Patient-Centered Notes

Sara Jackson, MD, FACP
Kim O'Connor MD, MACP
Russell Berg, MD PhD

WA ACP Nov 9, 2024

Goals

- Re-examine how we document
- Understand literature re: stigmatizing language
- Inspire you to change medical culture

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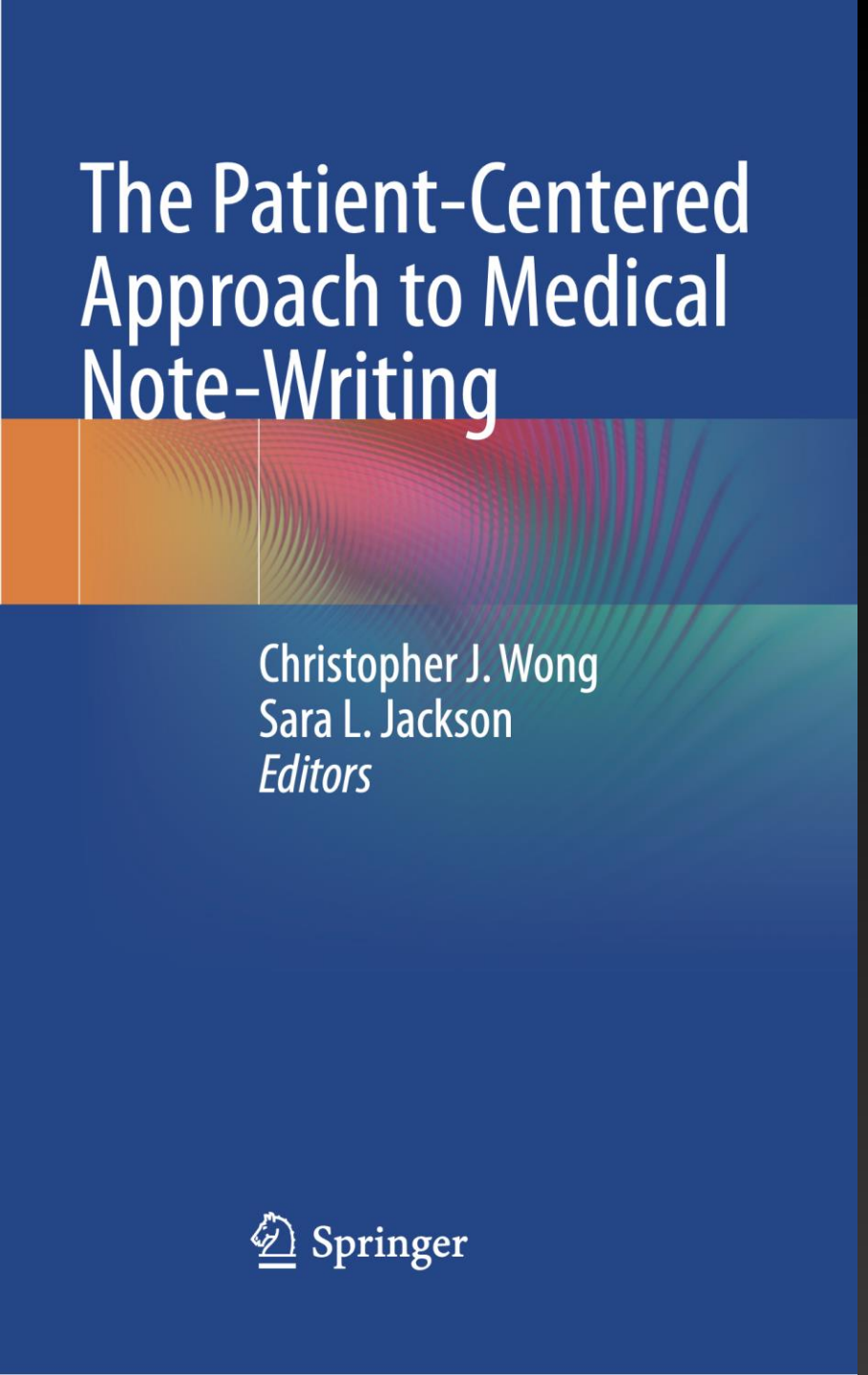
Patient-Centered Notes



Disclosures

Book is out now!

Jessica Bender
Russ Berg
Margaret Isaac
Jocelyn James
Jared Klein
Sarah Leyde
Renata Thronson

Sheida Aalami
Becca Ellis
Cody Gehring
Anna Hagan
Scott Hagan

Kim O'Connor
Angad Singh
Sarah Steinkruger
Jenny Wright

Workshop Agenda

- History of Open Notes
- Review evidence related to stigmatizing language
- Discuss actual (and a few invented) chart notes
  - Small group discussion
  - Large group discussion
- Conclusion
- Q&A

Dark Ages

pre 1990s

Dark Ages

pre 1990s

EMR

1990s-2000s

Annals of Internal Medicine | ORIGINAL RESEARCH

Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead

Tom Delbanco, MD*; Jan Walker, RN, MBA*; Sigall K. Bell, MD; Jonathan D. Darer, MD, MPH; Joann G. Elmore, MD, MPH; Nadine Farag, MS; Henry J. Feldman, MD; Roanne Mejilla, MPH; Long Ngo, PhD; James D. Ralston, MD, MPH; Stephen E. Ross, MD; Neha Trivedi, BS; Elisabeth Vodicka, BA; and Suzanne G. Leveille, PhD, RN

Dark Ages

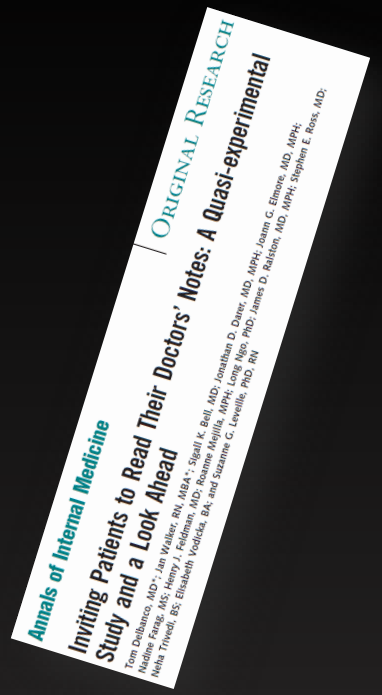
EMR

Open Notes

pre 1990s

1990s-2000s

2010



Dark Ages

EMR

Open Notes

UW

pre 1990s

1990s-2000s

2010

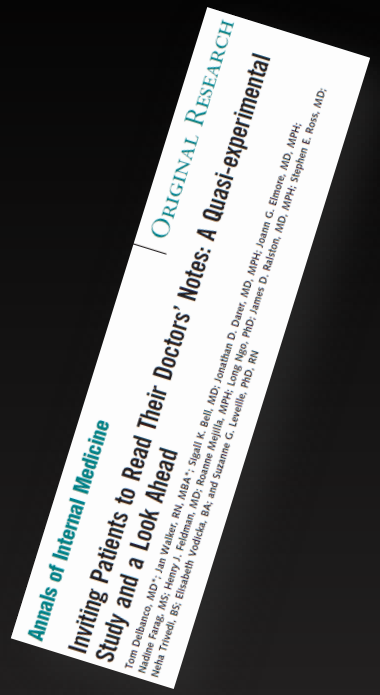
2014

Dark Ages

pre 1990s

EMR

1990s-2000s



Open Notes

2010

UW

2014

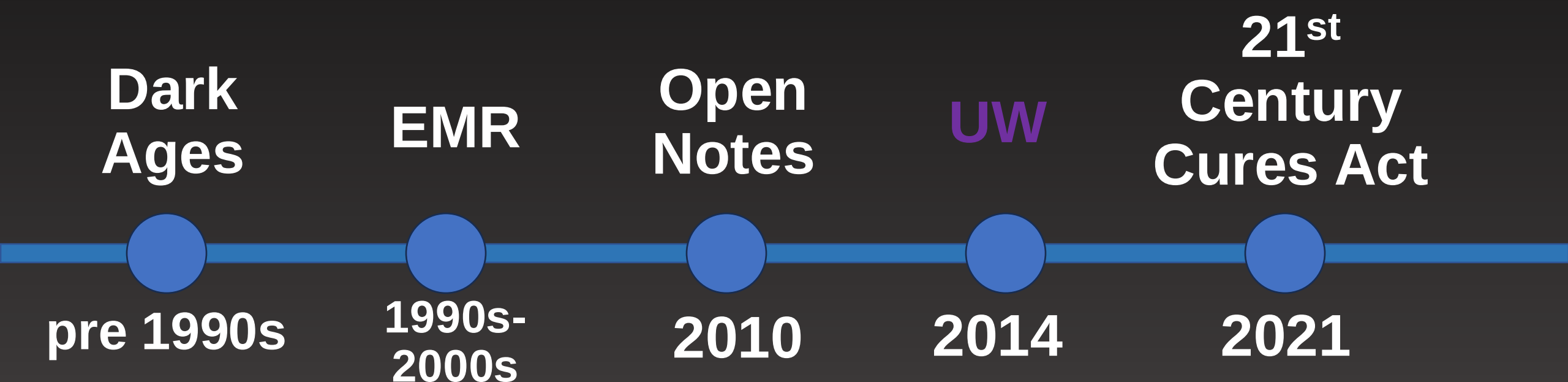
21st Century Cures Act

2021

This means:

Open notes is required

Patients are reading your notes



Not only are patients reading…
they're not liking (some of) what they see

Words Matter: What Do Patients Find Judgmental or Offensive in Outpatient Notes?

Leonor Fernández, MD[1,2], Alan Fossa, MPH[1,3], Zhiyong Dong, MS[1], Tom Delbanco, MD[1,2], Joann Elmore, MD[4,5], Patricia Fitzgerald, MS[1], Kendall Harcourt, MPA[1], Jocelyn Perez, BS[1], Jan Walker, RN, MBA[1,2], and Catherine DesRoches, DrPH[1,2]

JGIM Sept 2021

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JGIM

Sept 2021

Survey @ Geisinger, BI, UW

Inclusion: Reported reading at least 1 outpt visit note (n>20,000)

"Have you ever felt offended by something you read in a visit note?"

"Have you ever felt judged by something you read in a note?"

If Yes: "Please explain what offended you / made you feel judged."

Words Matter: What Do Patients Find Judgmental or Offensive in Outpatient Notes?

Leonor Fernández, MD[1,2], Alan Fossa, MPH[1,3], Zhiyong Dong, MS[1], Tom Delbanco, MD[1,2], Joann Elmore, MD[4,5], Patricia Fitzgerald, MS[1], Kendall Harcourt, MPA[1], Jocelyn Perez, BS[1], Jan Walker, RN, MBA[1,2], and Catherine DesRoches, DrPH[1,2]

