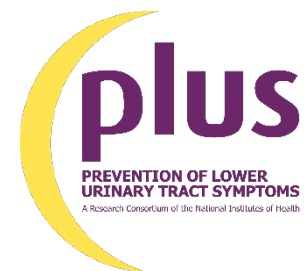




Prevention of Lower Urinary Tract Symptoms (PLUS) Research Consortium



Overview

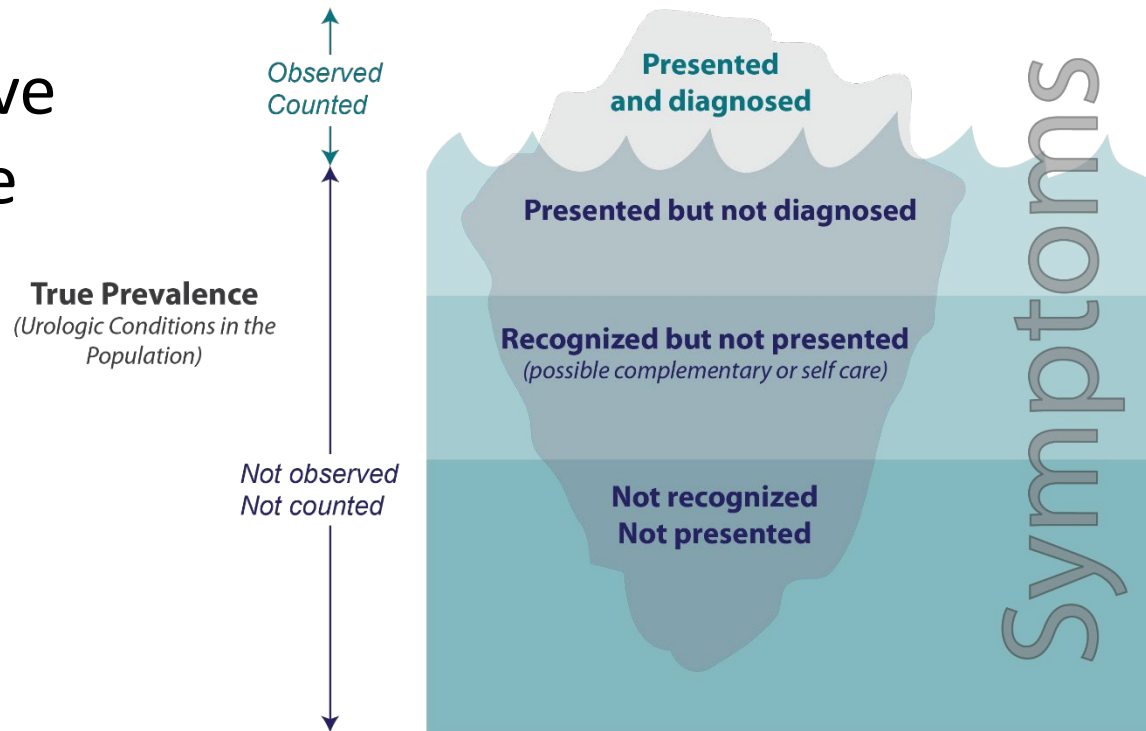
- **Primary goal of the Prevention of Lower Urinary Tract Symptoms (PLUS) Consortium**
 - A multi-center network funded by the NIH/NIDDK
 - Prevention of LUTS in women and girls by advancing bladder health
- **Transdisciplinary members**
 - Includes physicians, nurses, psychologists, sociologists, public health and prevention scientists, epidemiologists, and biostatisticians
- **Consortium work**
 - Provide an overview of the PLUS consortium, including ongoing efforts to define and measure bladder health

Prevalence of LUTS

- **Boston Area Community Health 2002-2005**
- **Gaps in urologic epidemiologic data**
 - Population based prevalence
 - Age specific prevalence/incidence
 - Disparities in conditions
 - Changes in symptoms
 - Gender differences

The Urologic Iceberg

- 20% women 30 yrs and older have moderate-severe symptoms
- 73% community dwelling women report at least 1 symptom



Iceberg concept adapted from Last (1963; 2001)

