will be able to:



View your medicines, vaccines, visit notes, and test results



Request appointments and prescription refills



Help you communicate with your health care team



Share portions of your chart with other doctors and hospitals

Choose a MyChart Proxy

UR Medicine patients age 18 and older can appoint any adult as a MyChart Proxy.

Pick someone you trust to help with your healthcare. Your Proxy can be a close friend, a family member, or someone who lives nearby.

You can appoint more than one MyChart Proxy. This is helpful if someone manages your health from far away.

Who do you trust most with your healthcare? Write their name here and talk with them about it.

My MyChart Proxy:

My Proxy's email address:

MyChart is compliant with federal and state laws. Your health information is private and secure.



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Effective use of existing functions

- Collaboration between Johns Hopkins University (Wolff), University of Colorado (Hillary Lum), OpenNotes, and others
- Using the patient portal to identify care partners
- Funded by the National Institute on Aging



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* Indicates a required field.

Which of these applies to you?

I am the patient, and I am completing this form by myself

I am the patient, and someone else is helping me complete this form

I am not the patient

* What is your name?

* What is your relationship to the patient?

spouse/partner

adult child

other relative

friend/neighbor

paid attendant

other



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Patient/Care Partner Generated EHR Content

- Collaboration between OpenNotes, JHU (Wolff), and ARCHANGELS (Alex Drane)
- 3 clinical sites
 - Catholic Health (Buffalo, NY)
 - Beth Israel Lahey Health Primary Care (Eastern MA)
 - ?
- Identify care partners in the clinical setting and connect them with services
 - IT Component
 - In person component
- Funded by the Ralph C. Wilson Jr. Foundation



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Pre-visit questionnaire

Are you caring for a relative or friend?

This could include things like helping with person needs, household chores, health care, driving to appointments, or visiting regularly to see how they are doing.

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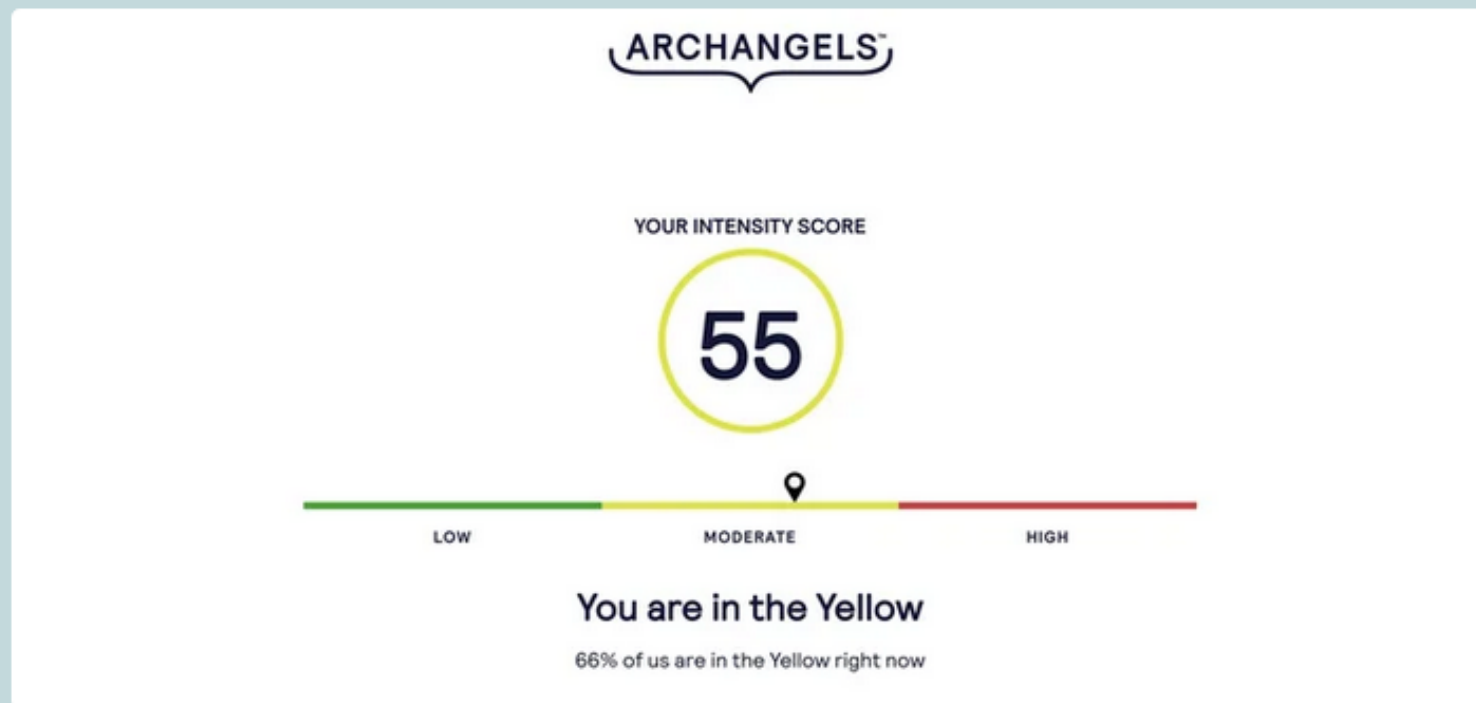
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WHAT'S YOUR INTENSITY SCORE?