JGIM

Sept 2021

~ **10%** felt offended and/or judged

Framework

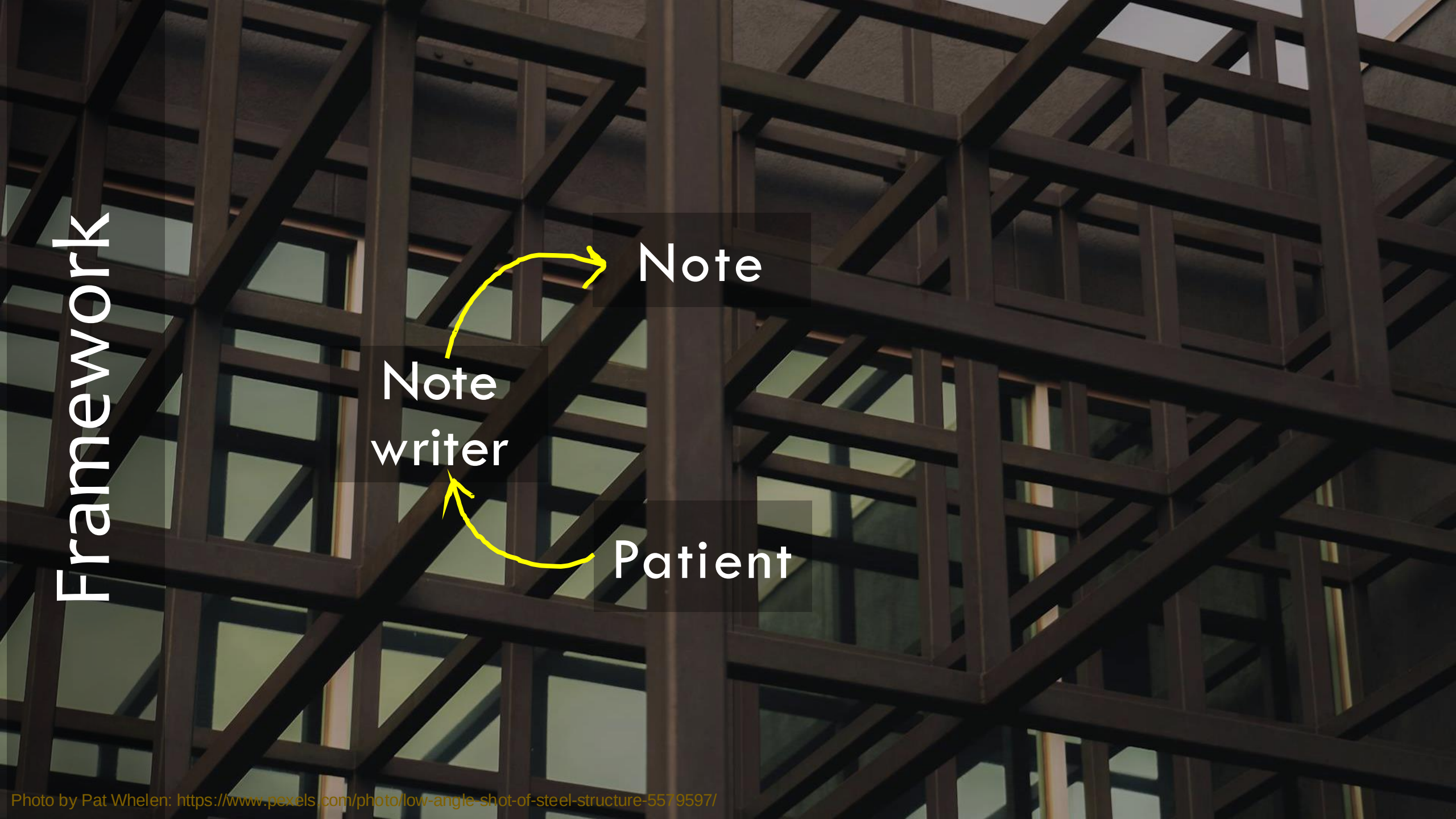
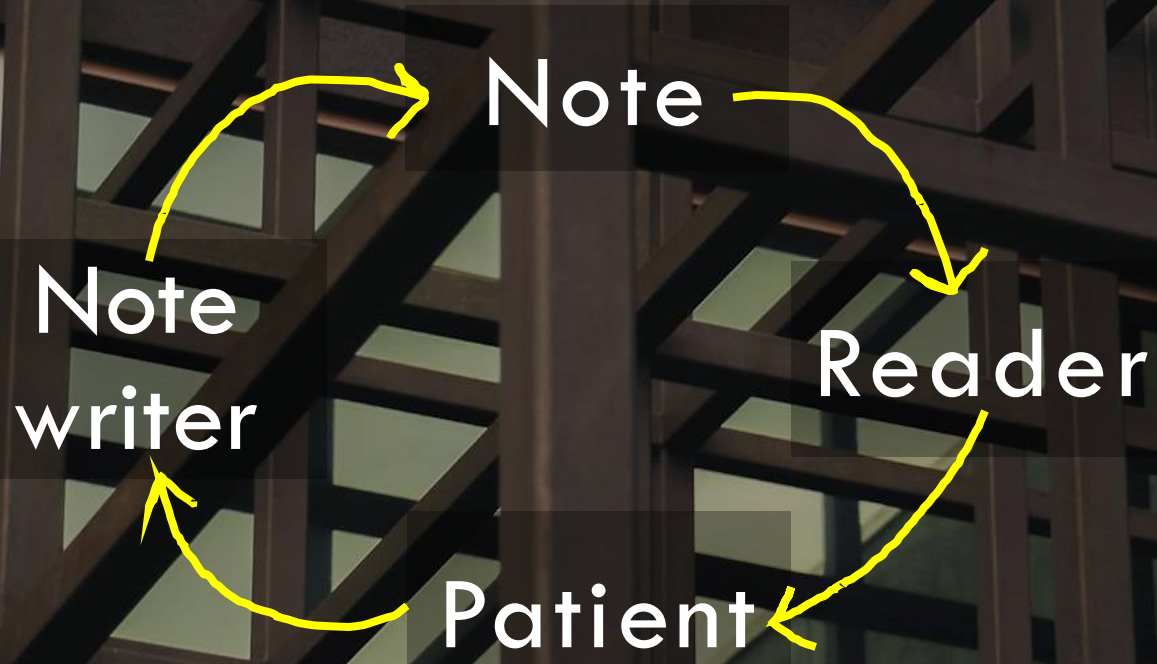


Photo by Pat Whelen: https://www.pexels.com/photo/low-angle-shot-of-steel-structure-557 9597/

Framework



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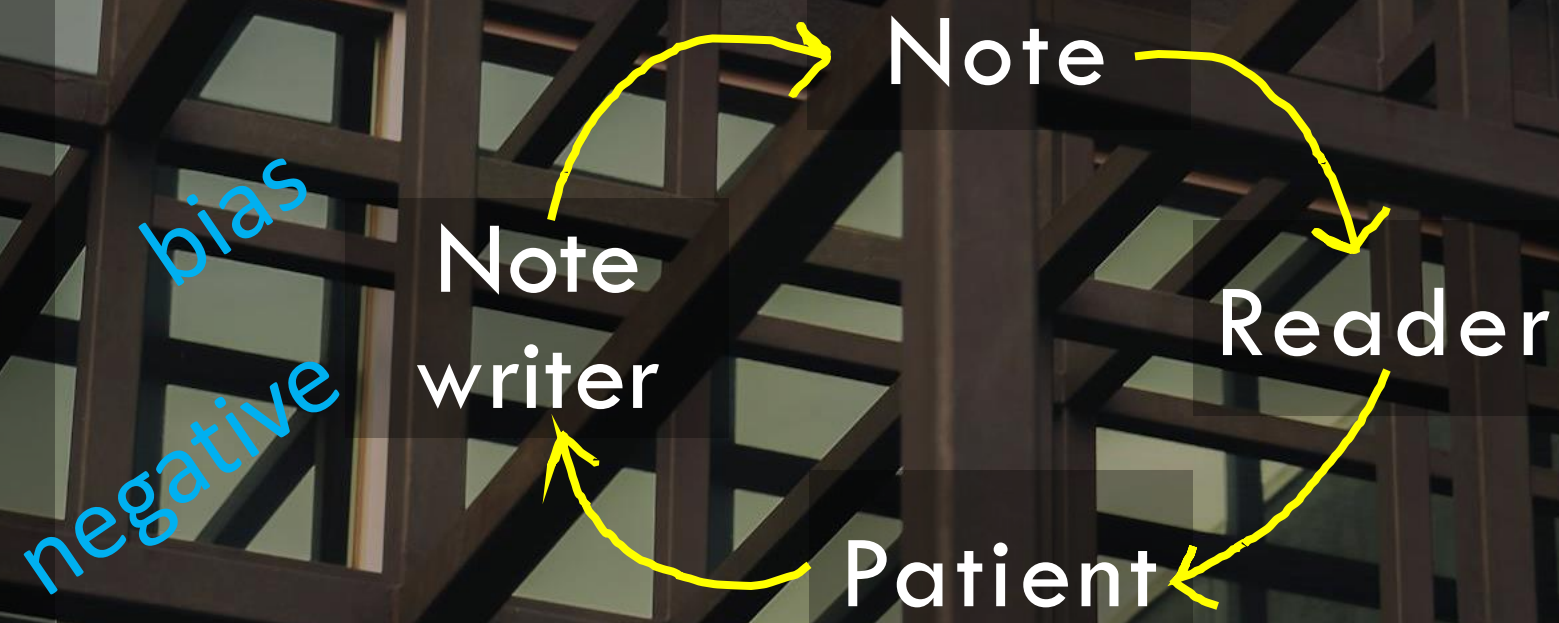
Negative language: vicious cycle?

Framework



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Negative language: vicious cycle?

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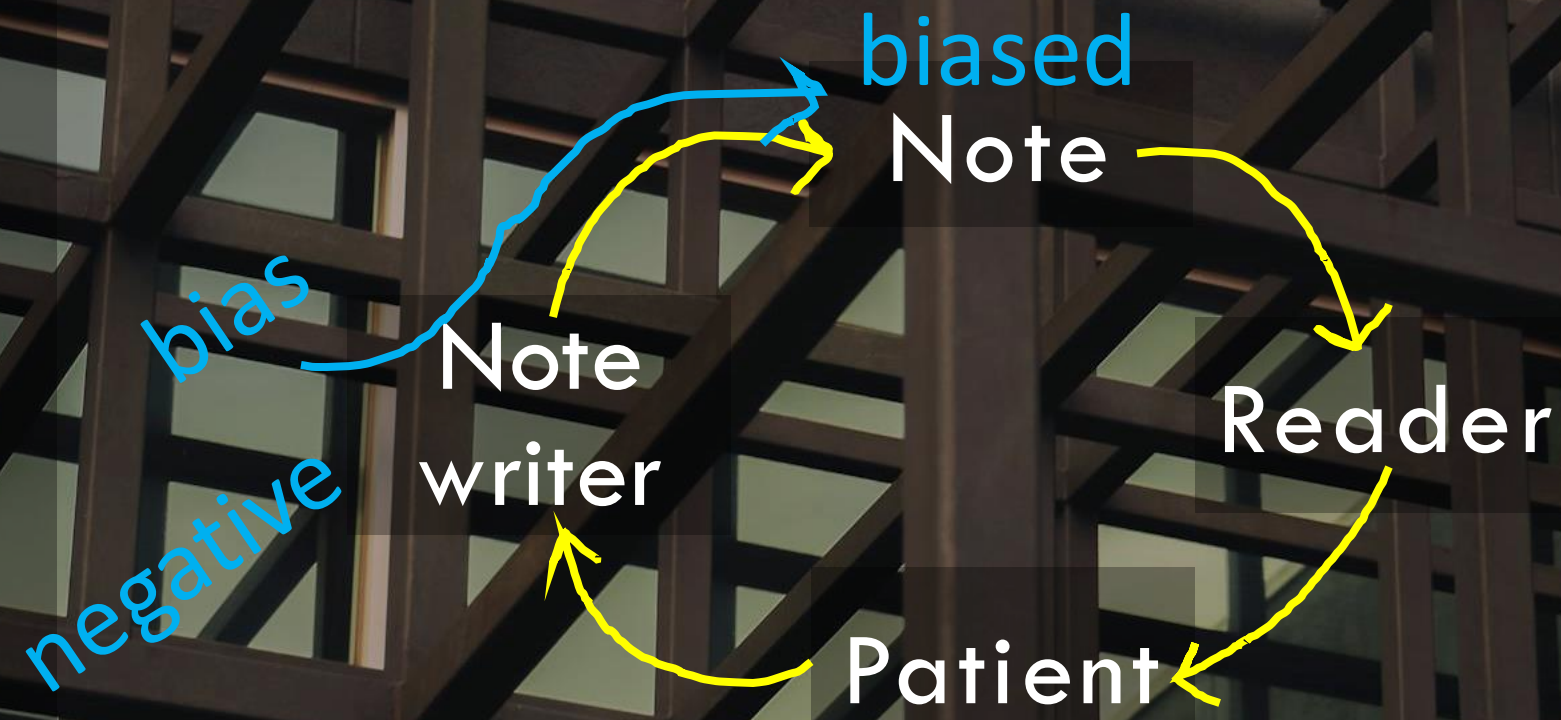

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Negative language: vicious cycle?

