# Measuring Stigma Types & Quantitative Measurement

FIC Stigma Research Training Institute

June 8, 2021

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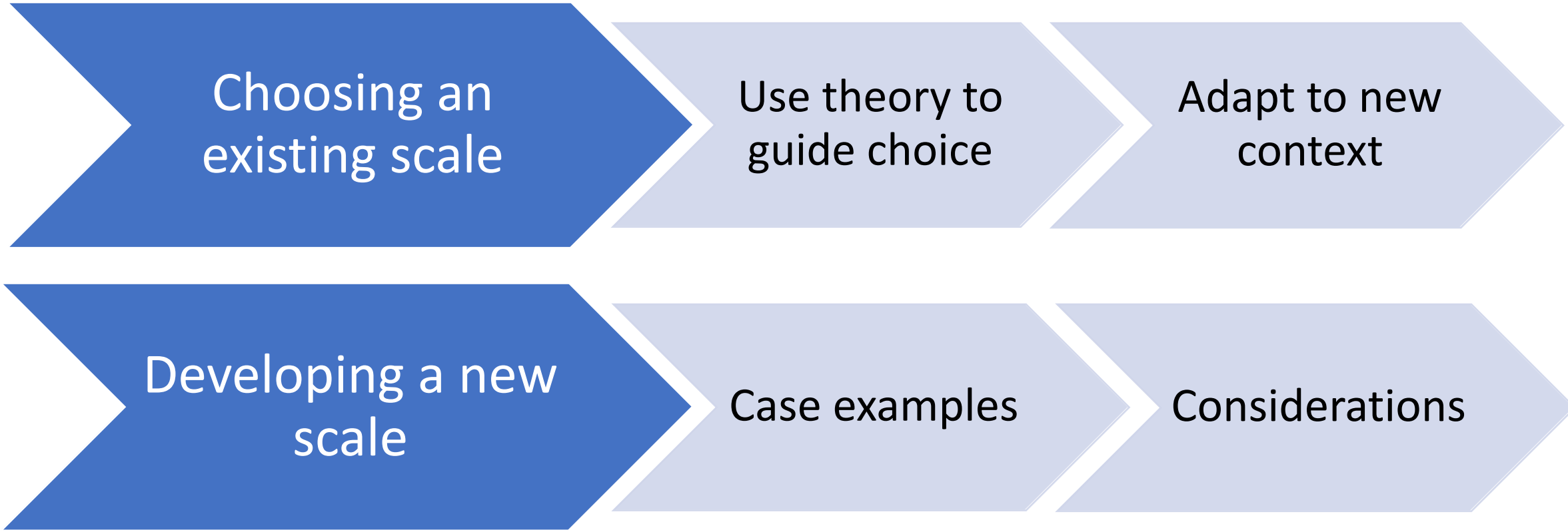
STIGMA

MEASURE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Use theory to guide choice
Adapt to new context
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Case examples
Considerations

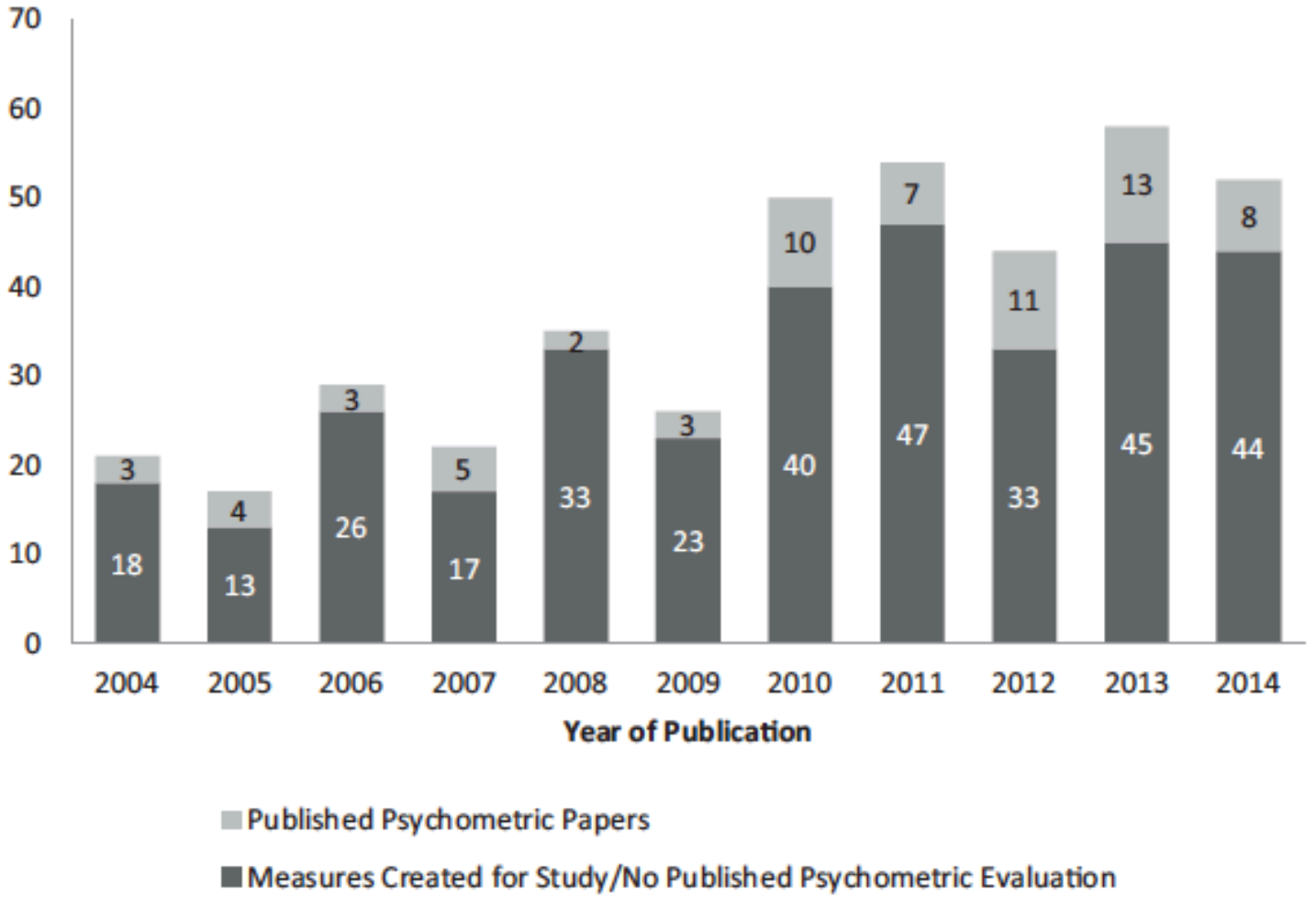
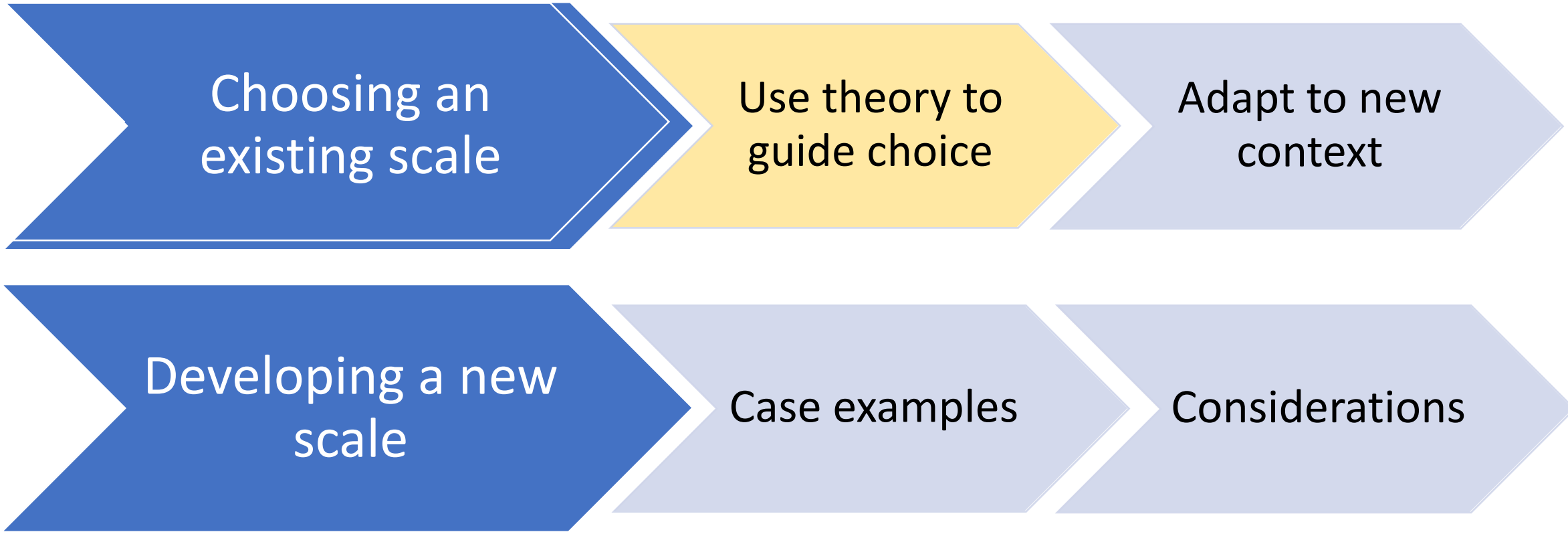



