

COMMUNITY AND CANCER SCIENCE NETWORK

Collaborative Workgroups to Address Cancer Disparities

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DISCLOSURES/FUNDING:

Staci Young, PhD

Nothing to disclose

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OPENING QUESTION & ACTIVITY:

WHAT IS COLLABORATION?

WHAT HINDERS COLLABORATION?

WHAT DRIVES COLLABORATION?



OVER THE NEXT HALF HOUR:

- WHAT IS THE CCSN
- WHAT ARE THE COLLABORATIVE WORK GROUPS
- HOW TEAMS COME TOGETHER AND HOW THE PROCESS WORKS
- HOW DOES IT INFLUENCE RELATIONSHIPS AND PROGRESS FORWARD



COMMUNITY AND CANCER SCIENCE NETWORK

- A TRANSDISCIPLINARY NETWORK FOCUSED ON ADDRESSING STATEWIDE CANCER DISPARITIES
- PRINCIPLES: DEEP EQUITY, SYSTEMS-CHANGE, AND THE INTEGRATION OF BIOLOGY TO POLICY



COLLABORATIVE WORK GROUPS



eliminating racism
empowering women
ywca
Southeast Wisconsin

Process:

Observe and understand

Discover and digest

Design







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Milwaukee CWG Meeting 15.pdf

Posted by Jada P. · May 23, 2023 · 659 KB





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MEDICAL
COLLEGE.
OF WISCONSIN



"Sometimes your only available transportation is a leap of faith."

- Lori Deschene

The quote "Sometimes your only available transportation is a leap of faith" suggests that in certain situations, the only way to move forward is to take a risk or make a bold decision, even if the outcome is uncertain. It emphasizes the importance of trusting in the process and having the courage to step into the unknown when no other options seem clear.