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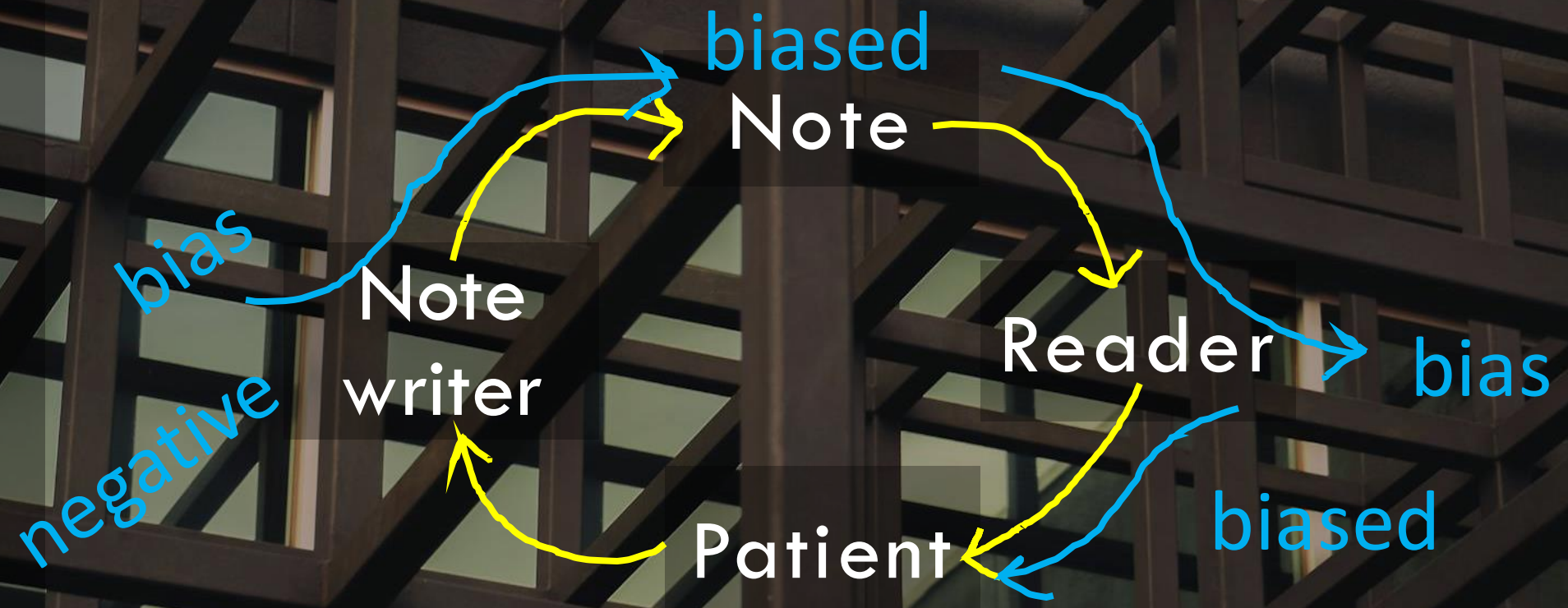

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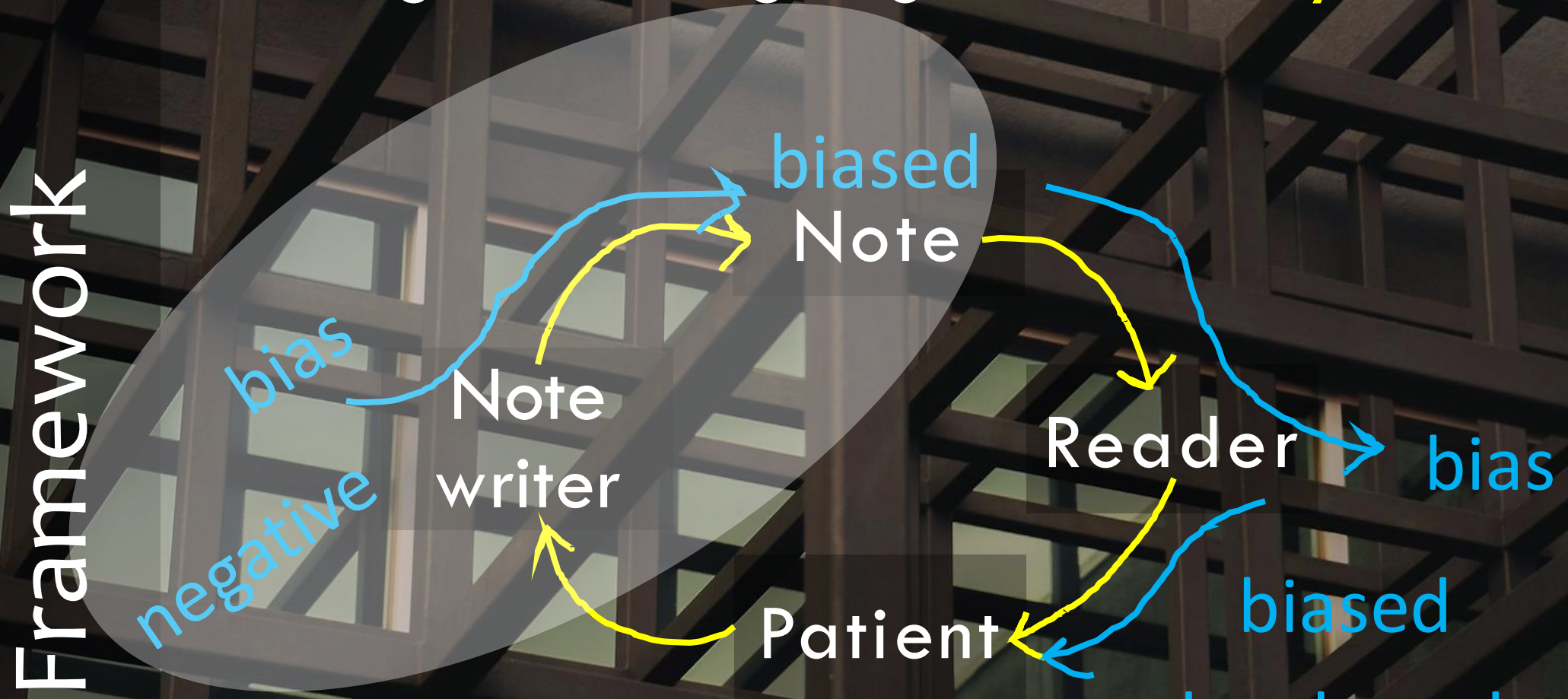
Negative language: vicious cycle?



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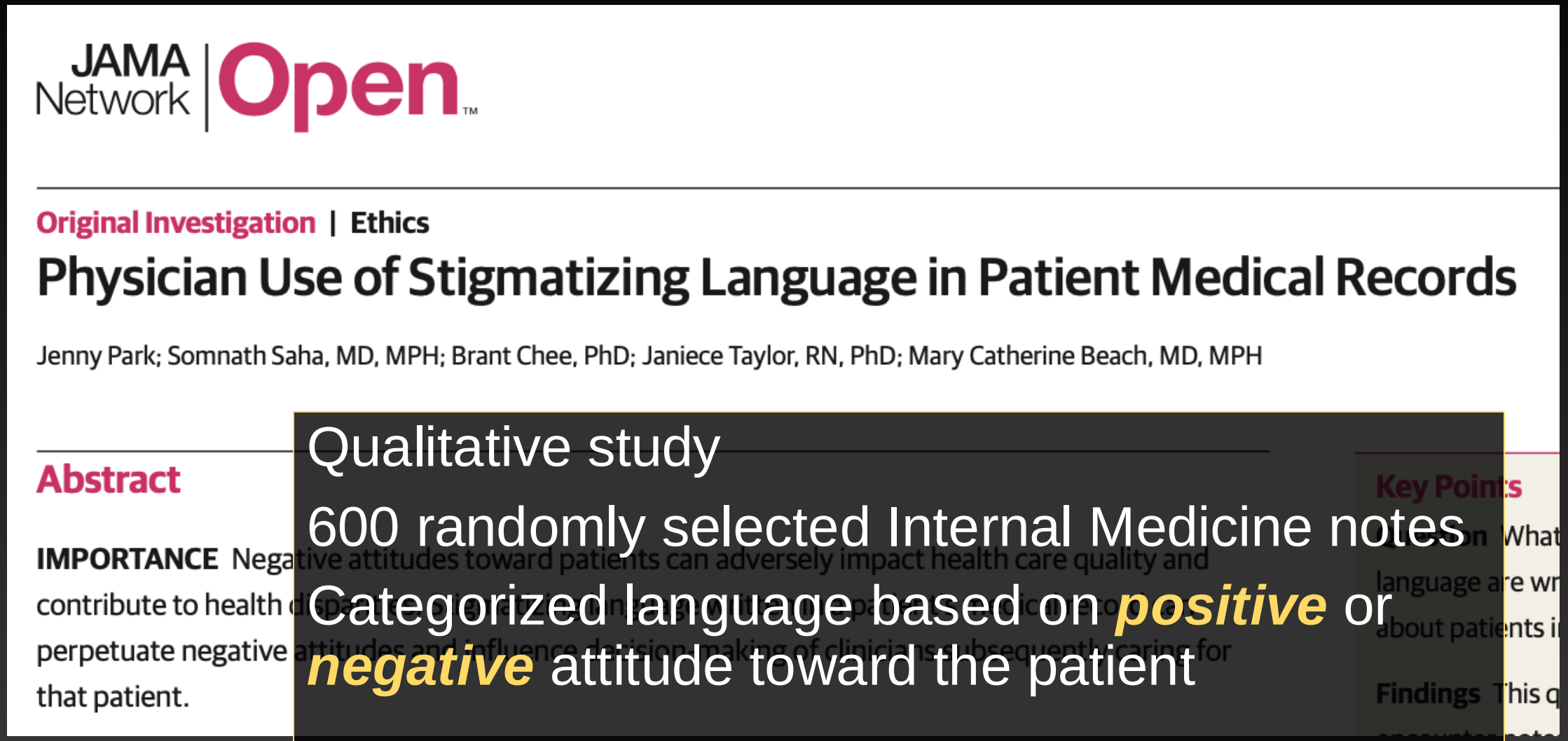
Bias going *into* a note



JAMA Network | Open™

Original Investigation | Ethics

Physician Use of Stigmatizing Language in Patient Medical Records

Jenny Park; Somnath Saha, MD, MPH; Brant Chee, PhD; Janiece Taylor, RN, PhD; Mary Catherine Beach, MD, MPH

Abstract

IMPORTANCE Negative attitudes toward patients can adversely impact health care quality and contribute to health disparities. Physicians' written communication may perpetuate negative attitudes and influence decision-making of clinicians subsequently caring for that patient.

Key Points

What language are written about patients in

Findings This q

Qualitative study

600 randomly selected Internal Medicine notes

Categorized language based on ***positive*** or ***negative*** attitude toward the patient

Park et al JAMA Network Open 2021;4(7):e2117052

Major Themes from Park et al (2021)