*Figure 2.* Mental health stigma measures identified in searches of EBSCO/PsycInfo databases, PubMed, and Web of Science, 2004–2014.

Fox, Earnshaw, Taverna, & Vogt (2018)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# Theory-driven considerations

1. Differentiate between stigma manifestations
2. Focus on sources of stigma
3. Account for intersectionality

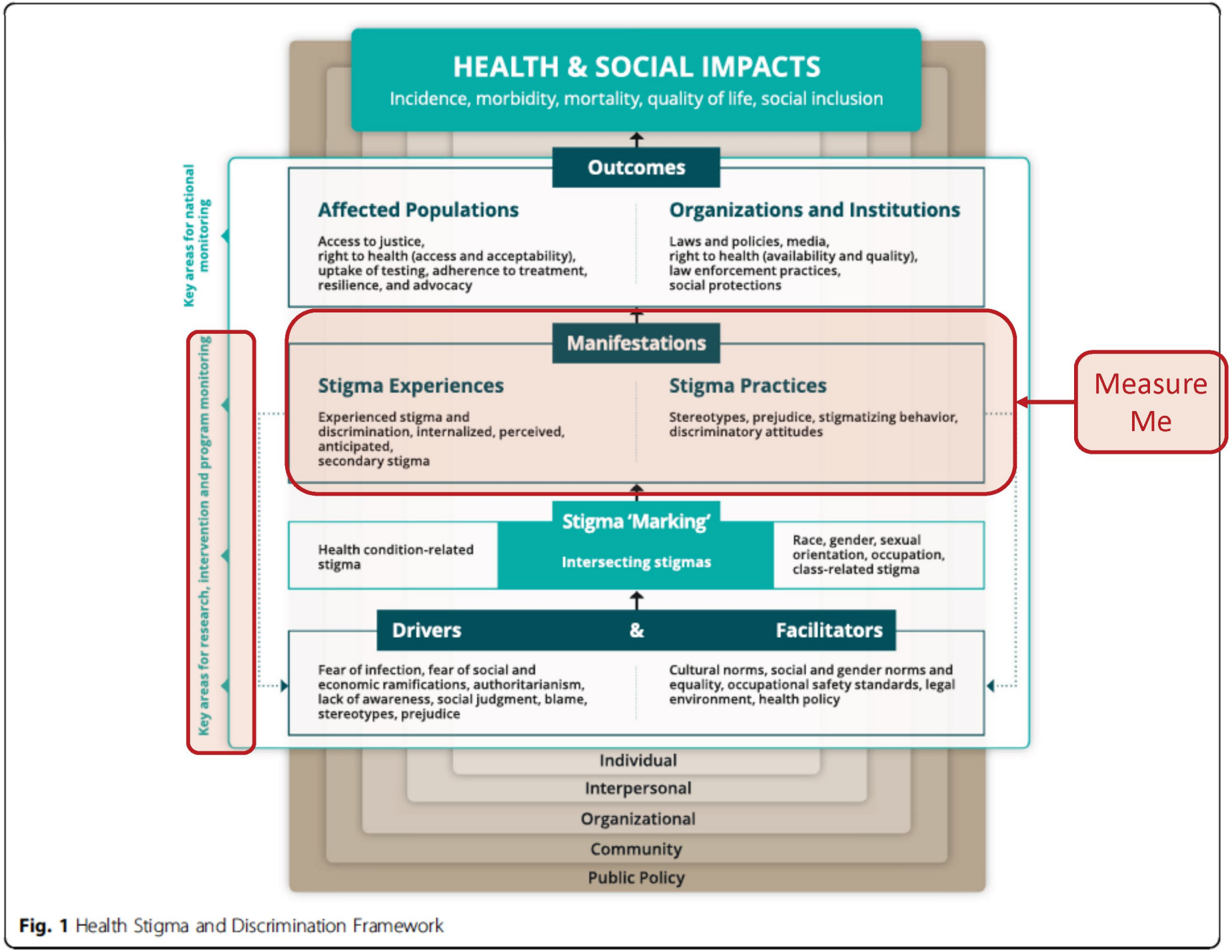


**Fig. 1** Health Stigma and Discrimination Framework

Stangl, Earnshaw, Logie, van Brakel, Simbayi, Barre & Dovidio (2019)

# Differentiate between stigma manifestations: Why?

- Stigma scales often mix questions for different stigma manifestations
- Problem because impossible to know which stigma manifestation(s):
  - Participants are experiencing more of
  - Is/are leading to bad health outcomes

Earnshaw & Chaudoir (2009); Fox, Earnshaw, Taverna, & Vogt (2018)

TABLE 3. *Perceptions of Stigma of HIV-Positive Women*

| | Often | | Sometimes | | Rarely | | Not at All | |
|---|---|---|---|---|---|---|---|---|
| | *n* | % | *n* | % | *n* | % | *n* | % |
| Felt blamed by others for illness | 6 | 7.3 | 18 | 22.0 | 3 | 3.6 | 55 | 67.1 |
| Felt ashamed of illness | 23 | 28.0 | 25 | 30.5 | 6 | 7.3 | 28 | 34.1 |
| Thought illness was punishment for things done in past | 19 | 23.2 | 22 | 26.8 | 3 | 3.7 | 38 | 46.3 |
| Feared I would lose my job if someone found out[a] | 16 | 28.1 | 8 | 14.0 | 1 | 1.8 | 32 | 56.1 |
| Felt compelled to change my residence because of illness | 14 | 17.1 | 6 | 7.3 | 5 | 6.1 | 57 | 69.5 |
| Avoided getting treatment because someone might find out | 6 | 7.3 | 6 | 7.3 | 3 | 3.7 | 67 | 81.7 |
| Feared people would hurt my family if they learned about my illness | 20 | 24.4 | 14 | 17.1 | 8 | 9.8 | 40 | 48.8 |
| Thought other people were uncomfortable being with me[b] | 19 | 23.5 | 26 | 32.1 | 10 | 12.3 | 26 | 32.1 |
| Felt people avoiding me because of my illness[c] | 16 | 20.3 | 13 | 16.5 | 9 | 11.4 | 41 | 51.9 |
| Feared I would lose my friends if they learned about my illness | 26 | 32.1 | 18 | 22.2 | 4 | 4.9 | 33 | 40.7 |
| Feared my family would reject me if they learned about my illness | 16 | 19.5 | 12 | 14.6 | 4 | 4.9 | 50 | 61.0 |
| Felt I wouldn't get as good health care if people learned about my illness | 9 | 11.0 | 10 | 12.2 | 3 | 3.7 | 60 | 73.2 |
| People who know I am HIV positive treat me with kid gloves[d] | 12 | 15.0 | 8 | 10.0 | 5 | 6.2 | 55 | 68.8 |

[a]Twenty-five participants responded "not applicable" (n = 57). [b]One response missing (*n* = 81). [c]Three responses missing (*n* = 79). [d]Two responses missing (*n* = 80).