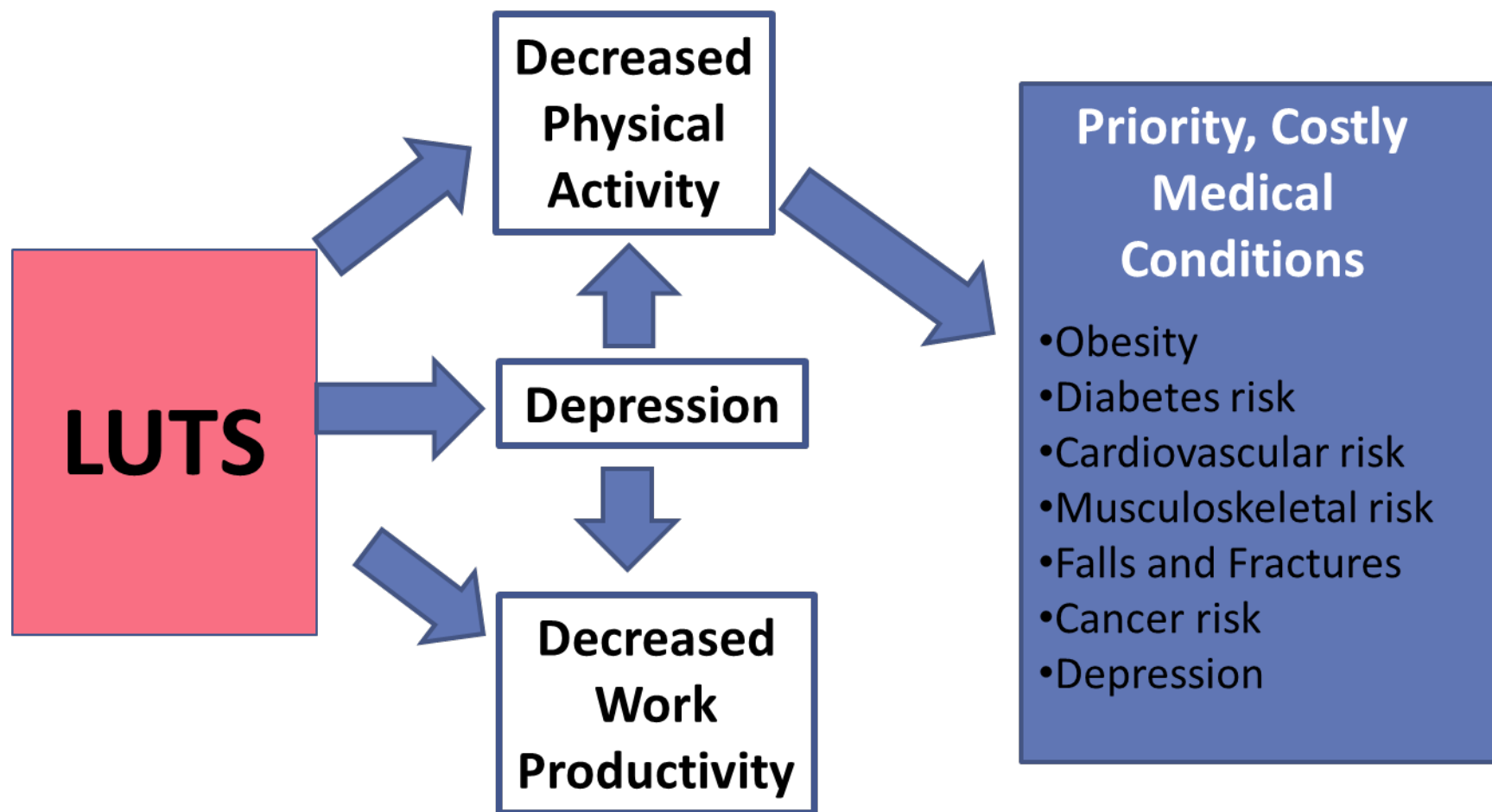
Kupelian et al, JAMA 2006

Hall et al, BJUI, 2008

LUTS impact

- **Economic**
 - OAB costs alone estimated at \$66 billion in 2006
 - Recurrent UTIs \$2 billion annually
 - LUTS associated with decreased work productivity
- **Morbidity/health**
 - Depression, weight gain, obesity, decreased physical activity, and diabetes linked to LUTS
 - LUTS independently predict increased ED visits when controlled for comorbidities, age, and race

Reframing LUTS: Important Medical Condition with Quality of Life Impact



Opportunities Provided by a Bladder Health and LUTS Prevention Strategy

People With Bladders

Educate about bladder function, healthy behaviors and abnormal symptoms and spectrum of treatment options

More sufferers recognize their situation as abnormal and treatable

More sufferers seek evaluation and treatment with basic understanding of problem, treatment options and their role in treatment

Opportunity to change unhealthy behaviors and incorporate behaviors that promote healthy bladder function