Negative language

Disapproval

Question credibility

Unilateral Decisions

Stereotyping

Difficult Patient

Positive language

Approval

Bilateral Decisions

Compliment

Personalize

Self-disclosure

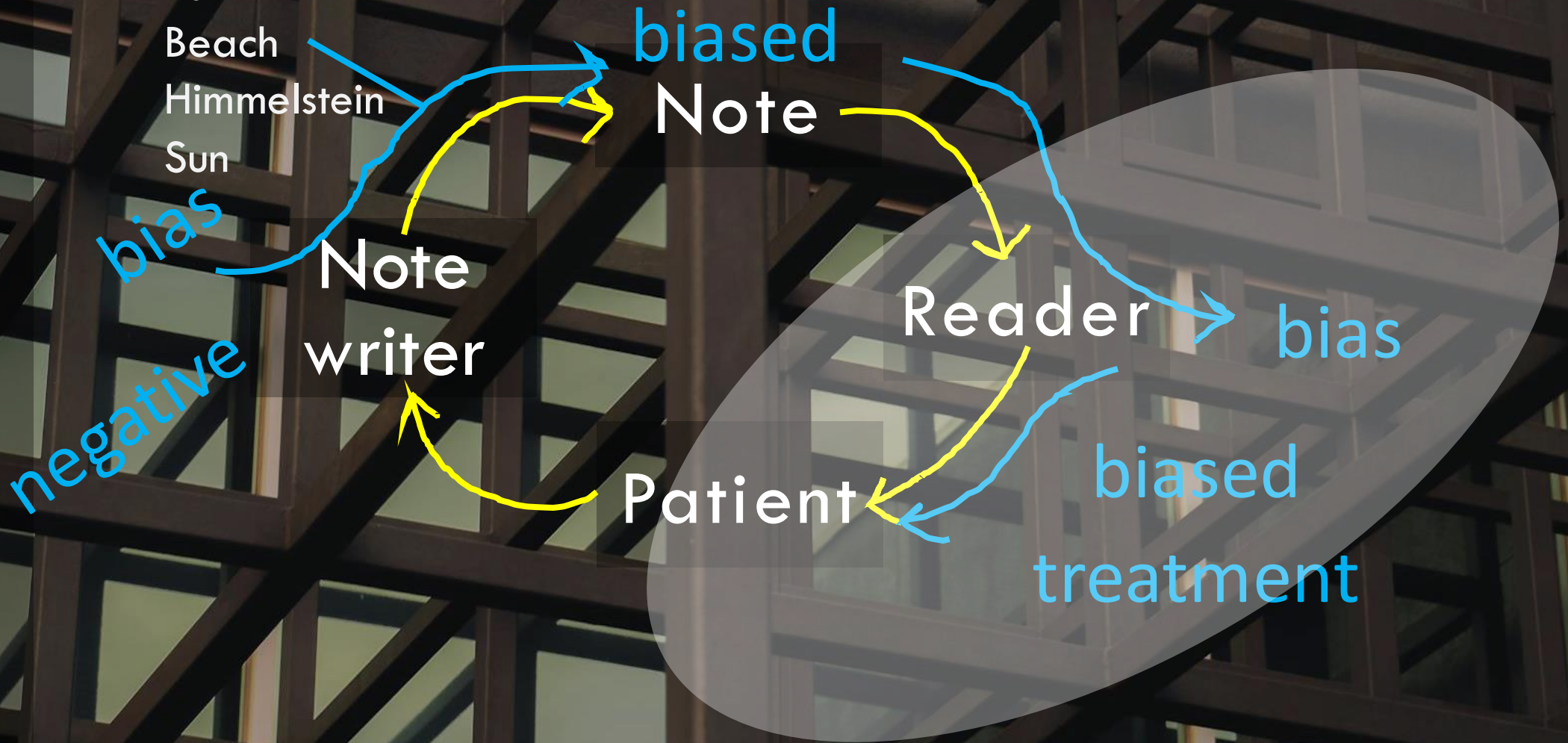
Minimize blame

Park et al JAMA Network Open 2021;4(7):e2117052

Negative language: vicious cycle?

Framework

Fernandez
Park
Beach
Himmelstein
Sun



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Bias going out: Do notes affect the reader?

Gave vignettes (neutral vs stigmatizing) to IM/EM residents

Surveyed

- pain management intensity
- attitudes toward the patient

Goddu et al JGIM 2018;33(5);685-691

Mr. R is sleeping but easily arousable and seems distressed. He is not tolerating the oxygen mask and still has 10/10 pain. His girlfriend is by his side but will need to go home soon.

neutral

Mr. R is sleeping but easily arousable and has been cussing at the nurse. He refuses to wear his oxygen mask and is insisting that his pain is "still a 10." His girlfriend is lying on the bed with shoes on and requests a bus token to go home.

stigmatizing

Goddu et al JGIM 2018;33(5);685-691

Mr. R is sleeping but easily arousable and seems distressed. He is not tolerating the oxygen mask and still has 10/10 pain. His girlfriend is lying on the bed with him and will need to go home soon.

Positive attitude toward patients
+ 5 pts on 7-35 scale

Pain management
+ 0.6 pts on 2-7 scale

neutral

Mr. R is sleeping but easily arousable and has been cussing at nurse. He refuses to wear his oxygen mask and is insisting that his pain is "still a 10." His girlfriend is lying on the bed with [illegible] and requests a bus[illegible]

stigmatizing

Goddu et al JGIM 2018;33(5);685-691

Bias going out: Do notes affect the reader?

Kelly et al (2010)

Randomized mental health care providers (attending a conference) to vignettes

Surveyed attitudes

Mr. Williams is a **substance abuser** and is attending a treatment program through the court. As part of the program Mr. Williams is required to remain abstinent from alcohol and other drugs…
Mr. Williams has been a **substance abuser** for the past few years…

Mr. Williams has a **substance use disorder** and is attending a treatment program through the court. As part of the program Mr. Williams is required to remain abstinent from alcohol and other drugs…
Mr. Williams has had a **substance use disorder** for the past few years… .

Kelly Intl J Drug Policy 2010

Mr. Williams is a **substance abuser** and is attending a treatment program through the court. As part of the program Mr. Williams is required to remain abstinent from alcohol and other drugs…
Mr. Williams has been a **substance abuser** for the past few years…

Mr. Williams has a **substance use disorder** and is attending a treatment program through the court. As part of the program Mr. Williams is required to remain abstinent from alcohol and other drugs…
Mr. Williams has had a **substance use disorder** for the past few years… .

More likely to agree with:

- "His problem is caused by a reckless lifestyle"
- "Mr. Williams is responsible for causing his problem"
- "He should be given some kind of jail sentence to serve as a wake-up call"
- "His problem is caused by poor choices that he made"

Kelly Intl J Drug Policy 2010

Other studies: notes influence us

Study	Description	Findings
Goddu et al 2018	Randomized IM, ER residents and medical students to neutral vs stigmatizing vignettes (n=413) Asked how they'd treat pt and attitudes	Stigmatizing vignette: fewer pain medications, less positive attitude toward pt
Kelly et al 2010	Randomized mental health care providers (attending a conference) to vignettes (n=728) *Mr. ___ is a substance abuser* vs *Mr. ___ has a substance use disorder* Surveyed for agreement with statements re: treatment, threat, punishment, individual responsibility	Term not associated with: pt as a "social threat" or treatment recommended Term associated with: punitive action, personal culpability
Mamede et al 2015	Randomized IM residents (n=74) to vignettes of "difficult" vs "neutral" patients. Asked to recall clinical findings and behaviors.	Difficult vs neutral vignettes: Diagnostic accuracy: lower Clinical findings: recalled fewer Behaviors: recalled more

Large studies: who gets more negative language in their notes?

Study	Description	Findings*
Beach et al 2021	9000+ outpatient notes, academic medical center "Evidentials" (choosing to indicate source eg *reports*) Judgment words (e.g. *claims, insists, adamant*) Quotations	Black/African American vs White/Caucasian: More evidentials (0.3 more per note) More judgment words (aOR 1.25) More quotations (aOR 1.48) Women vs Men: More quotations (OR 1.22) No difference in evidentials/judgment words
Himmelstein et al 2022	48,000+ inpatient admission notes, academic medical center Stigmatizing word frequency (e.g. *adherence, compliance, refused, belligerent, difficult, abuse)*	Overall prevalence: 2.5 % of notes Likelihood of stigmatizing language associated with: Black vs White (non-Hispanic), esp relating to adherence, substance use, and perceived attitude Diabetes: less well controlled
Sun et al 2022	40,000+ outpt, ER, inpt notes of pts tested for COVID; academic medical center Negative patient descriptors	Overall prevalence: 8.2% of patients Black vs White more likely to have negative descriptors (aOR 2.5)

*Note: in all studies, race/ethnicity/gender data and categories were from EMR

Negative language: vicious cycle?

Framework

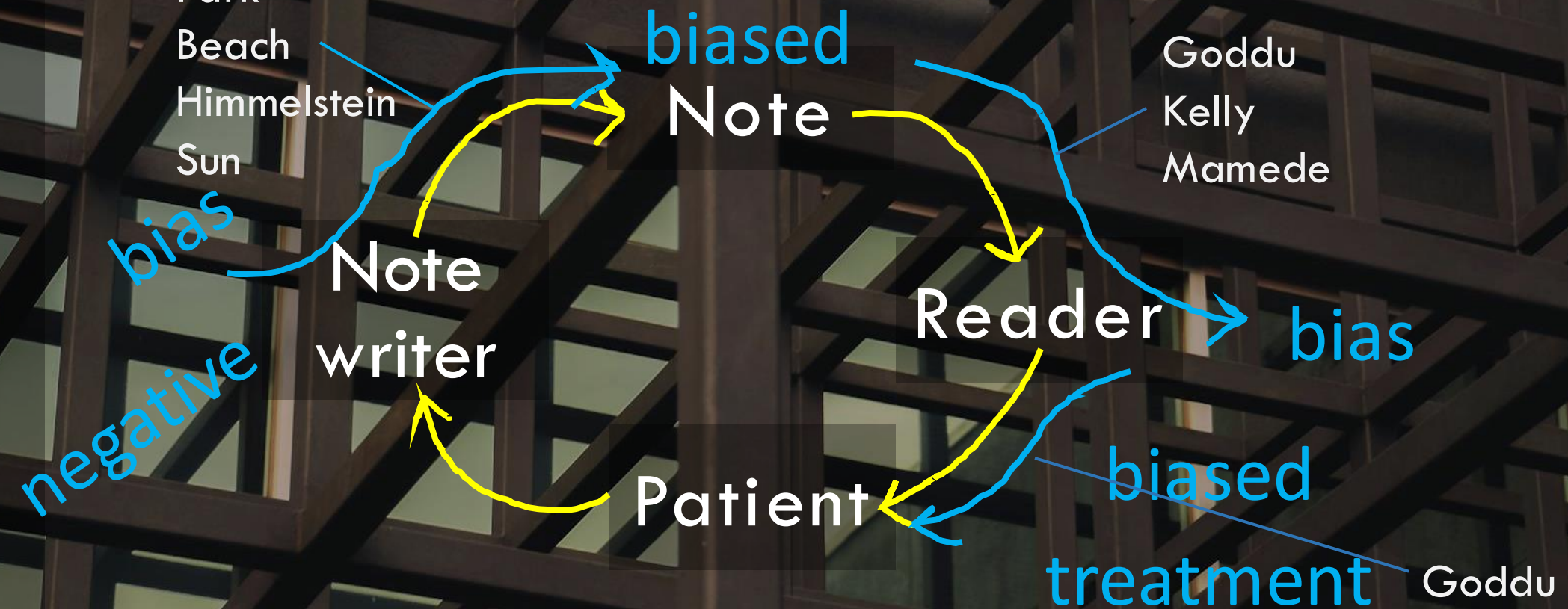


Photo by Pat Whelen: https://www.pexels.com/photo/low-angle-shot-of-steel-structure-5579597/

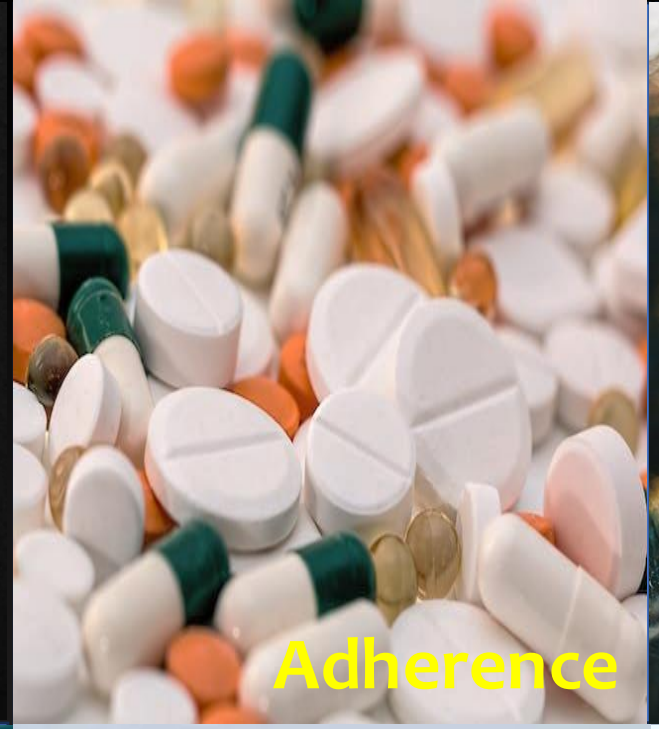
Small Group Discussions

- Read **excerpts** of chart notes
  - Real and made up
- Knowing that patients are reading these notes:
  - Are there **potential problems/issues** with how they are written?
  - If so, what is the **potential impact**?
  - How could you **write it differently**?
  - *Is it necessary, it is useful, is it kind?*

Large group discussion

- Are there **potential problems/issues** with how they are written?
- If so, what is the **potential impact**?
- How could you **write it differently**?
- Is it **necessary, it is useful, is it kind**?