Sowell et al., (1997)

# Differentiate between stigma manifestations: How?

1. Use different scales
2. Use one scale, with subscales, example:
    - Substance Use Stigma Mechanism Scale[1]
    - Subscales:
        - Enacted (experienced) stigma
        - Anticipated stigma
        - Internalized stigma

[1]Smith, Earnshaw, Copenhaver, & Cunningham (2016)

**Table 3**
Structural validity: five-factor SU-Stigma Mechanism model standardized estimates ($N = 178$).

| Construct | Source | Item | Factor loading | (SE) |
|---|---|---|---|---|
| Enacted | | | | |
| Factor 1 | FAM | 1. Family members have thought that I cannot be trusted | 0.914*** | (0.017) |
| | FAM | 2. Family members have looked down on me | 0.964*** | (0.011) |
| | FAM | 3. Family members have treated me differently | 0.972*** | (0.010) |
| Factor 2 | HCW | 4. Healthcare workers have not listened to my concerns | 0.884*** | (0.026) |
| | HCW | 5. Healthcare workers have thought that I'm pill shopping, or trying to con them into giving me prescription medications to get high or sell | 0.925*** | (0.019) |
| | HCW | 6. Healthcare workers have given me poor care | 0.958*** | (0.014) |
| Anticipated | | | | |
| Factor 3 | FAM | 7. Family members will think that I cannot be trusted | 0.951*** | (0.011) |
| | FAM | 8. Family members will look down on me | 0.950*** | (0.013) |
| | FAM | 9. Family members will treat me differently | 0.953*** | (0.012) |
| Factor 4 | HCW | 10. Healthcare workers will not listen to my concerns | 0.891*** | (0.020) |
| | HCW | 11. Healthcare workers will think that I'm pill shopping, or trying to con them into giving me prescription medications to get high or sell | 0.948*** | (0.016) |
| | HCW | 12. Healthcare workers will give me poor care | 0.913*** | (0.019) |
| Internalized | | | | |
| Factor 5 | SELF | 13. Having used alcohol/drugs makes me feel like I'm a bad person | 0.905*** | (0.017) |
| | SELF | 14. I feel I'm not as good as others because I use alcohol/drugs | 0.942*** | (0.011) |
| | SELF | 15. I feel ashamed of having used alcohol/drugs | 0.873*** | (0.020) |
| | SELF | 16. I think less of myself because I used alcohol/drugs | 0.911*** | (0.014) |
| | SELF | 17. Having used alcohol/drugs makes me feel unclean | 0.848*** | (0.023) |
| | SELF | 18. Having used alcohol/drugs is disgusting to me | 0.798*** | (0.029) |

FAM = 'Family members' stigma source, HCW = 'Healthcare Workers' stigma source. Factor loading is significant at 0.001 (***), 0.01(**), or 0.05(*) level (2-tailed).

# Focus on sources of stigma: Why?

- From whom?
  - Stigma scales often don’t ask about sources of stigma
  - Sources: family, friend, employer, healthcare provider, others

Earnshaw, Smith, & Copenhaver (2013)

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# Focus on sources of stigma: How?

- Use subscales to measure enacted + anticipated stigma from different sources

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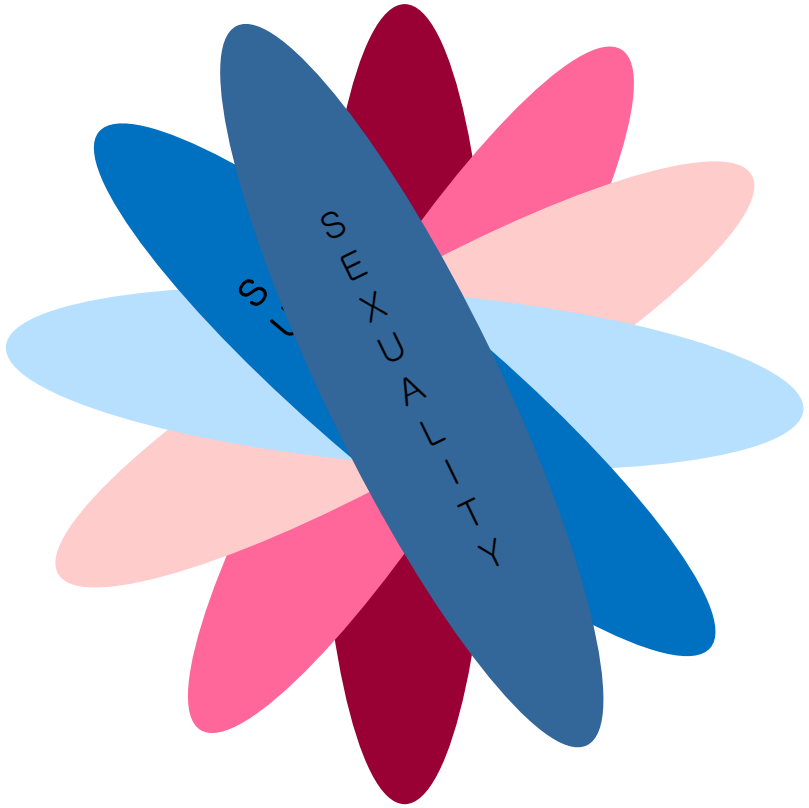
# Account for intersectionality: Why?




Collins (1990), Crenshaw (1991), hooks (1989) Rosenthal (2016);
**Slide Credit: Lisa Rosenthal, Ph.D.**

Turan et al. BMC Medicine (2019) 17:7
https://doi.org/10.1186/s12916-018-1246-9

BMC Medicine

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# Challenges and opportunities in examining and addressing intersectional stigma and health

Janet M. Turan[1*†], Melissa A. Elafros[2†], Carmen H. Logie[3,4], Swagata Banik[5], Bulent Turan[6], Kaylee B. Crockett[6], Bernice Pescosolido[7] and Sarah M. Murray[8]

# Account for intersectionality: How?

**Generalist**

- Measure experiences of stigma in general (participants can make attributions)
- E.g., Everyday Discrimination Scale[2], Intersectional Discrimination Index[3]

[1]Turan et al. (2019), [2]Stucky et al (2011), [3]Scheim & Bauer (2019); [4]Bogart et al (2013), [5]Rosenthal & Lobel (2018)

# Account for intersectionality: How?

Table 1
*Loadings From A Four-Factor Exploratory Factor Analysis With Oblique Oblimin Rotation and WLSMV Estimation In The Educational Diversity Project*

| | Factors | | | |
|---|---|---|---|---|
| Item | 1 | 2 | 3 | 4 |
| You are treated with less courtesy than others | **1.02** | −0.01 | −0.04 | −0.03 |
| You are treated with less respect than others | **0.81** | 0.03 | 0.08 | 0.09 |
| You receive poorer service in restaurants or in stores | **0.45** | 0.23 | 0.13 | 0.04 |
| People act like you are not as smart | 0.01 | **0.86** | 0.00 | 0.02 |
| Act as if they are afraid of you | 0.01 | −0.04 | **0.76** | 0.04 |
| People act as if they think you are dishonest | 0.00 | 0.02 | **0.95** | −0.02 |
| People act like they think they are better than you | 0.28 | 0.40 | 0.18 | 0.05 |
| You are called names or insulted | −0.06 | 0.09 | 0.03 | **0.83** |
| You are threatened or harassed | 0.06 | −0.07 | −0.03 | **0.86** |

*Note.* Factor loadings in bold represent locally dependent subsets of items (i.e., method factors) resulting from context effects (e.g., item location, item content, and item wording). Factor intercorrelations ranged from $r = .41$ to .71.