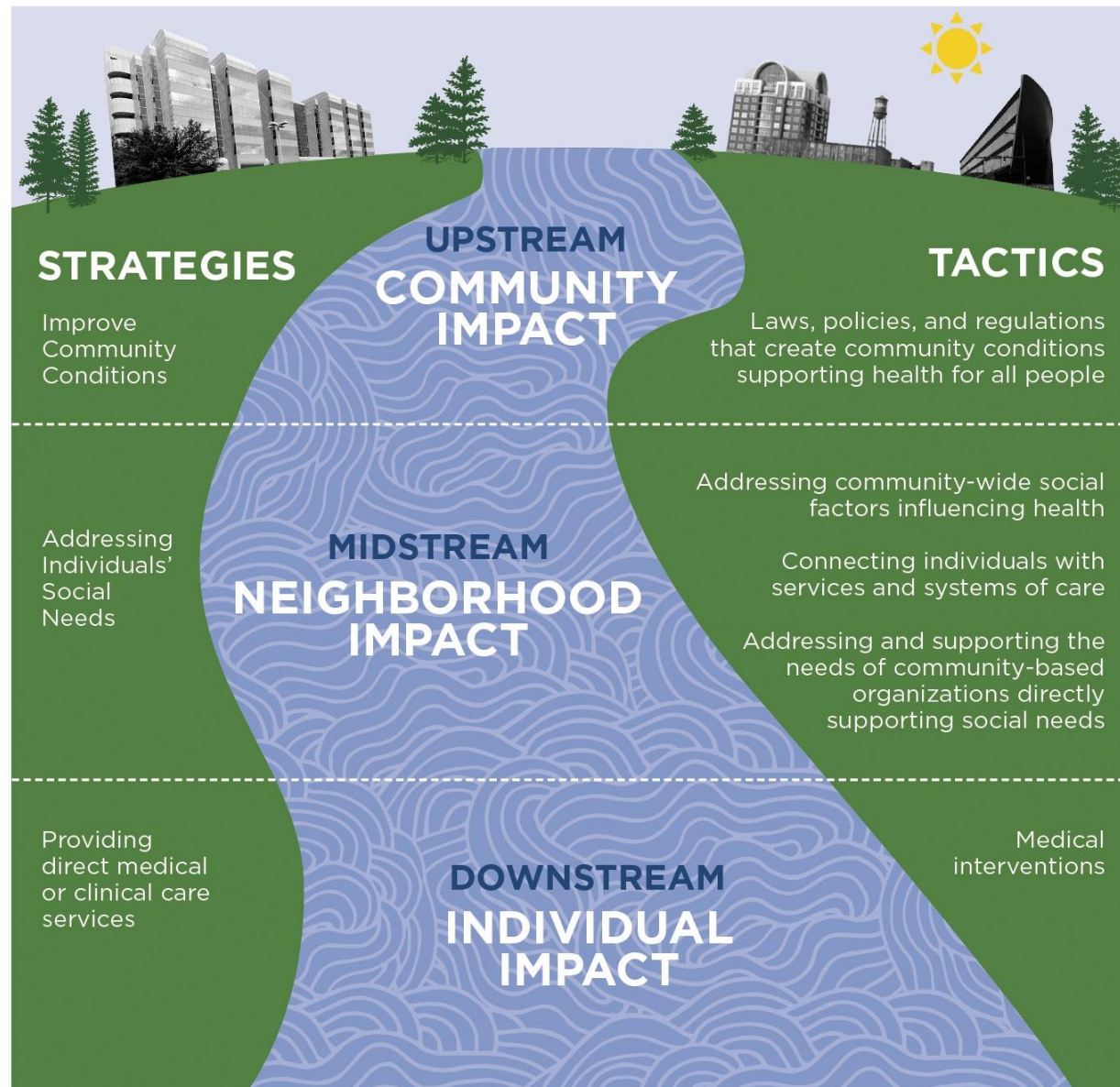




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Graphic adapted from de Beaumont Foundation and Trust for America's Health. (January 2019)
 "Social Determinants and Social Needs: Moving Beyond Midstream"



Upstream



DAN HEATH

*New York Times bestselling coauthor of
Made to Stick and Switch*



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BREAST CANCER DISPARITIES: MOVING BEYOND THE DATA

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TREATMENT:

- INTEGRATIVE CARE
- TRANSPORTATION
- OPPORTUNITIES TO HAVE CONVERSATIONS AT MULTIPLE POINTS IN TIME
- MAKE PEOPLE AWARE OF FERTILITY CHOICES
- GOOD RELATIONSHIP WITH PROVIDER

COMORBIDITIES:

- MENTAL HEALTH before, during & after
- LOWER AGE OF OCCURRENCE
- COST
- CAREGIVERS CARE
- FEAR
- NOT TALKING ABOUT IT
- GENERATIONAL DIFFERENCES

SOCIAL FACTORS:

- VARIABILITY OF PROVIDER CARE CONTINUUM
- I FOUND MY PEOPLE!
- GOD'S GOT ME
- SOCIAL NETWORK IS KEY!
- NOT KNOWING HOW TO ADVOCATE FOR SELF
- SHARE FAMILY HISTORY
- WEED OUT NAYSAYERS

MAMOGRAPHIC PROCESS:

- EXPERIENCE OF 1ST TIME
- COMMUNICATION! POSITIONING, WHAT WILL HAPPEN
- KNOWLEDGE OF PROCESS
- QUALITY OF PROVIDER
- LISTEN!
- COMPASSION MAKES BIG DIFFERENCE!
- HOW DOES IT FEEL?

SHARE YOUR STORY!

- HAVE FAMILY DIALOGUE
- AGE & RACE
- COST
- EDUCATION
- BE COMFORTABLE WITH WHO YOU ARE

GENDER ROLES

- IF I TALK ABOUT CANCER, I MIGHT GET IT
- LACK OF VALIDATION OF YOUR JOURNEY
- AFFIRMATION OF SUPPORT NETWORK
- PRESENCE

INSURANCE:

- PATIENTS NOT COMING IN FOR MAMOGRAMS
- DEDUCTIBLES
- INELIGIBILITY BASED ON INCOME
- COST
- NEED TRANSPARENCY
- NOT ENOUGH COVERAGE FOR TREATMENT & NEEDS AFTERWARD
- PRE-AUTHORIZATION TAKES LONG TIME
- STIGMA
- STATE AID
- RETENTION OF MEDICAL STAFF
- SELF-ADVOCACY & COMMUNITY ADVOCATES
- WRITE INTO CONTRACTS

SCREENING:

- BARRIERS: PRESS 1
- HARD TO MAKE APPOINTMENT
- FEAR OF RESULTS
- HEALTH LITERACY
- KNOW YOUR BODY
- HIGH DEDUCTIBLE
- AFRAID TO TAKE OFF WORK - WANT TO SAVE PTO FOR CHILDREN
- ANXIETY BETWEEN SCREENINGS
- GENETIC / PRE-DISPOSITION
- DIMISSED BY DOCTORS
- EXPOSURE & ENVIRONMENTAL

MEANINGFUL MARKS

with a message of information

MCW MEDICAL COLLEGE OF WISCONSIN



IMPACTS HOW WE THINK

AND WHAT WE DO...