Labels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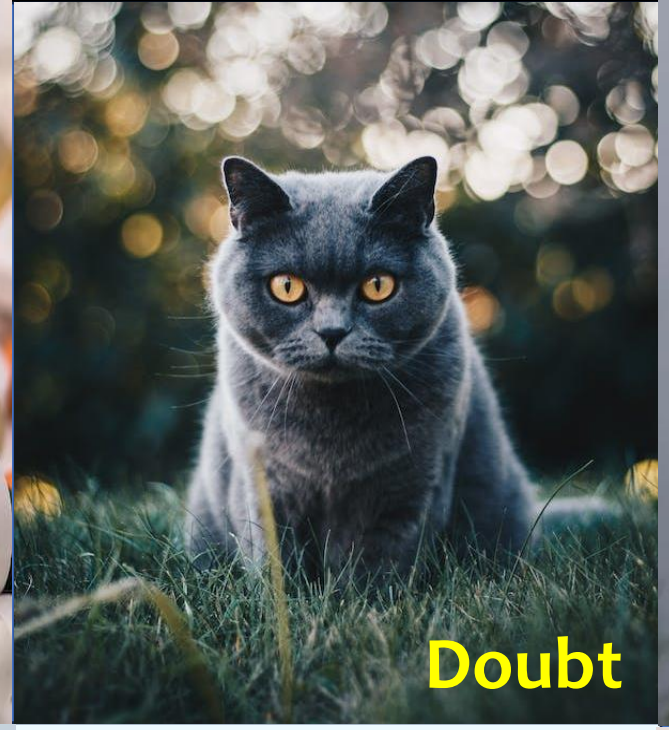
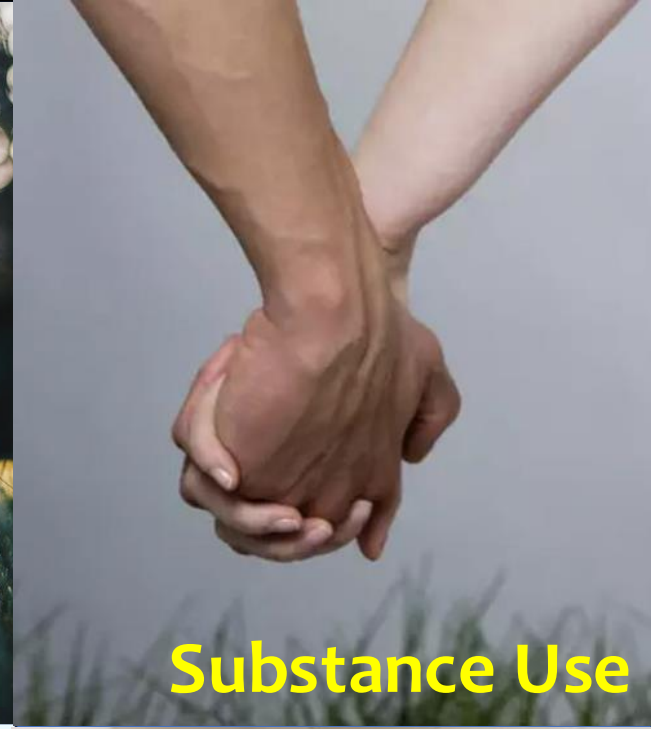
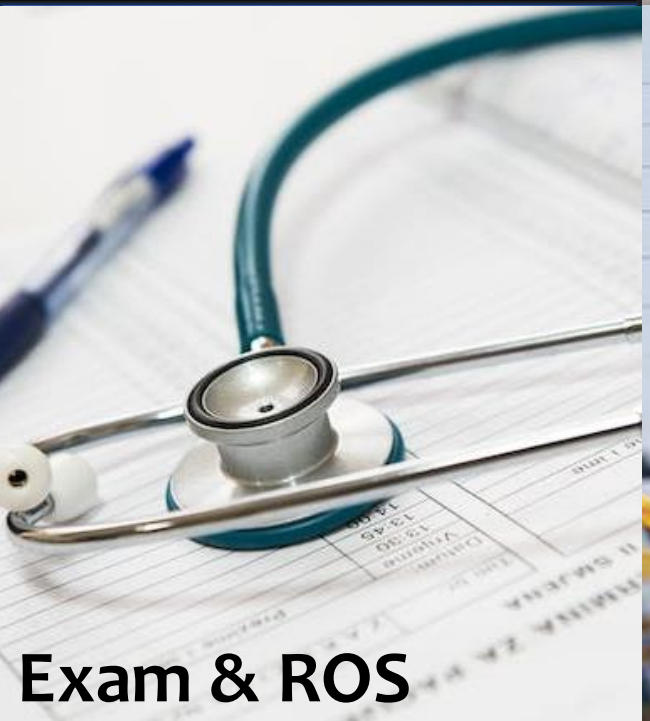
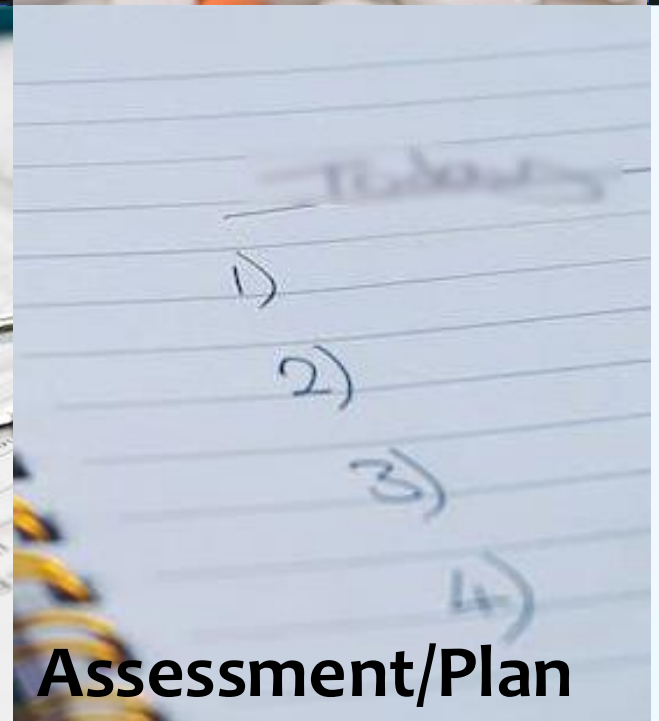
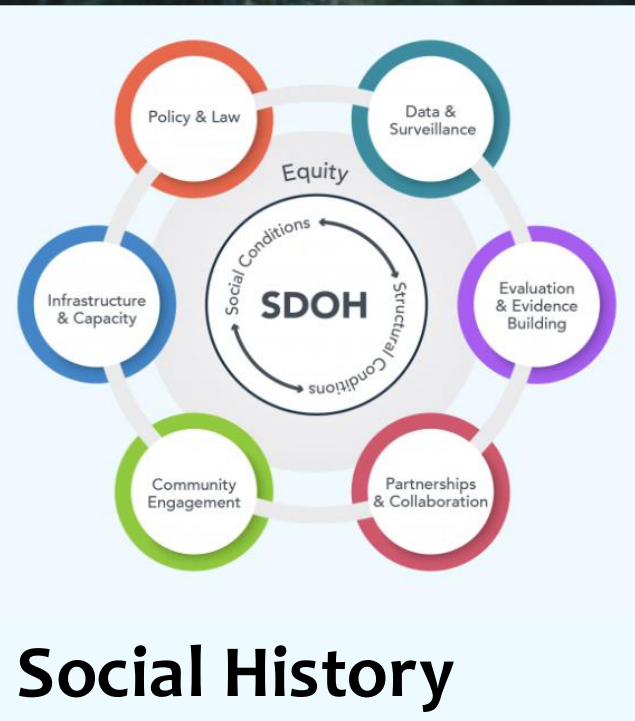
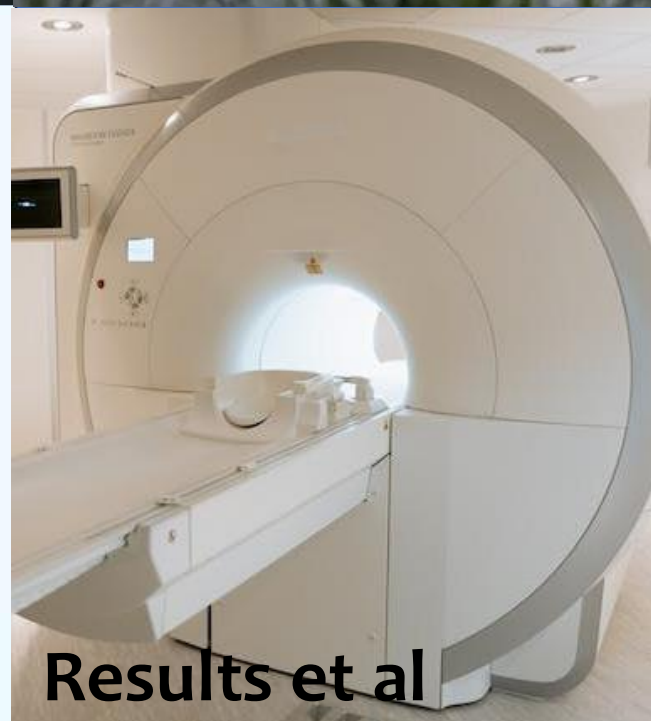

Doubt


Substance Use


Exam & ROS


Assessment/Plan


Policy & Law
Data & Surveillance
Equity
Social Conditions
SDOH
Structural Conditions
Infrastructure & Capacity
Evaluation & Evidence Building
Community Engagement
Partnerships & Collaboration
Social History


Results et al

Group 1

… is a homeless 34 year old type 1 diabetic here for …

… is a 42 year old Vietnamese-speaking female who …

68-year-old Caucasian gentleman with a history of end-stage renal disease on hemodialysis, liver transplant in 2012, recurrent hepatitis C, COPD, …

Group 1

… is a **homeless** 34 year old type 1 diabetic here for …

… is a 42 year old Vietnamese-speaking female who …

68-year-old Caucasian gentleman with a history of end-stage renal disease on hemodialysis, liver transplant in 2012, recurrent hepatitis C, COPD, …

homeless

Social history:

- No consensus on what social history elements belong in one-liner
- First lines tend to bias the reader/listener
- Is *that* important?
- Get terms right!

Group 1

… is a homeless 34 year old **type 1 diabetic** here for …

… is a 42 year old Vietnamese-speaking female who …

68-year-old Caucasian gentleman with a history of end-stage renal disease on hemodialysis, liver transplant in 2012, recurrent hepatitis C, COPD, …

type 1 diabetic

Diseases/conditions:

- What to include:
  - Generally agreed to put some in
  - Art / in evolution / varies by practitioner
  - Careful re: biases – certain conditions tend to get included whether relevant or not (e.g. substance use, pain, transgender status)
- Words to use:
  - Generally avoid labeling a person as their condition/disease e.g. *vasculopath, diabetic, drug user*

Group 1

… is a homeless 34 year old type 1 diabetic here for …

… is a 42 year old **Vietnamese-speaking** female with who …

68-year-old Caucasian gentleman with a history of end-stage renal disease on hemodialysis, liver transplant in 2012, recurrent hepatitis C, COPD, …

Vietnamese-speaking

Language:

- Is it necessary in the one-liner?
- What does Vietnamese-*speaking* actually mean?
  - Preference?
  - Proficiency? (often implied)
  - 1st or native language?
- **Epic** actually has a definition for imported field:
  - **Preferred language** – but: depends on accuracy of data collection
- If you choose to use it, must use for everyone (not just non-English)
  - Consider listing differently

Group 1

… is a homeless 34 year old type 1 diabetic here for …

… is a 42 year old Vietnamese-speaking female who …

68-year-old **Caucasian** gentleman with a history of end-stage renal disease on hemodialysis, liver transplant in 2012, recurrent hepatitis C, COPD, …

Caucasian

Race and Ethnicity:

- Both social constructs
  - Race is an artificially created scheme to group people, poorly defined, often used for ill
  - Ethnicity does have meaning and definition
- Is important, but does not belong in one-liner (ID, HPI, Exam, A/P)
- Data collection often an issue

First impressions and labelling

What's really important in that opening line?