# Account for intersectionality: How?

| | |
|---|---|
| Generalist | • Measure experiences of stigma in general, participants make attributions<br>• E.g., Everyday Discrimination Scale[2] |
| Parallel | • Measure experiences of stigma in relation to several attributions<br>• E.g., Multiple Discrimination Scale[4] |

[1]Turan et al. (2019), [2]Stucky et al (2011), [3]Scheim & Bauer (2019); [4]Bogart et al (2013), [5]Rosenthal & Lobel (2018)

# Parallel: Multiple Discrimination Scale

**Table 2** Multiple Discrimination Scale (MDS) item endorsement, descriptive statistics, and reliability coefficients for 181 Black and 167 Latino MSM

| | Blacks | | | Latinos | | |
|---|---|---|---|---|---|---|
| | MDS-Race | MDS-HIV | MDS-Gay | MDS-Race | MDS-HIV | MDS-Gay |
| In past year: | | | | | | |
| Treated with hostility/coldness by strangers | 28 % | 15 % | 28 % | 22 % | 16 % | 24 % |
| Ignored/excluded/avoided by people close to you | 18 % | 17 % | 19 % | 14 % | 22 % | 23 % |
| Rejected by a potential sexual/romantic partner | 15 % | 29 % | 13 % | 8 % | 25 % | 7 % |
| Someone acted as if you could not be trusted | 36 % | 15 % | 16 % | 19 % | 15 % | 17 % |
| Denied a place to live/lost a place to live | 10 % | 9 % | 9 % | 6 % | 6 % | 5 % |
| Treated poorly/made to feel inferior when receiving health care | 10 % | 8 % | 6 % | 7 % | 10 % | 9 % |
| Denied a job/lost a job | 7 % | 3 % | 6 % | 14 % | 8 % | 8 % |
| Someone insulted/made fun of you | 17 % | 18 % | 34 % | 27 % | 15 % | 32 % |
| Personal property damaged/stolen | 7 % | 6 % | 11 % | 7 % | 6 % | 10 % |
| Physically assaulted/beaten up | 6 % | 5 % | 6 % | 6 % | 3 % | 4 % |
| Sum (M, SD) | 1.5 (2.2) | 1.2 (2.1) | 1.5 (2.2) | 1.3 (2.2) | 1.2 (2.2) | 1.5 (2.3) |
| Range | 0–10 | 0–10 | 0–10 | 0–10 | 0–10 | 0–10 |

# Account for intersectionality: How?

| | |
|---|---|
| Generalist | • Measure experiences of stigma in general, participants make attributions<br>• E.g., Everyday Discrimination Scale[2] |
| Parallel | • Measure experiences of stigma in relation to several attributions<br>• E.g., Multiple Discrimination Scale[3] |
| Tailored | • Measure unique experiences of stigma at the intersection of attributions<br>• E.g., Gendered Racism Scale[4] |

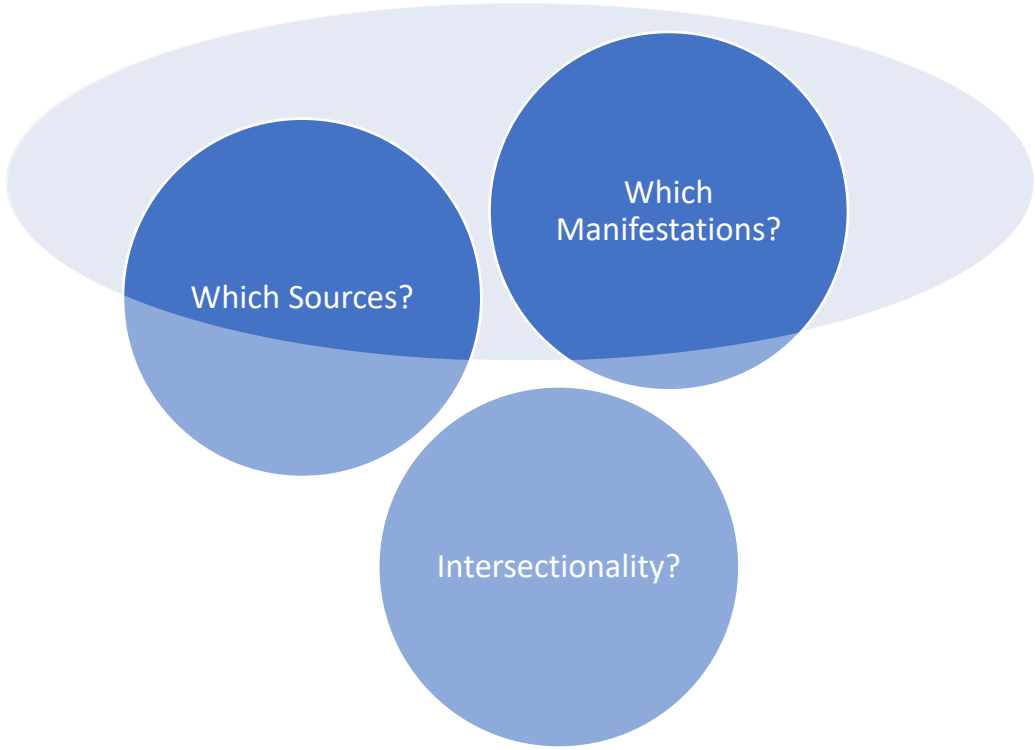
[1]Turan et al. (2019), [2]Stucky et al (2011), [3]Bogart et al (2013), [4]Rosenthal & Lobel (2018)

# Tailored: Gendered Racism Scale

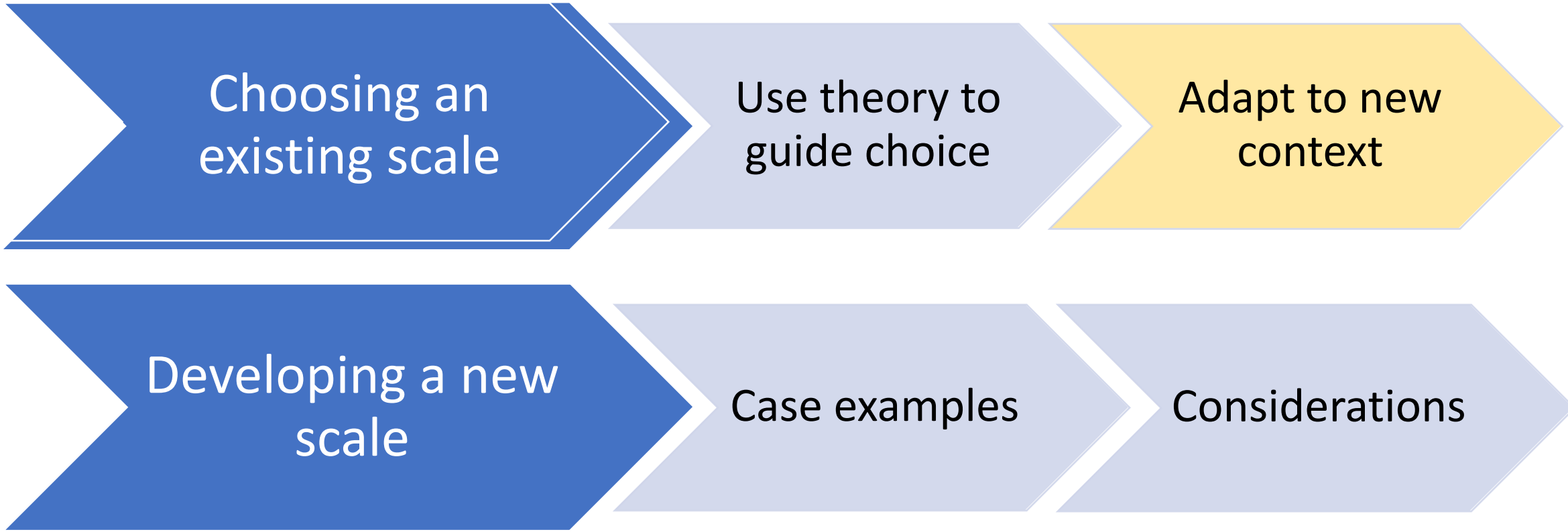
- 15 Likert-type items, anchors reflect frequency [1 (never) – 4 (all the time)]

- Examples
  - “How often do you feel that people make negative assumptions about how many sexual partners you have, based on being a **woman** of your **racial/ethnic background**?”
  - “During your most recent pregnancy, how worried were you that people were making assumptions about whether the father of the child would play a role in raising the child, based on being a **women** of your **racial/ethnic background**?”

Decisions for you to make based on the aims of your study:




Your Measure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# Cultural Adaptation of Measures- Why do it?