How Do We MEET?

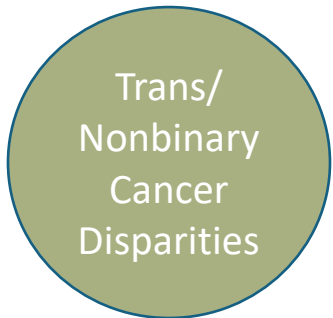


EXAMPLES OF WORK WE DEVELOP



Original Root Cause

Some causes appear in multiple locations on diagram

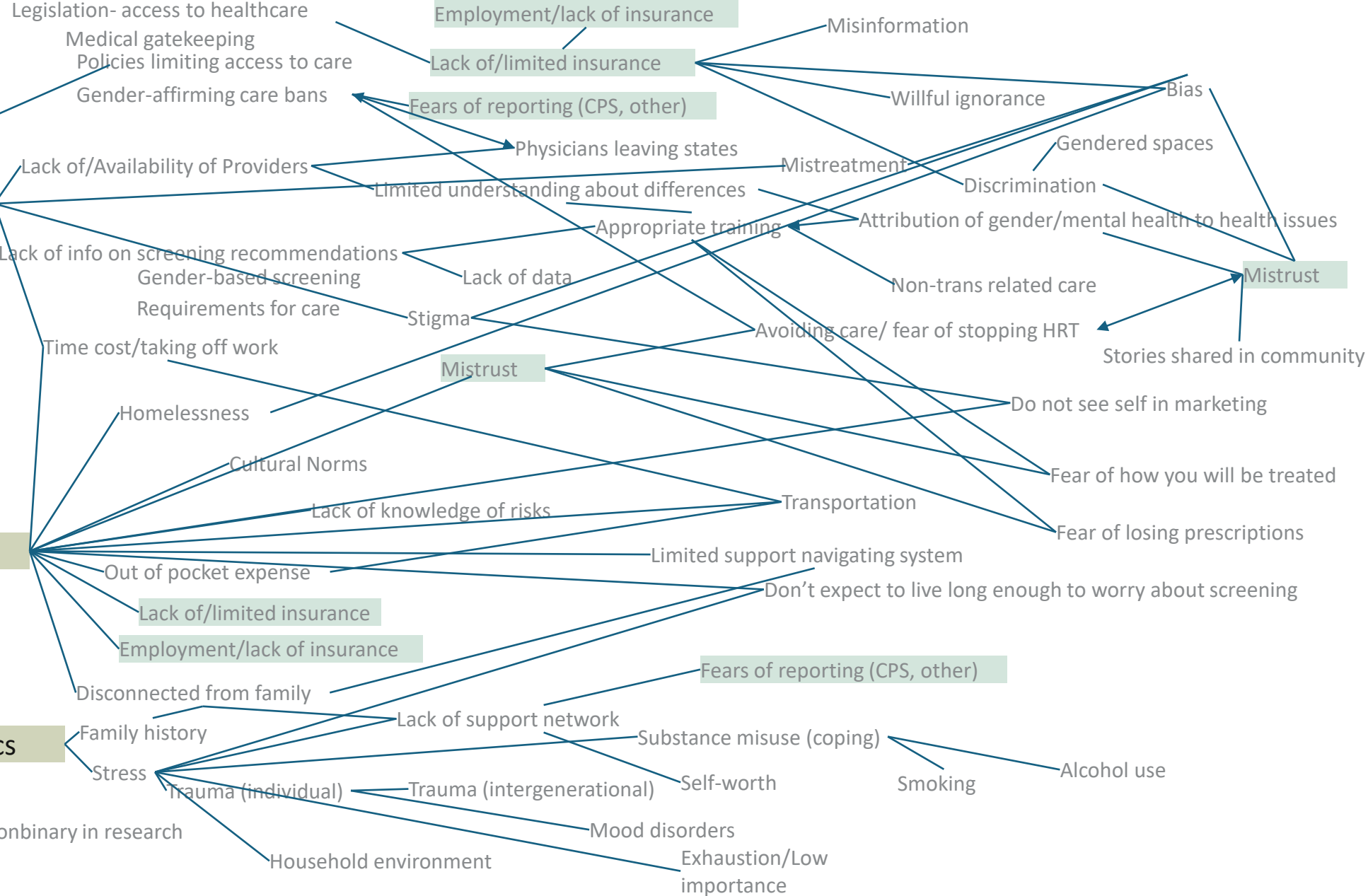


System issues

Healthcare

Individual

Biological Responses/ Genetics



RESULTS: DISCUSSION SESSION

➤ **Community Discussions - 21 people**

General sessions, older trans individuals, parents

➤ **Researcher Discussions – 14 people**

Basic science, clinical, population health

➤ **Health Care Provider Discussions – 12 people**

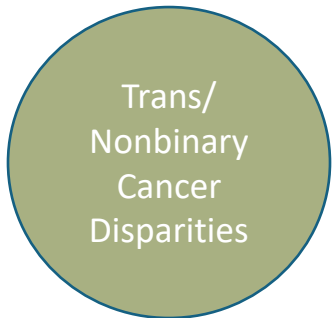
Physicians, allied health providers – with MCW/Froedtert and other systems

RESEARCHER INPUT

Inadequate education beyond language

Employment/lack of insurance

Judging/Judgement



System issues

Healthcare

Individual

Biological Responses/ Genetics

Legislation- access to healthcare
Medical gatekeeping
Policies limiting access to care
Gender-affirming care bans

Lack of/Availability of Providers

Lack of info on screening recommendations
Gender-based screening
Requirements for care

Time cost/taking off work

Homelessness

Cultural Norms

Lack of knowledge of risks

Out of pocket expense

Lack of/limited insurance

Employment/lack of insurance

Disconnected from family

Family history

Stress

Trauma (individual)

Trauma (intergenerational)

Limited Funding

Lack of data

Data doesn't "talk" between disciplines

Small Population/Too small to power studies

Physical/emotional risk to patient

Lack of/limited insurance

Fears of reporting (CPS, other)

Physicians leaving states

Limited understanding about differences