Like any other job, there is intensity related to being an Archangel. Take a minute to check in on yourself and find out your Intensity Score. You'll find out whether you are "in the red," "yellow" or "green," and if you'd like, get connected to trusted support.



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Sharing your score and whether you are "in the red," yellow," or "green" is an easy way to let others know how you are doing and builds a common language for recognizing when someone could use a lift.

COMPLEXITY OF INFORMATION TECHNOLOGY USE
LOW

HIGH

Feedback loops
for clinical care

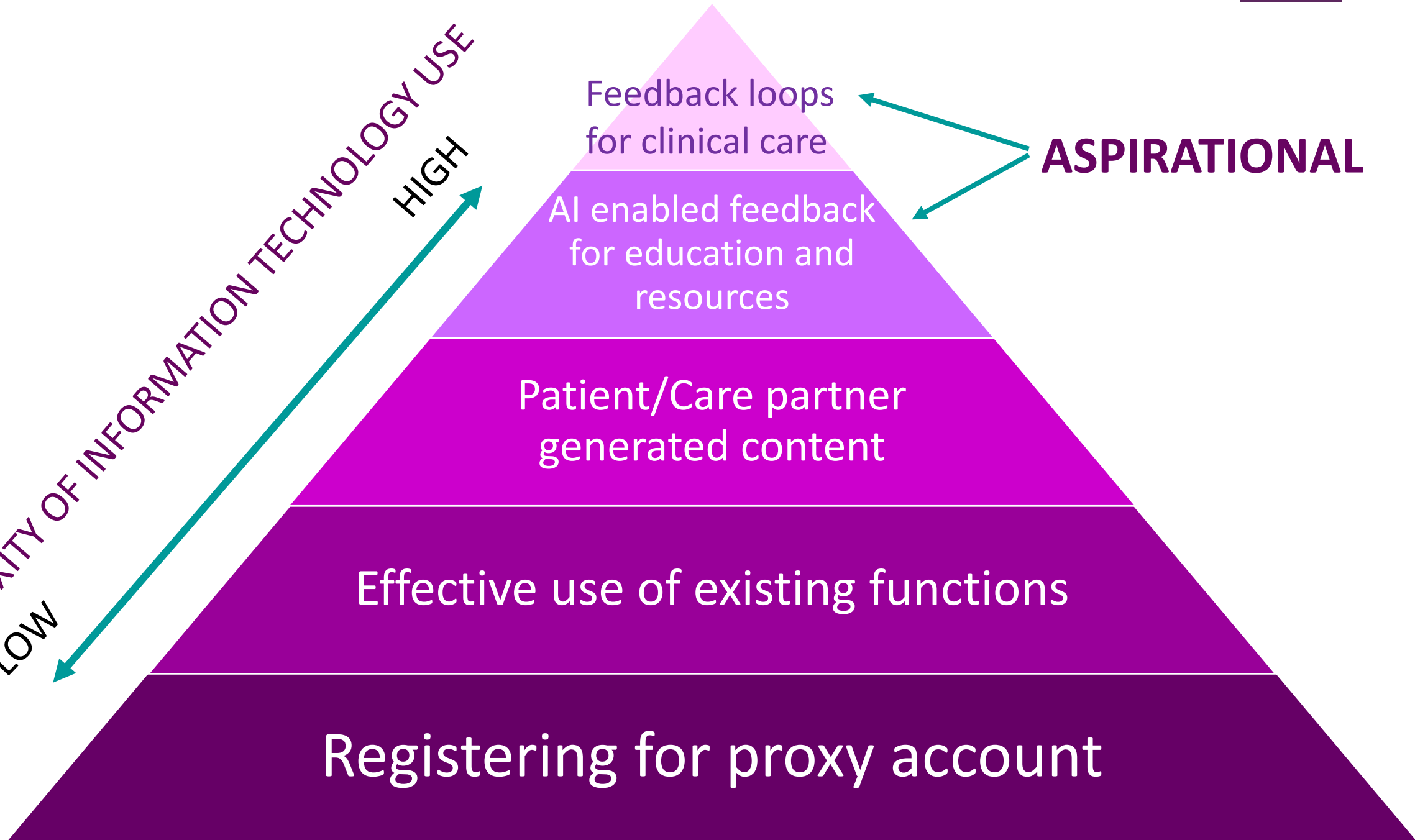
AI enabled feedback
for education and
resources

Patient/Care partner
generated content

Effective use of existing functions

Registering for proxy account

ASPIRATIONAL



Questions?

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