- Adequacy of measure in one culture does not guarantee reliability or validity in another

- Not using culturally sensitive measures may compromise reliability, validity and generalizability of study results

# Instrument Selection

- Prerequisite to yielding valid measure of variable across cultures
  - 1) Instruments already validated cross-culturally– both reliability and validity
  - 2) Instrument has sound psychometric properties in one culture but not tested in other cultures
  - 3) Instrument has high face validity-- requires psychometric testing in country of origin

# Overview

- Cultural Adaptation of Measures
  - Five Types of Equivalence
    - **Content**-- Content of each item of the instrument is relevant to the phenomena of each culture
    - **Semantic**--Meaning of each item same in each culture after translation
    - **Technical**--Method of assessment comparable with respect to data that it yields
    - **Criterion**--Instrument's relationship to previously established and independent criteria for the same phenomena
    - **Conceptual**--Instrument measuring same theoretical construct in each culture

# Content Equivalence

- Show that test items sample the universe of possible items related to the concept of interest
  - i.e., shows “Content Validity”

- If content validity has been established in the original culture:
  - Content of each item of the instrument is relevant to the phenomena of each culture

# Content Equivalence

- Does the phenomenon (item) occur in and is noticed by members of the culture?
  - Content team (experts of the phenomenon from each culture) rates each item as: 1) relevant, 2) irrelevant, or 3) questionably relevant for each new culture
    - Can eliminate items rated as irrelevant (one member) or questionably relevant (two members)

# Content Equivalence

- If any items eliminated– reliability of modified instrument must be reexamined
  - If eliminated items not substituted:
    - » Advantage: can apply single instrument across cultures
    - » Disadvantage: if too many items dropped, internal consistency may be too low

# Content Equivalence

- May need to add new items to:
  - 1) achieve content equivalence and
  - 2) restore internal consistency
- Find equivalent content areas in each culture on an item-by-item basis
  - yields two different instruments equivalent in content

- What if you want to add culturally-salient items?
  - Disadvantage: no longer directly comparable to one another cross-culturally
  - One solution: Can add new “cultural” items at the end of the questionnaire

# Content Equivalence (Example)

- Section A:  Devaluation- Discrimination
- "I am now going to read you some statements about how most other people in your community may think about or treat people with mental illness."

- Questions re: Patient:
- 1) Most people in your community think that a person with a serious mental illness is dangerous and unpredictable.
- 2) Most people in your community feel that having a mental illness is worse than being addicted to drugs
- 3) Most people in your community would accept a person who once had a serious mental illness as a close friend.

# Content Equivalence (Example)

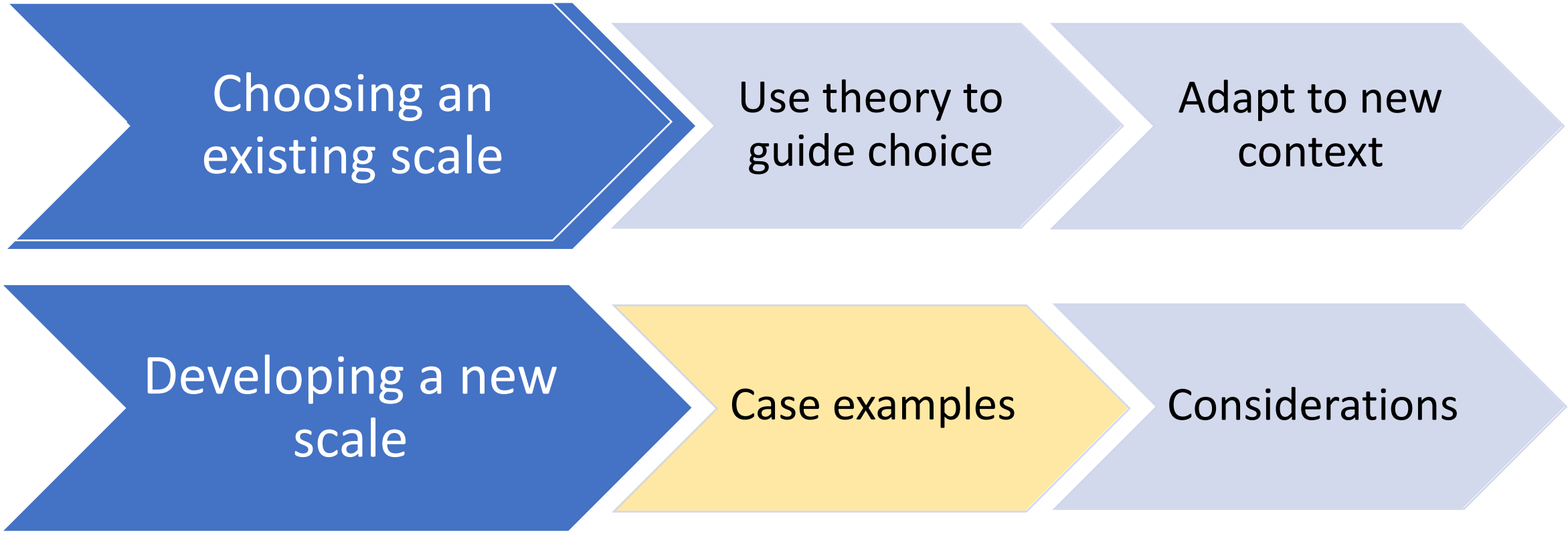
- 4) Most people in your community look down on someone who once was a patient in a mental hospital
- 5) Most employers will hire a person who once had a serious mental illness if he or she is qualified for the job
- 6) Most people in your community think less of a person who has been a patient in a mental hospital
- 7) Most people in your community feel that entering psychiatric treatment is a sign of personal failure
- 8) Most people would not marry a man who has been treated for a serious mental disorder
- ***9) Most people in your community think that having mental illness would cause a person to lose face (new Culture-specific item)***

# Content Equivalence

- Original:
- 6) Most people in your community think less of a person who has been a patient in a mental hospital
  - "Think less of a person" too close to "look down on"
  - Chinese- Replaced with phrase "is incomplete (or not a full person)"- analogous concept that certain persons who are ill or are not fully adult yet "are not whole"
- 7) Most people in your community feel that entering psychiatric treatment is a sign of personal failure
  - "sign of personal failure" difficult to translate accurately
  - Chinese- replaced with phrase "is a sign of personal disgrace".

**Item-Total Statistics**

| | Scale Mean if Item Deleted | Scale Variance if Item Deleted | Corrected Item-Total Correlation | Squared Multiple Correlation | Cronbach's Alpha if Item Deleted |
|---|---|---|---|---|---|
| Patient Devaluation Discrimination re: patient Q1 Dangerous | 20.9130 | 8.356 | .513 | .478 | .672 |
| Patient Devaluation Discrimination re: patient Q2 Addicted to Drugs | 21.4565 | 8.862 | .221 | .511 | .733 |
| Patient Devaluation Discrimination Q3-Reverse scored | 21.0652 | 8.393 | .459 | .399 | .681 |
| Patient Devaluation Discrimination re: patient Q4 Look down on | 21.0000 | 8.864 | .357 | .433 | .700 |
| Patient Devaluation Discrimination P5-Reverse scored | 21.1522 | 10.374 | -.056 | .351 | .769 |
| Patient Devaluation Discrimination re: patient Q6 Not complete person | 20.8913 | 8.954 | .433 | .480 | .689 |
| Patient Devaluation Discrimination re: patient Q7 Not proud of | 20.9565 | 7.953 | .625 | .547 | .651 |
| Patient Devaluation Discrimination re: patient Q8 Not married | 20.7174 | 7.132 | .675 | .547 | .629 |
| Patient Devaluation Discrimination re: patient Q9 Lose face | 20.7174 | 8.905 | .447 | .531 | .687 |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# Inadvertent Effects on Measurement

- Advantages to prior approach:
  - Enhancing scale reliability
  - Enhancing generalizability
  - Enhancing comparability across contexts

- Approaches inadvertently neutralize/diminish culture's importance

# Measuring Culturally- Salient Aspects of Stigma

Review of Culture-Salient elements within stigma measures (*Yang, Thornicroft, Alvarado, Vega, Link, 2014- Int. J of Epidemiology)*

- Literature Review (1990- 2012) of MI stigma in non-Western settings
- 5,292 abstracts-- 196 articles
- 77% of studies used translations of Western (U.S., U.K.) developed measures
- **<u>**ONLY 2%**</u> of studies used quantitative stigma measures developed within a non-Western European cultural group**
- 16.8% of studies used qualitative methods; demonstrated culturally-salient stigma processes