Lack of data

Mistrust

Stigma

Homelessness

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Physical/emotional risk to patient

Misinformation

Willful ignorance

Mistreatment

Appropriate training

Non-trans related care

Avoiding care/ fear of stopping HRT

Transportation

Limited support navigating system

Don't expect to live long enough to worry about screening

Fears of reporting (CPS, other)

Lack of support network

Substance misuse (coping)

Self-worth

Mood disorders

Exhaustion/Low importance

Lack of data standardization

Smoking

Alcohol use

Unsure how to develop questions

Concerns about sharing personal info



Bias

Gendered spaces

Discrimination

Attribution of gender/mental health to health issues

Mistrust

Stories shared in community

Do not see self in marketing

Fear of how you will be treated

Fear of losing prescriptions

Trauma/Stress of exams

Financial toxicity

Training/Education lack

RESEARCHER INPUT
COMMUNITY INPUT

Inadequate education beyond language

Employment/lack of insurance

Misinformation

Judging/Judgement

Limited collaboration between providers

Legislation- access to healthcare
Medical gatekeeping
Policies limiting access to care

Lack of/limited insurance

Willful ignorance

Bias
Providers uncomfortable discussing screenings that affect sex organs

System issues

Gender-affirming care bans

Fears of reporting (CPS, other)

Mistreatment

Discrimination
Gendered spaces

Healthcare

Lack of/Availability of Providers

Limited understanding about differences

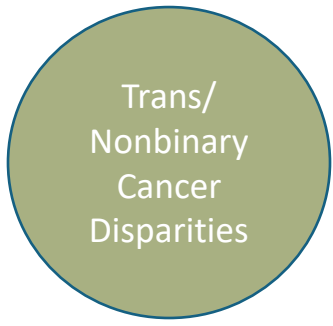
Attribution of gender/mental health to health issues