Definite **no**	**Consider** leaving out	OK but think	Evolving
Race Ethnicity	Language Social descriptors	Diseases/ Conditions • but don't label pt • Careful re: substance use, etc Jargon is ok	Gender

Potentially stigmatizing terms

Labels
Drug user
IVDUer
IV drug user

Outdated
abuse
Dependence
IVDU
IVDA

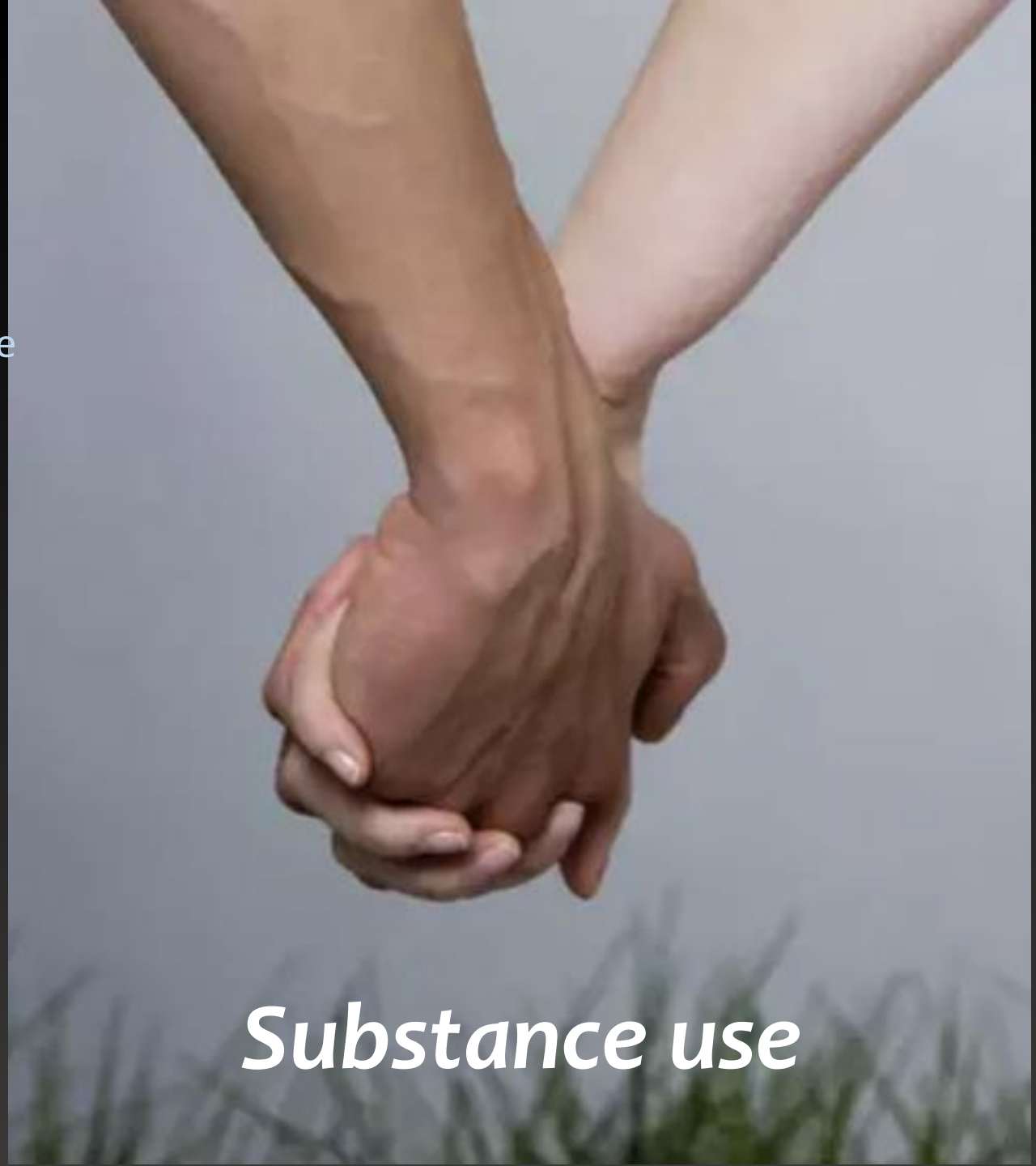
Judgmental
clean, dirty
relapse
treatment failure

language of failure

Policing
denies
tox
recidivism

Vague
illicits
illegal drugs
recreational

Sometimes patients identify with (discuss!)
Addict, sober



Substance use

Better practices

Substance use disorder
Addiction (in appropriate context)
Use
Misuse (in appropriate context)
Recovery
Using…
Not using…

Be descriptive
Details often better in HPI / narrative than ID/one liners

Group 2

The patient refuses labs.

The patient has been noncompliant with care.

Patient deferred rectal exam and anoscopy.

Group 2

The patient **refuses** labs.

The patient has been noncompliant with care.

Patient deferred rectal exam and anoscopy.

Refusals

Word choice : Refuse

- *Refuse:* is it something that one really *refuses*?
- *Decline* tends to be better
- What's missing? The **why**
- Alternative approach: discuss/describe:
  - "The patient declined a lab draw."
  - "I recommend xx lab test, but the patient preferred …. because … "

Group 2

The patient refuses labs.

The patient has been **noncompliant** with care.

Patient deferred rectal exam and anoscopy.

Noncompliance

Word choice

- *Noncompliant/noncompliance*
  - has a very labeling effect
  - judgment
- Same approach as with *refuse* – why/discuss/describe the situation

Group 2

The patient refuses labs.

The patient has been noncompliant with care.

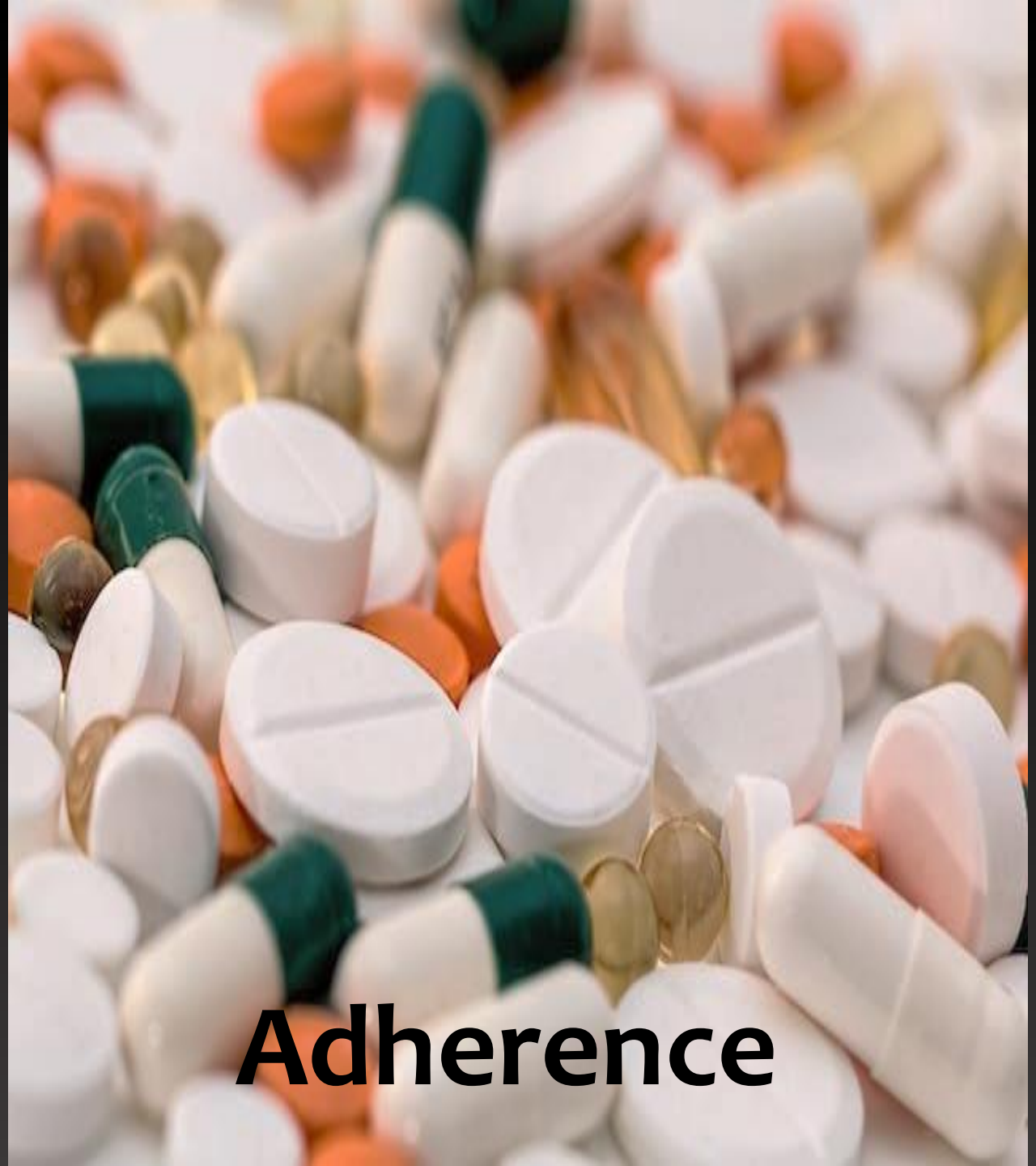
Patient **deferred** rectal exam and anoscopy.

Deferrals

Word choice: defer

- *Defer* means to put off to a later time
  - If using that meaning, fine
  - Don’t use when you really mean decline
- Who is deferring? (provider or patient?)
- Deferring until when? And why?

Patients can decide not to do any number of things that we recommend or really really really want them to do



Adherence

The key is to:

Be **curious**
Understand **why**
(often a “good” reason, but does not have to be – people can make choices for “bad” reasons!)

Document **using less judgmental terms**
(whether the terms betray judgment or were truly unintentional)

Group 3

He was adamant that he does not have prostate cancer because his “bowels are working fine.”

They claim that nicotine patches don’t work for them..

… insists she gets sick from vaccines..

She did try some oral anticoagulants including warfarin, but can't remember which other ones. She states that these oral medicines either "did not work", because of side effects, or she was always "at the wrong level".

Thoughts?

-Are there potential problems here?

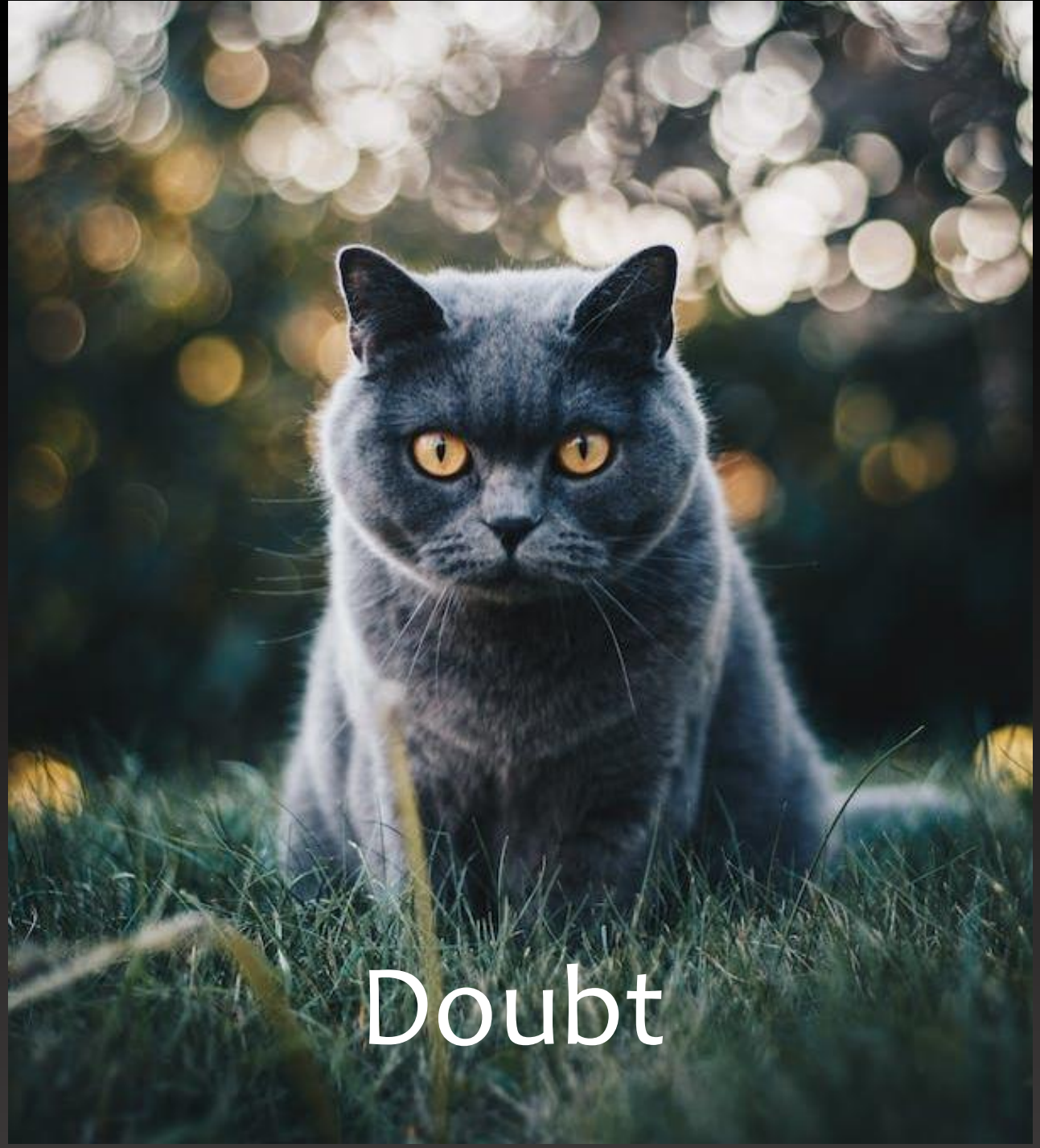
-What is the potential impact?