**IMPROVE
OVERALL
HEALTH**

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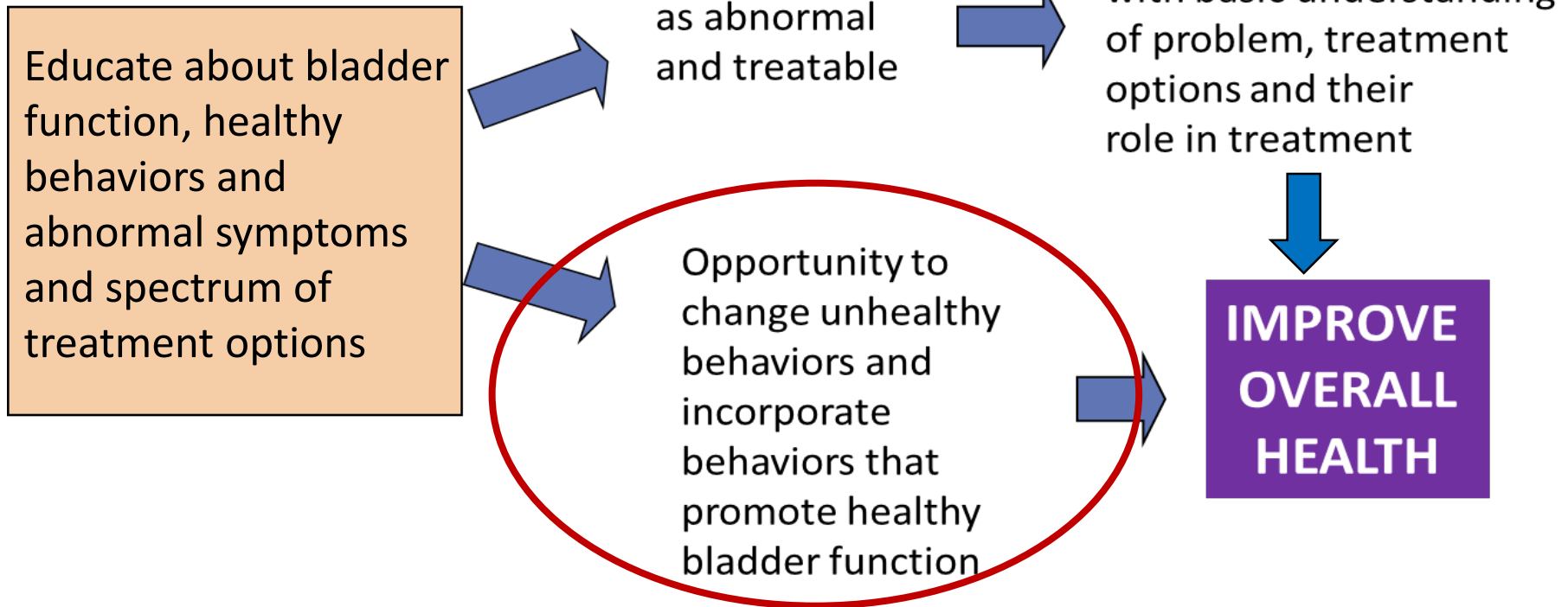
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Opportunities Provided by a Bladder Health and LUTS Prevention Strategy