*How can we address this glaring gap in understanding and measuring how stigma manifests in different cultural settings?*

# Operationalizing Culture

- Engage in what 'matter most' is to certify an individual as having full standing within a cultural group.
- **These activities can be empirically identified and operationalized.
- Advanced a new theory for stigma

- Yang et al (2014) Recent advances in cross-cultural measurement in psychiatric epidemiology: utilizing 'what matters most' to identify culture-specific aspects of stigma. *International J of Epi*

- NIMH K-award (2006-2010)
  - Chinese immigrants with psychosis in NYC
- Mental illness stigma acts in **culture-specific ways** to ***impair*** an actor's capacity to take part in the **core, everyday engagements** that certify one as a fully viable (or "fully moral") member of a local community *(Yang, Kleinman et al, 2007, Soc Sci and Med)*

**Proposal:**

Stigma will coalesce most forcefully around a Motswana woman's capacity to:

- *Bear and raise* **children**
- *Respect* **her husband**
- *Be the foundation* **for her home**

"With women, ***if you don't have children you are not really a woman***" (Woman– Known HIV status)

**Formulation:**

**-Perceived Promiscuity Violates 'Womanhood' to Intensify HIV Stigma**

"They (other people) ***think that someone living with HIV was very sexually active and promiscuous*** even though they may be wrong, they don't think of other ways of HIV transmission. Batswana mostly think that ***if you have HIV then it means you had unprotected sex with multiple partners-*** (Woman– Known HIV status)

# III. Fulfilling Capabilities as a "Good Mother" Can Mitigate Stigma

**Formulation:**

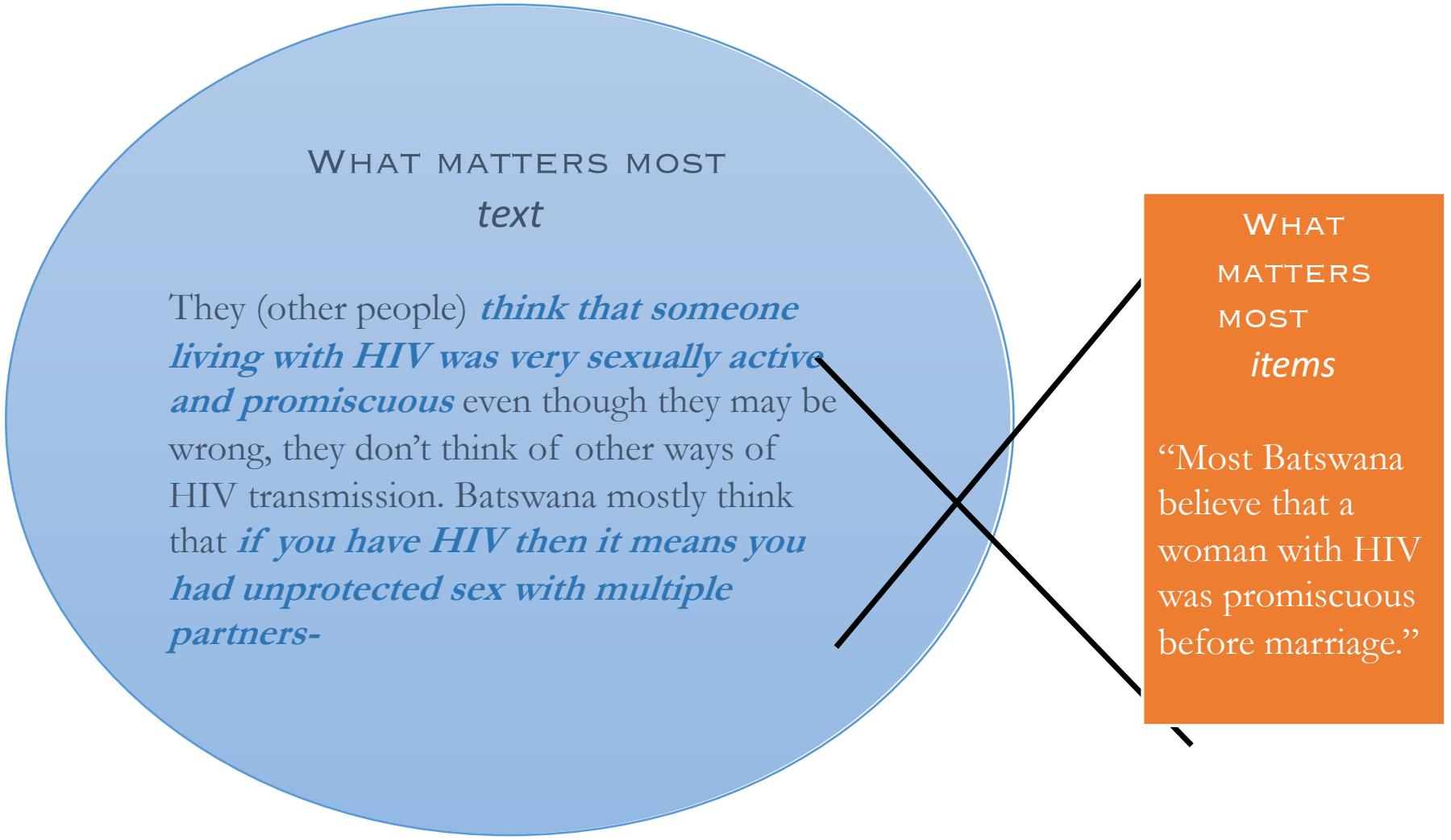
**If HIV occurs without affecting capabilities by which 'personhood' is judged, stigma may not affect one's claim to 'womanhood'.**

"***The woman who has HIV will be treated better, having children*** (compared to a childless person without HIV)…***Because that person has dignity***"- (Man– Unknown HIV status)