Gendered spaces

Providers learn from patients-including hormone use /patients feel like guinea pigs

Appropriate training

Attribution of gender/mental health to health issues



Lack of info on screening recommendations

Lack of data

Non-trans related care

Mistrust

Gender-based screening

Rude/dismissive staff

Avoiding care/ fear of stopping HRT

Stories shared in community

Requirements for care

Time cost/taking off work

Mistrust

Healthcare trauma

Do not see self in marketing

Homelessness

Stigma

Fear of how you will be treated

Body dysmorphia

Cultural Norms

Transportation

Fear of losing prescriptions

Individual

Lack of knowledge of risks

Limited support navigating system

Trauma/Stress of exams

Out of pocket expense

Lack of/limited insurance

Financial toxicity

Black/Grey market for hormones

Employment/lack of insurance

Don't expect to live long enough to worry about screening

Biological Responses/ Genetics

Disconnected from family

Fears of reporting (CPS, other)

Family history

Lack of support network

Substance misuse (coping)

Healthcare trauma

Stress

Trauma (individual)

Trauma (intergenerational)

Self-worth

Smoking

Training/Education lack

Inclusion of trans/nonbinary in research

Social environment

Mood disorders

Unsure how to develop questions

Limited Funding

Household environment

Exhaustion/Low importance

Concerns about sharing personal info

Lack of data

Data doesn't "talk" between disciplines

Lack of data standardization

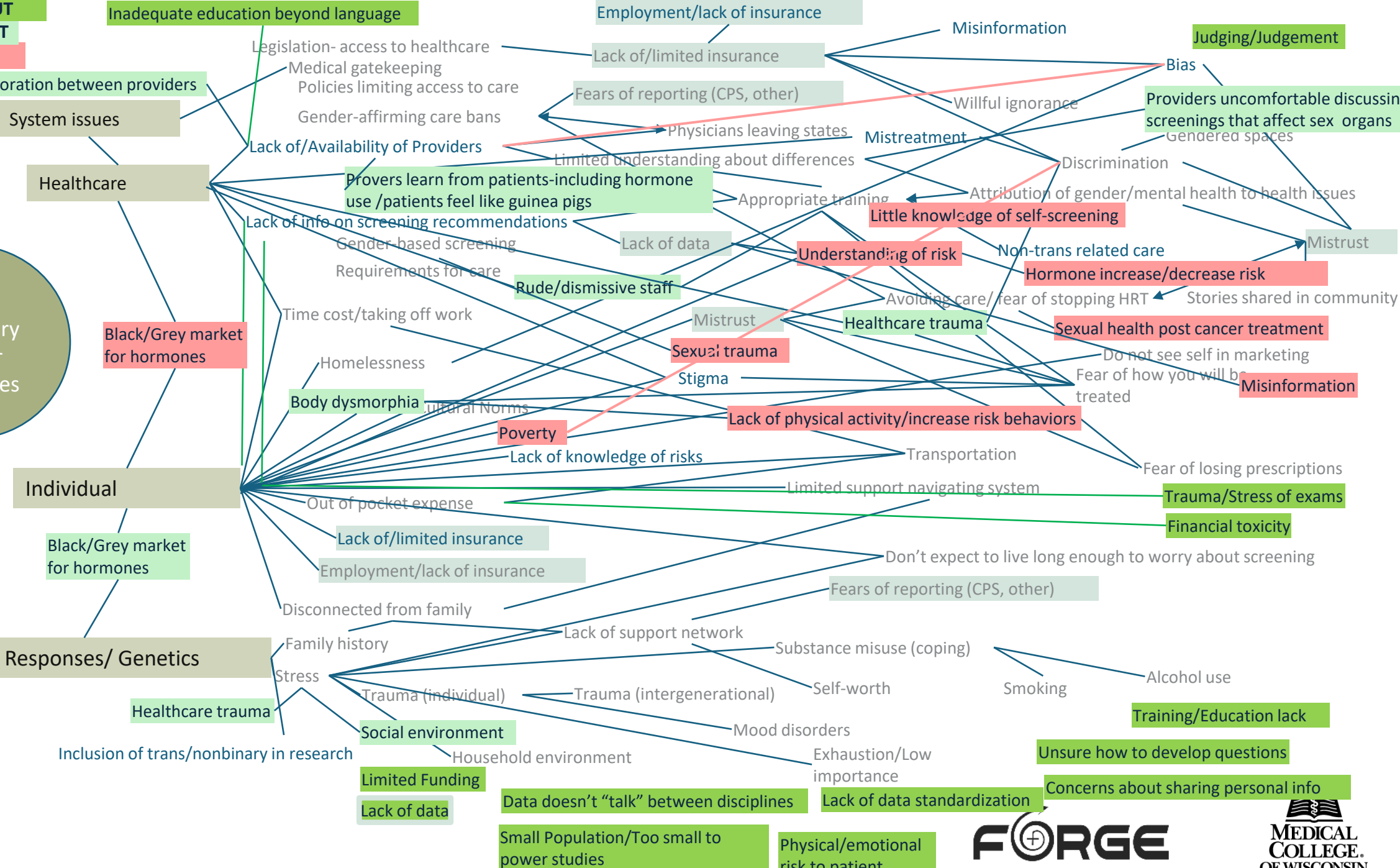
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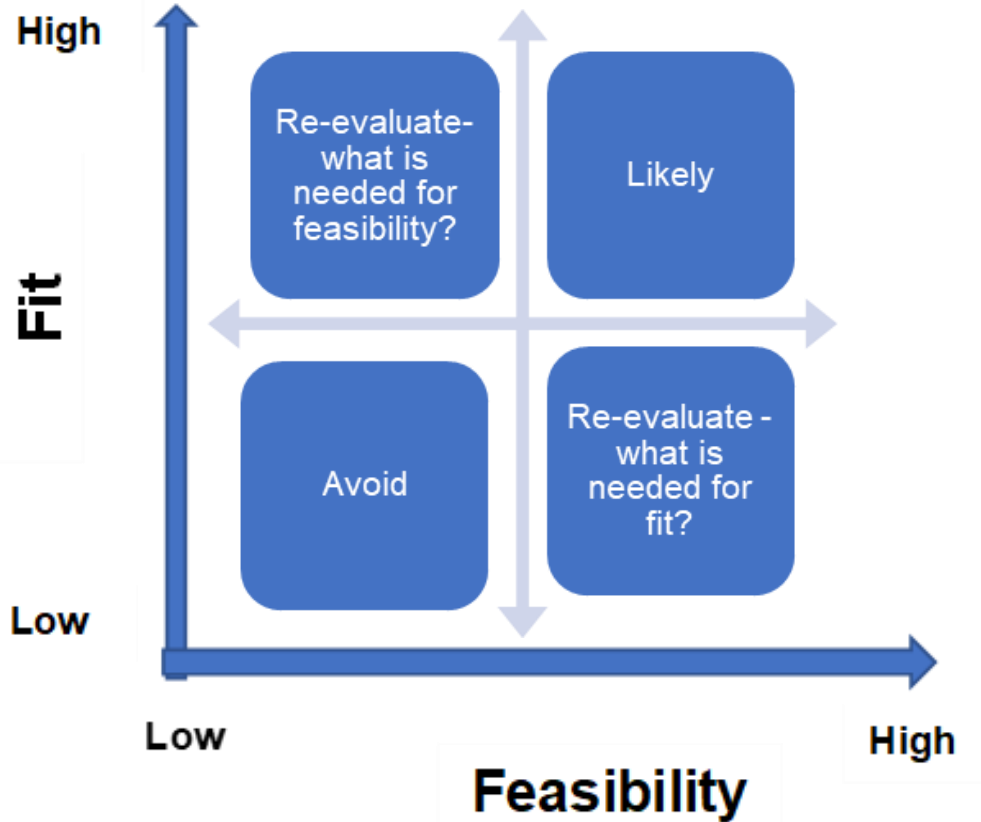


RESEARCHER INPUT
COMMUNITY INPUT
PROVIDER INPUT

Trans/
Nonbinary
Cancer
Disparities



CRITERIA RANKING



LEADING TO ACTIONABLE RESEARCH QUESTIONS

INFLUENCE HOW WE ADDRESS PROBLEMS
AND QUESTIONS – RESEARCH, SOCIAL
ACTION, ETC.



THANK YOU!!!