-How could you write it differently?

-Is it necessary, is it useful, is it kind?

Word choice: questioning a patient's **credibility**

Claims
Insists
Supposedly
Apparently



Grammar:

Use of quotations – tends to express **doubt**

But:

Some specialties use quotations really well

-palliative care

-psychiatry

Use with care!

If it enriches narrative or voice, then use

If it's doubting or doesn't add, then paraphrase

Park et al JAMA Network Open 2021;4(7):e2117052

Current documentation	Alternatives
He was **adamant** that he does not have prostate cancer because his **“bowels are working fine.”**	*His view is that he does not have prostate cancer because he does not have any symptoms in the lower abdomen or gastrointestinal symptoms such as*
They **claim** that nicotine patches don’t work for them.	*They tried a nicotine patch several times, but it never reduced their cravings enough to stop smoking.*
… **insists** she gets sick from vaccines..	*She would prefer not to have any vaccines due to her previous experiences: when she had the flu shot, 1 day later she had [describe] …*
She did try some oral anticoagulants including warfarin but can't remember which other ones. She states that these oral medicines either **"did not work"**, because of side effects, or she was always **"at the wrong level".**	*She has taken warfarin in the past along with other anticoagulants that she cannot recall the names of. She experienced side effects from these medications. She also found it frustrating that the levels of these medications changed so often and was hard to manage*.

Group 4

Patient was adamant that she leave AMA on 8/11 and was prescribed 2 weeks of linezolid.

A/P:
Tobacco abuse

Depression: patient failed 3 different SSRIs.

Morbid obesity: candidate for referral to bariatric surgery.

Sinusitis: the pt is adamant that they need antibiotics for this and refuses to listen.

The Assessment & Plan

Thoughts?

-Are there potential problems here?

-What is the potential impact?

-How could you write it differently?

-Is it necessary, is it useful, is it kind?

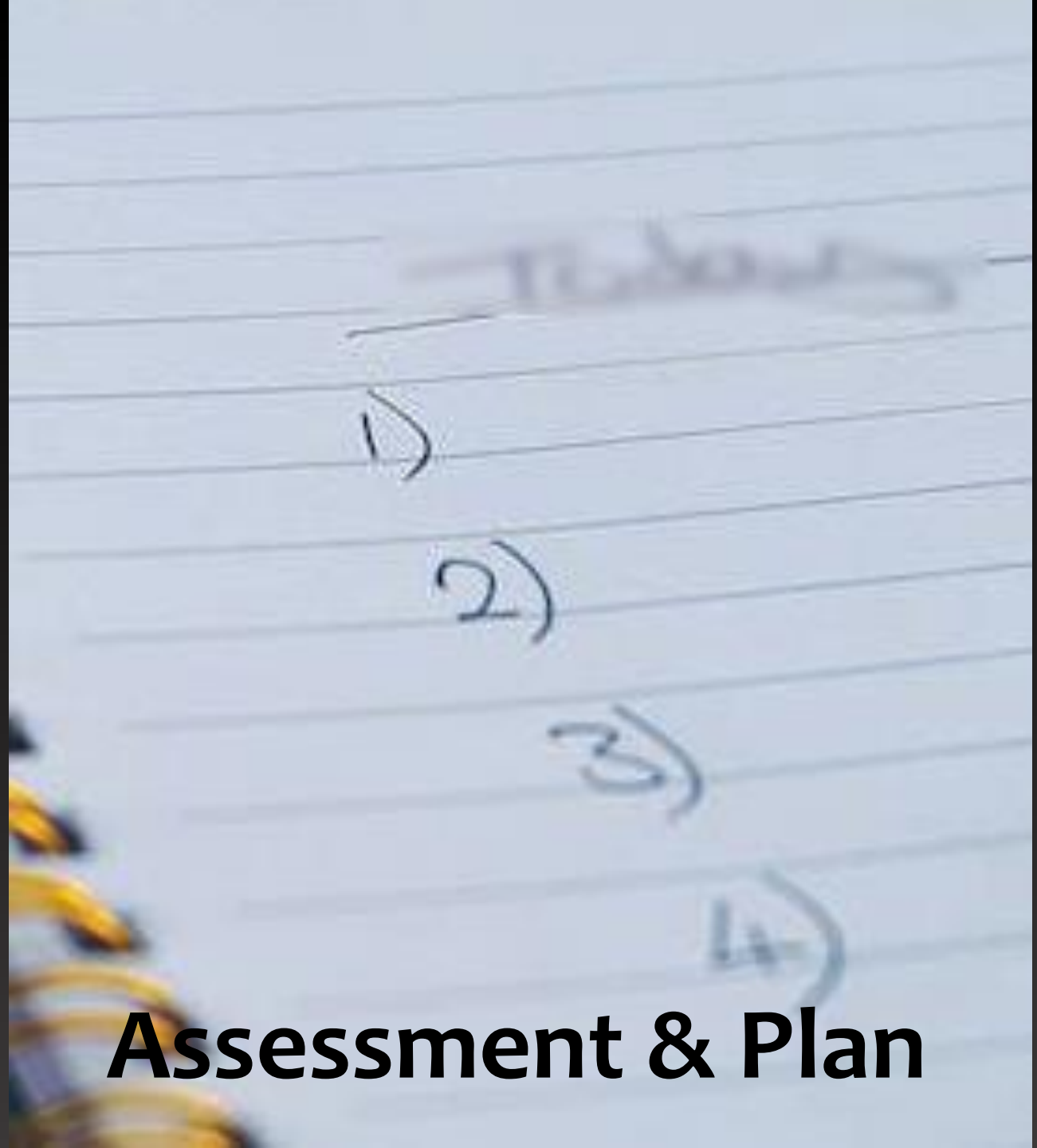
The section people read!!!

One liner
If used, be careful…
(covered previously)

Naming Problems
Avoid stigmatizing terms (e.g. polysubstance abuse, morbid obesity etc)

Decision-making
Collaboration?

Differences of opinion
Explain, don't blame



Assessment & Plan

No surprises!
Diagnoses (ddx), tests not discussed in person

OK to keep some problem terms that are confusing to patients:

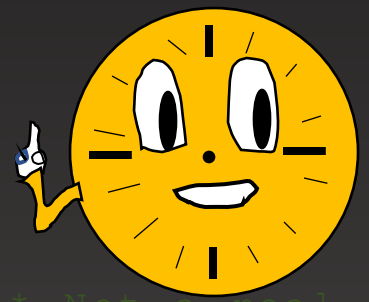
Heart failure
End Stage Liver Disease

But: You may need to explain the terms to your patients / educate them re: medical jargon

Current Documentation	Impact	Alternative
Patient was **adamant** that she leave **AMA** on 8/11 and was prescribed 2 weeks of linezolid.	Judgmental Labeling leading to future harm Paternalistic	Recognize autonomy Share decision making *We encouraged the patient to stay for inpatient treatment. She preferred to leave and was prescribed…*
Tobacco **abuse**	Terms may be imported from other parts of EHR. Check for accuracy/impact	Tobacco **use**
Depression: patient **failed** 3 different SSRIs.	The treatment failed the patient, not vice versa.	*The patient tried 3 different SSRIs but experienced side effects and did not feel they were helpful in controlling her symptoms.*
Morbid obesity: candidate for referral to bariatric surgery	Outdated or at the very least unnecessary	Is it necessary information? Use Severe / Class / or just list BMI
Sinusitis: the pt is **adamant** that they need antibiotics for this and **refuses** to listen.	Suggests the the patient is being unreasonable and challenging	*The patient is very concerned that they will not get better without antibiotics and feels strongly about receiving a Rx*

Verbally:

“There was a little something on your chest x-ray so we’re going to get a scan just to be sure.”



Note:

“Spiculated lung nodule and hx of smoking, concerning for lung cancer.”

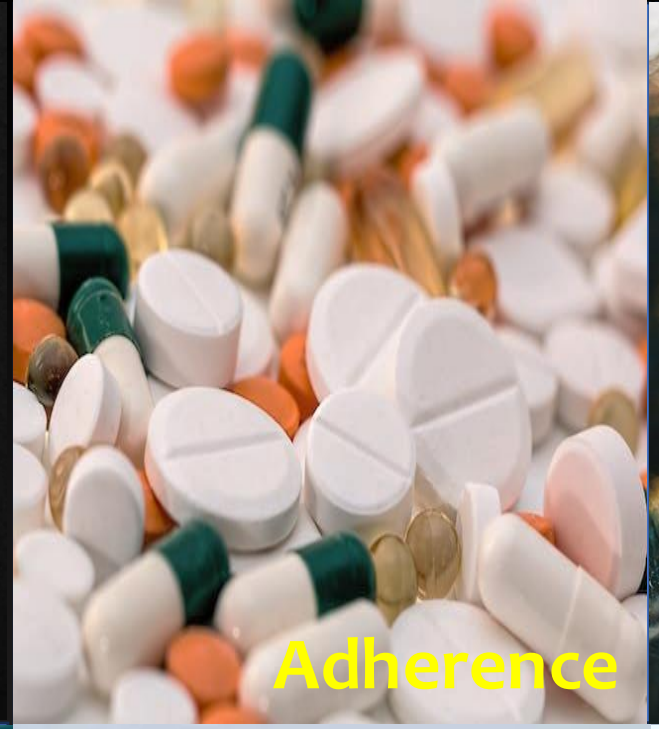
* Not a real chart note – based on a real case

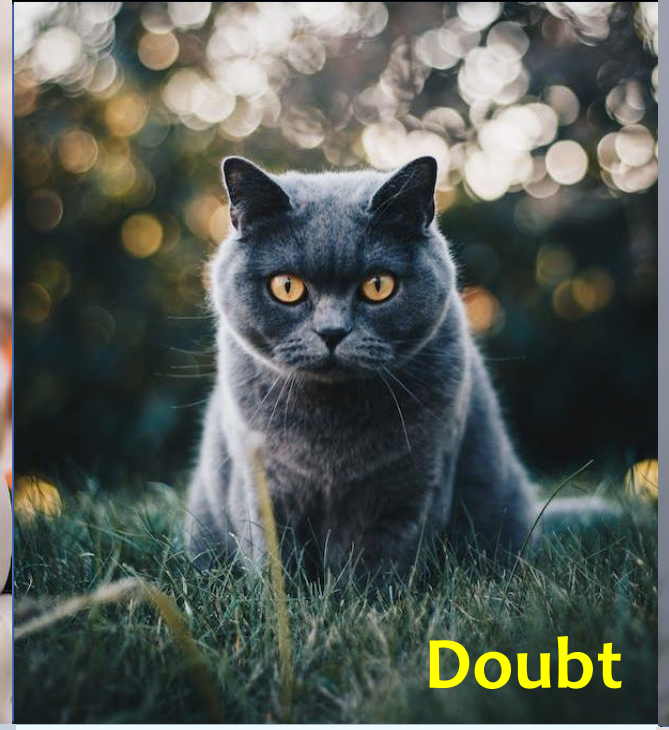
No surprises!