# Study 2: Operationalizing 'What Matters Most'

*(Yang*, Ho-Foster*, et al, 2020, AIDS and Behavior)*

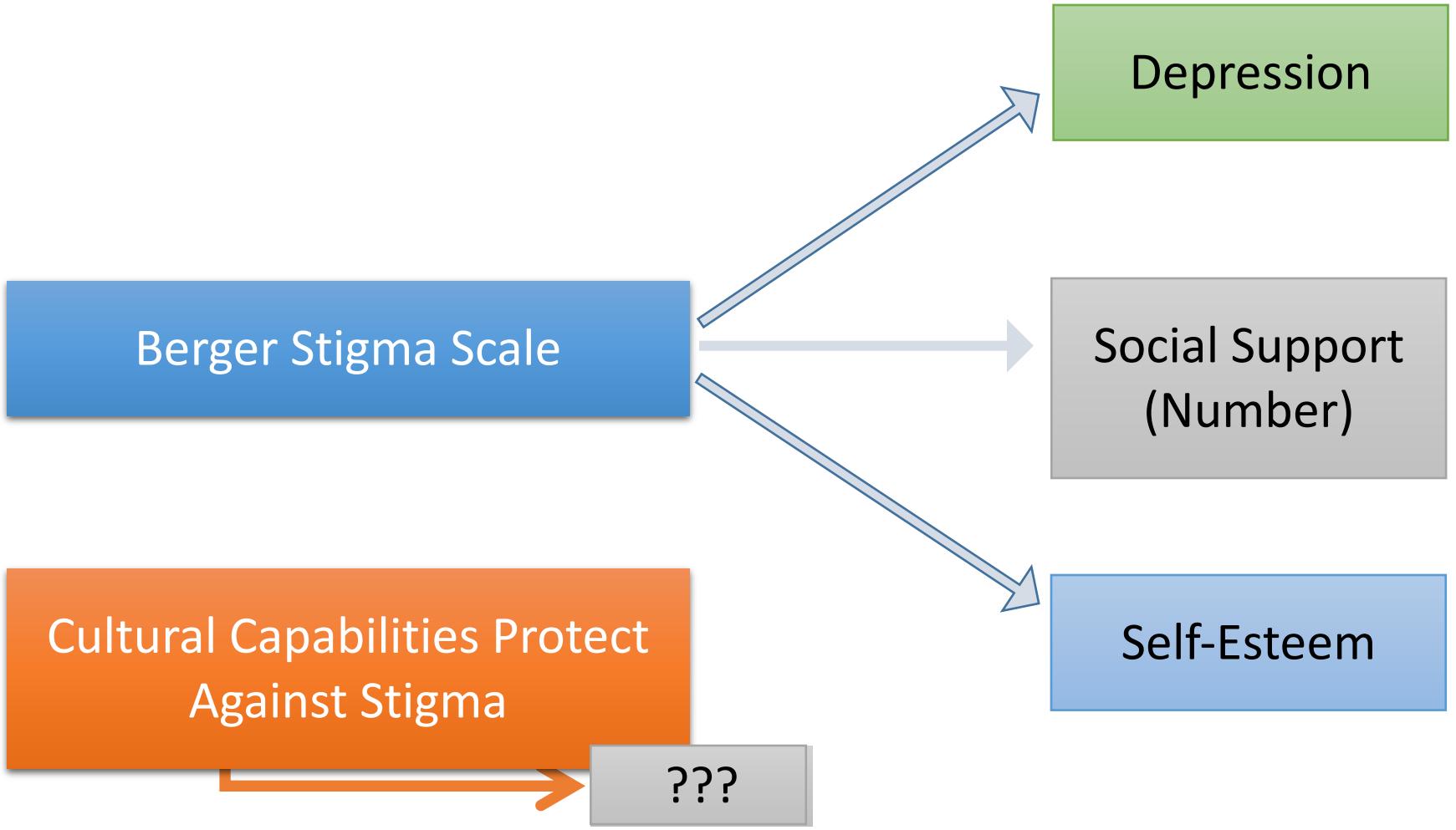
# What Matters Most

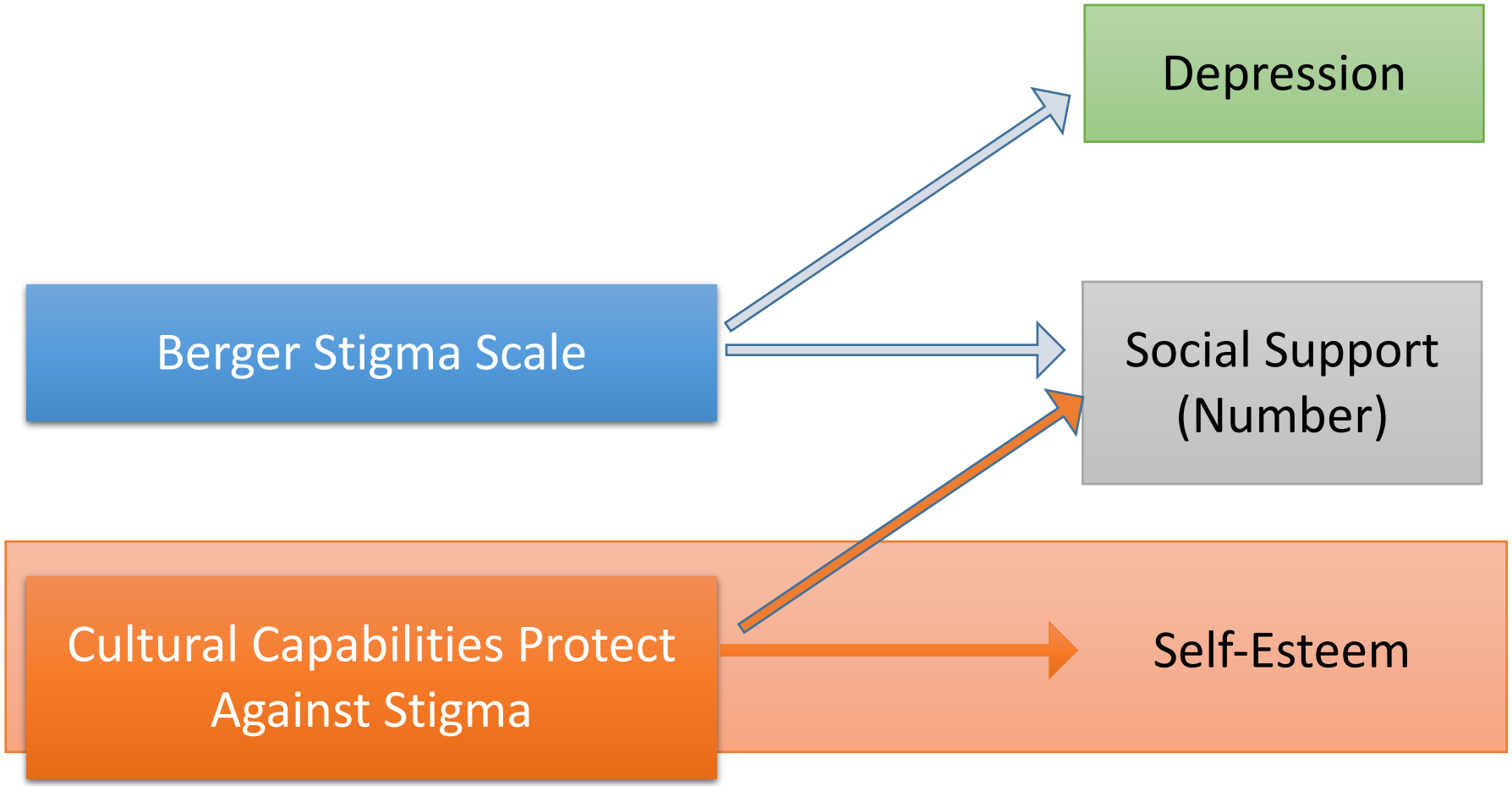


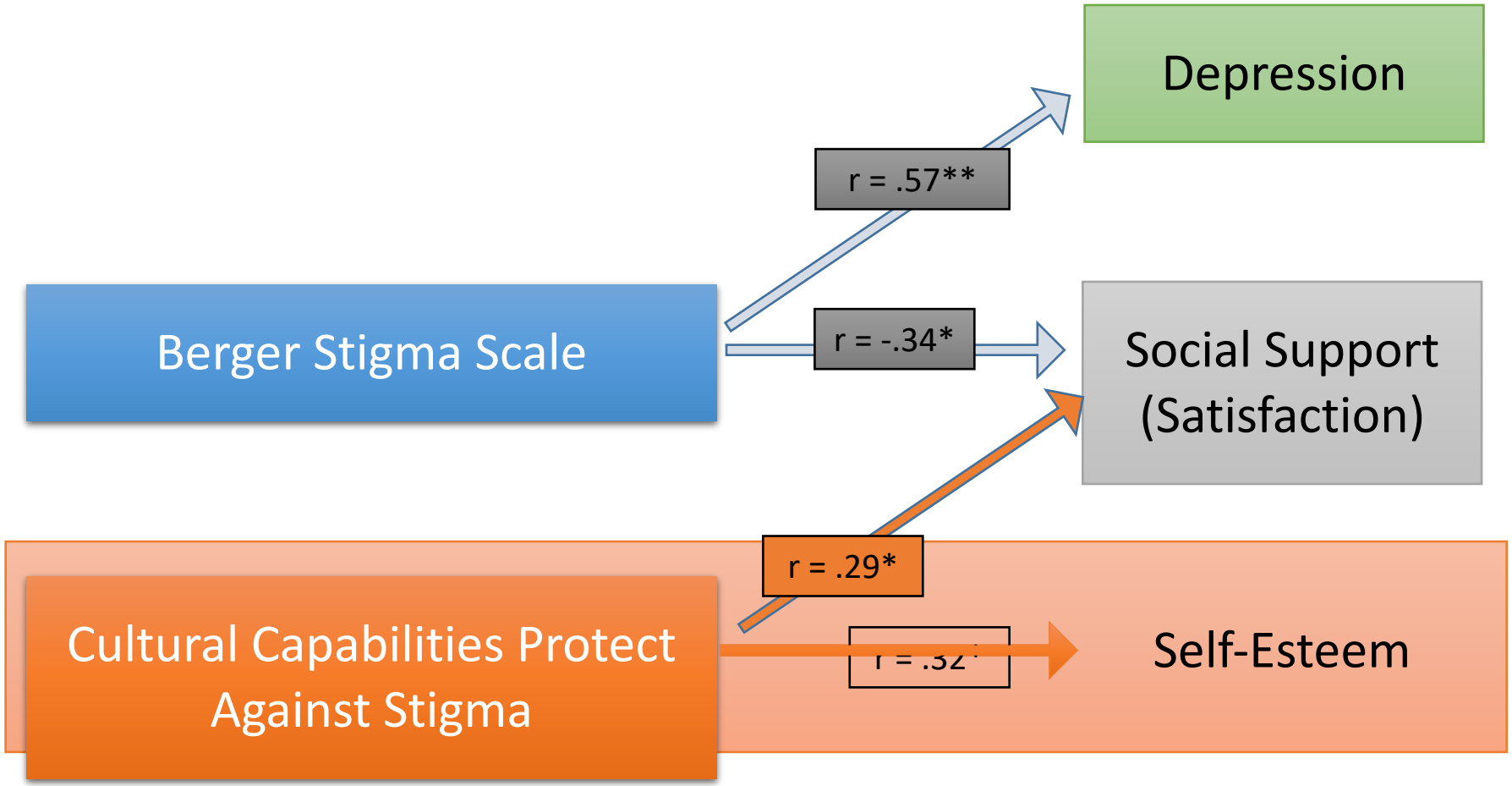
# "What Matters Most" For women

## (*N*=98 Individuals identified with HIV)

| Cultural Factors Shape Stigma |
| --- |
| Most Batswana believe that a woman with HIV is unable to take care of her children. |
| Most Batswana believe that a woman with HIV does not have the ability to properly take care of her home. |
| Most Batswana believe that a woman with HIV is not a reliable foundation for her family. |
| Most Batswana believe that a woman with HIV was promiscuous before marriage. |
| **Culture Capabilities Protect Against Stigma** |
| Most Batswana will not look down on a woman with HIV who is loyal to her husband. |
| Most Batswana will not look down on a woman with HIV who has children. |
| Most Batswana respect a woman with HIV who raises successful children |
| Most Batswana will respect a woman with HIV who properly cares for her husband. |


Depression
Berger Stigma Scale
Social Support (Number)
Cultural Capabilities Protect Against Stigma
Self-Esteem
???


Depression
Berger Stigma Scale
Social Support (Number)
Cultural Capabilities Protect Against Stigma
Self-Esteem


Depression
r = .57**
Berger Stigma Scale
r = -.34*
Social Support
(Satisfaction)
r = .29*
Cultural Capabilities Protect
Against Stigma
Self-Esteem

# Comparison Across Cultures

- Comparing culturally-salient scales across cultural groups with scales consisting of different items is more complex
- Could use both standardized and culturally-salient measures, thus enabling direct comparison + assessment of local forms
- Comparison of culturally-salient forms might be evaluated for commonalities and variations across cultures, thus promoting further understanding of a construct's 'universal' aspects.
- Use of culturally-valid instruments might promote interventions that are effective within local contexts

# Case Example 2: Chronic Illness Anticipated Stigma Scale

"The consequences of stigma are remarkably similar in different health conditions, cultures and public health programmes"

"Development of generic instruments to assess health-related stigma may be possible"

van Brakel (2006)

J Behav Med (2013) 36:270–282
DOI 10.1007/s10865-012-9422-4

# Development and psychometric evaluation of the Chronic Illness Anticipated Stigma Scale

Valerie A. Earnshaw · Diane M. Quinn · Seth C. Kalichman · Crystal L. Park

Received: August 3, 2011 / Accepted: March 31, 2012 / Published online: April 13, 2012