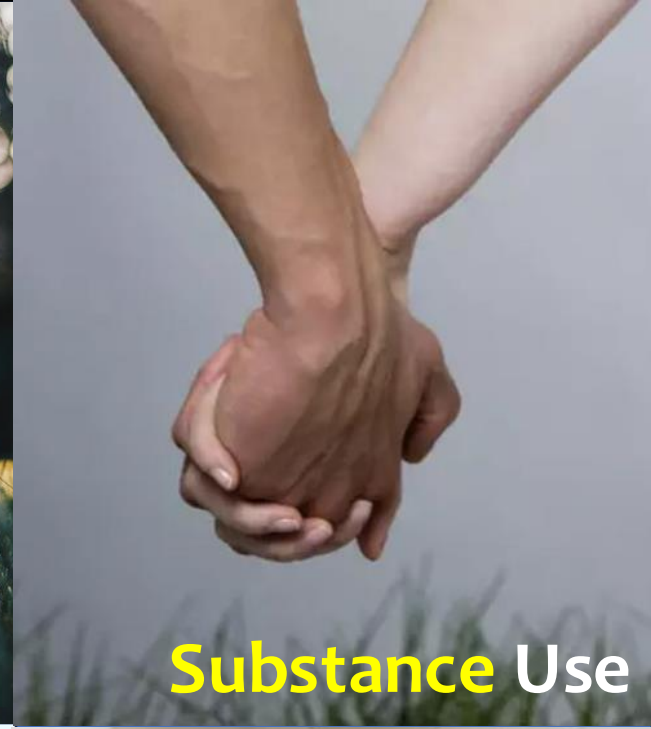
Don’t put new serious ddx in your note if you didn’t discuss in person

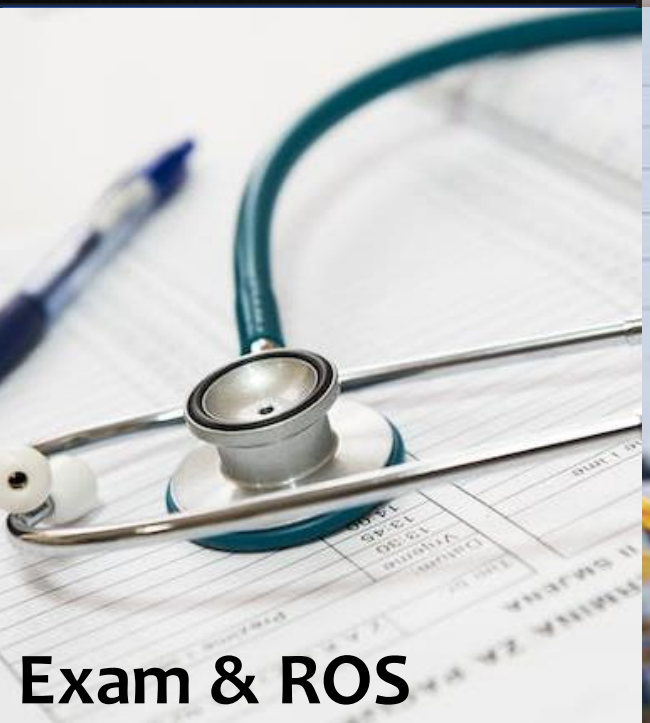
i.e *the note should reflect the conversation*

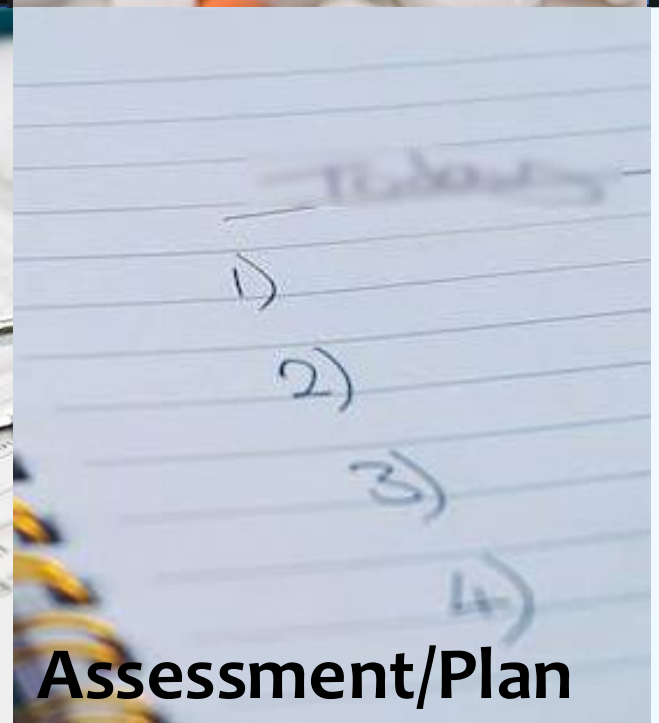
Labels

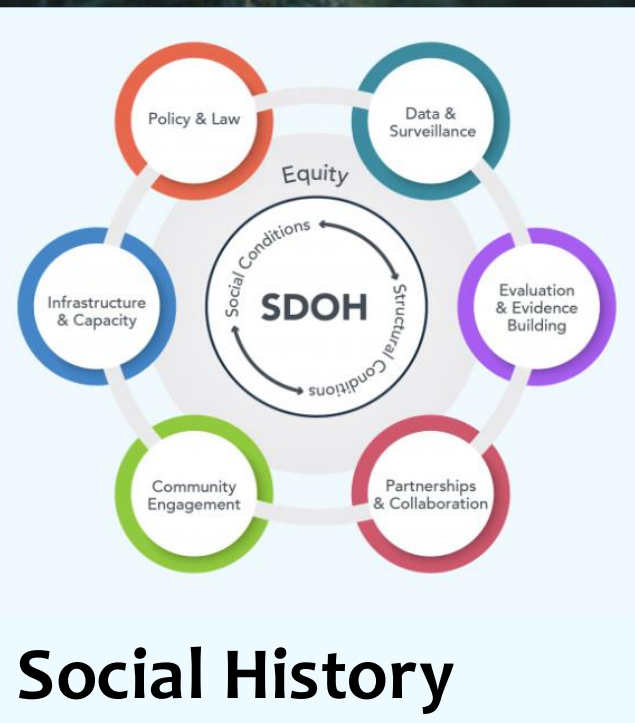

Adherence

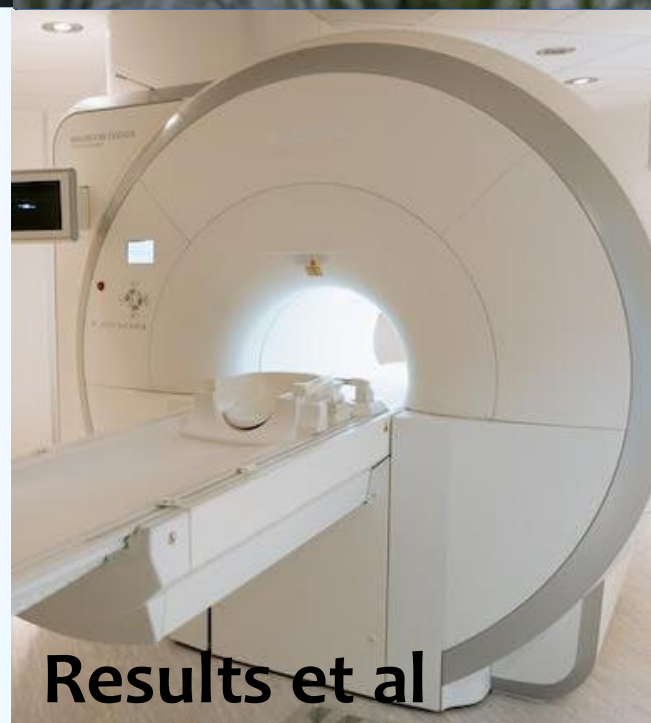

Doubt


Substance Use


Exam & ROS


Assessment/Plan

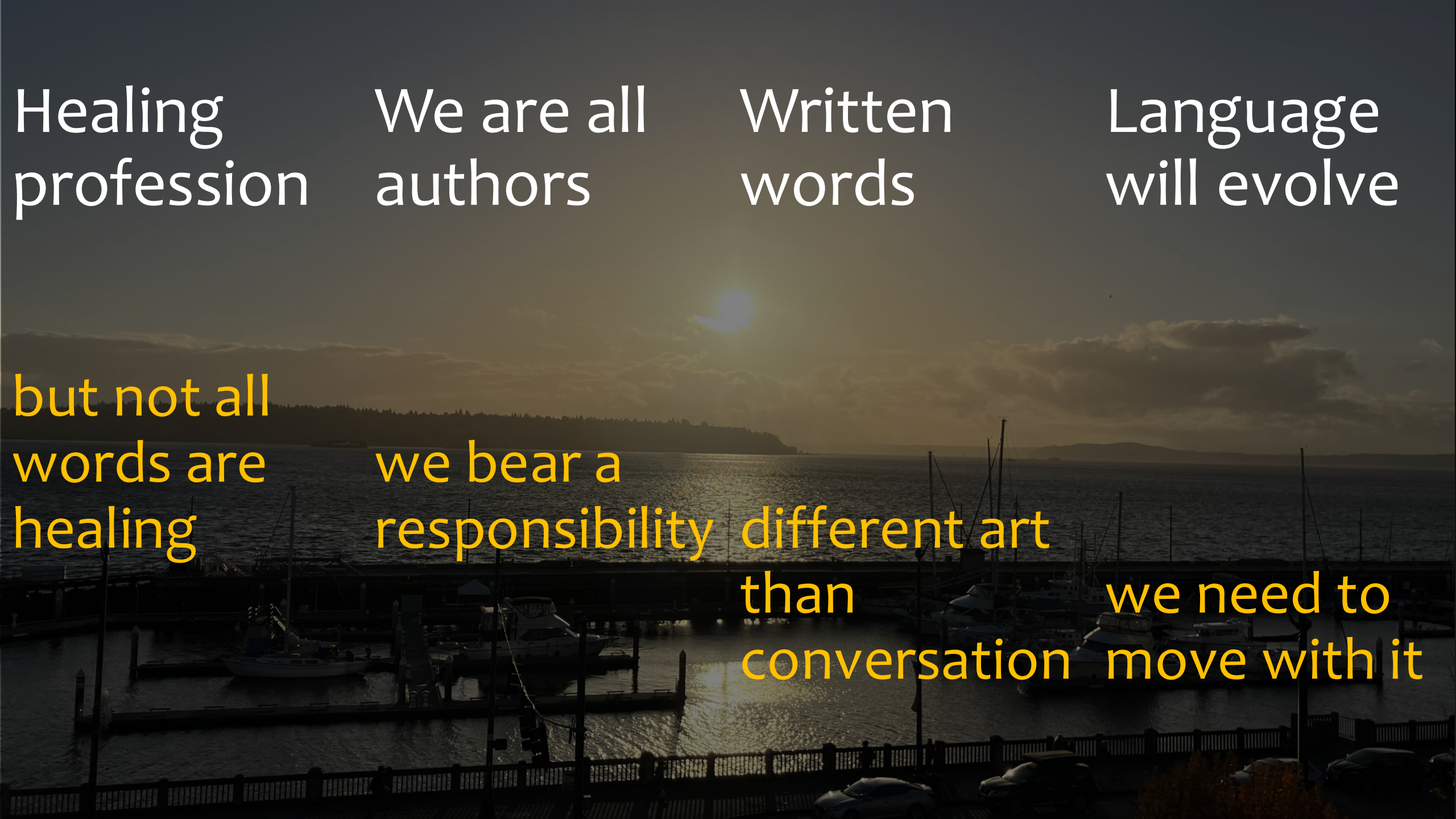

Policy & Law
Data & Surveillance
Equity
Social Conditions
SDOH
Structural Conditions
Infrastructure & Capacity
Evaluation & Evidence Building
Community Engagement
Partnerships & Collaboration
Social History


Results et al

Healing profession
but not all words are healing

Healing profession
We are all authors
but not all words are healing
we bear a responsibility

Healing profession
We are all authors
Written words
but not all words are healing
we bear a responsibility
different art than conversation


Healing profession
We are all authors
Written words
Language will evolve
but not all words are healing
we bear a responsibility
different art than conversation
we need to move with it

Goals

- Re-examine how we document
- Understand literature re: stigmatizing language
- Inspire you to change medical culture

Questions

Patient-Centered Notes

Sara Jackson, MD, FACP
Kim O'Connor MD, MACP
Russell Berg, MD PhD

WA ACP Nov 9, 2024

Teaching Peer Evaluation (TPE) for GIM faculty

Sara Jackson, MD, FACP

Russ Berg, MD, PhD

Kim O’Connor, MD, MACP