**Abstract** The Chronic Illness Anticipated Stigma Scale (CIASS) was developed to measure anticipated stigma (i.e., expectations of prejudice, stereotyping, and discrimination) among people living with chronic illnesses. The CIASS is a 12-item scale with three subscales differentiating among sources of anticipated stigma, including friends and family members, work colleagues, and healthcare workers. Results support the reliability, validity, and generalizability of the CIASS in two samples of people living with chronic illnesses. The CIASS was correlated with other stigma-

## Introduction

> I feel so embarrassed by this–this thing… Who would want a wife like this? How can I go out and not feel unable to look people in the eyes and tell them the truth? Once I do, who would want to develop a friendship, I mean a close one? (Milo quoted by Kleinman, 1988; p. 163)

**Table 2** Structural validity of the CIASS: factor loadings from confirmatory factor analysis

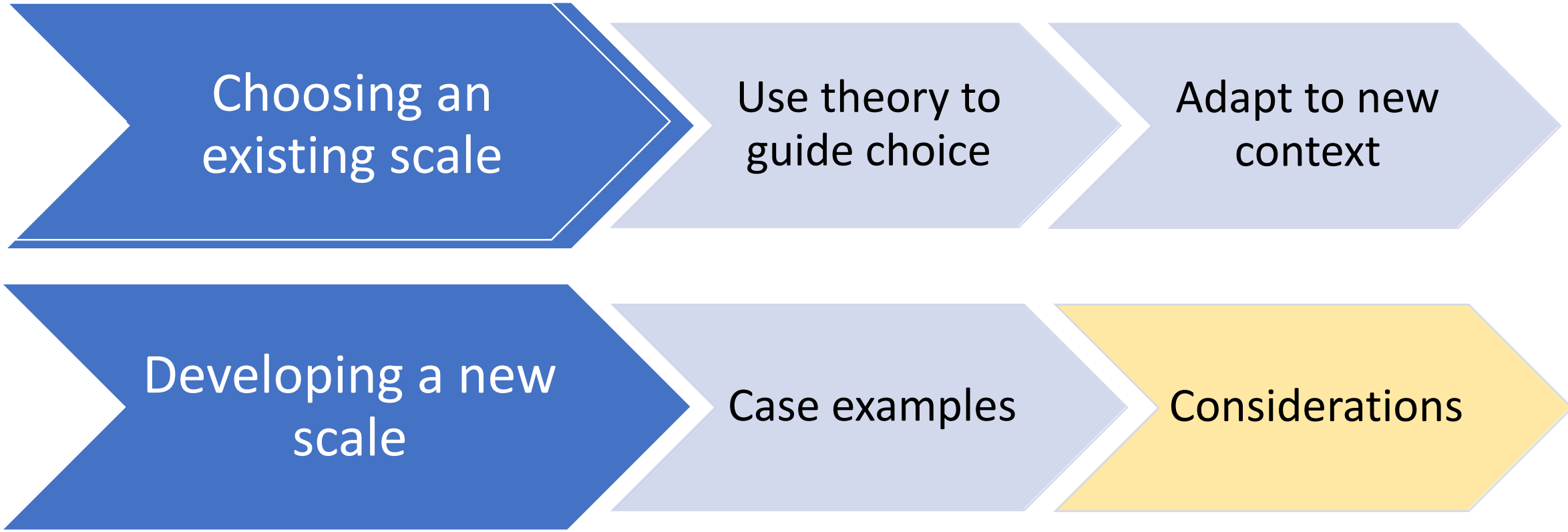
| Item |
|---|
| Friends and family |
| A friend or family member will think that your illness is your fault |
| A friend or family member will not think as highly of you |
| A friend or family member will blame you for not getting better |
| A friend or family member will be angry with you |
| Work colleagues |
| Someone at work will think that you cannot fulfill your work responsibilities |
| Your employer will assign a challenging project to someone else |
| Someone at work will discriminate against you |
| Your employer will not promote you |
| Healthcare workers |
| A healthcare worker will blame you for not getting better |
| A healthcare worker will be frustrated with you |
| A healthcare worker will give you poor care |
| A healthcare worker will think that you are a bad patient |

** $p \leq .001$

[1]Earnshaw, Quinn, Kalichman, Park (2013)

# Case Example 2: Chronic Illness Contexts

- Autism
- Cancer
- Chronic Neurological and Pulmonary Diseases
- Diabetes
- Multiple Sclerosis
- Obesity
- Parkinson's Disease
- Pernicious Anaemia
- Rheumatic Diseases
- As well as samples with various chronic illnesses


Choosing an existing scale
Use theory to guide choice
Adapt to new context
Developing a new scale
Case examples
Considerations

# Team


Stigma Expert
Context Expert
Community Stakeholders
Psychometrician

# Resources

- Courses/Trainings
  - Psychometrics
  - Scale Development
  - Item Response Theory
- Books + articles
  - DeVellis RF. Scale development: Theory and applications. Sage publications; 2016.
  - Articles in resource page of Moodle