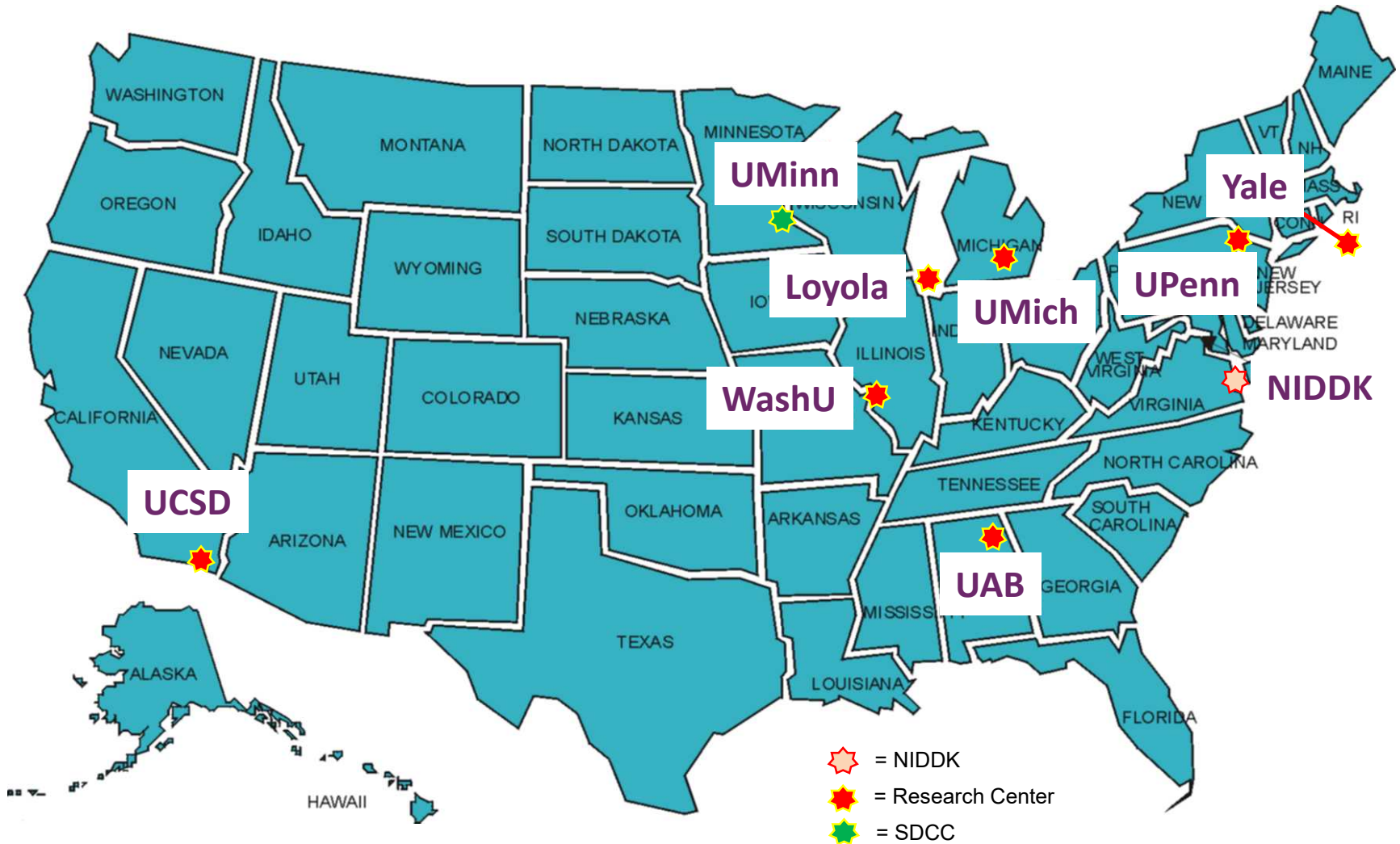
People With Bladders



PLUS Research Consortium Investigator Specialties



PLUS Research Centers



NIH “Bladder/Pelvic Floor” Networks

NIDDK

PLUS

Define Bladder Health and LUTS Risk Factors



MAPP

DEEP PHENOTYPING UCPPS



LURN

DEEP PHENOTYPING LUTS



PRO

Urinary Incontinence

NICHD

PFDN



Pelvic Organ Prolapse

Anal Incontinence

The GOAL

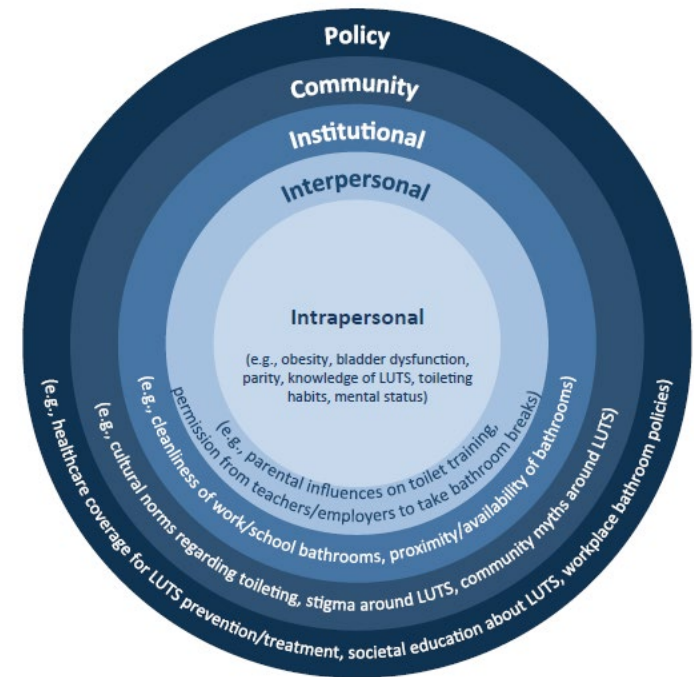
- To obtain the necessary information to plan future interventions to promote bladder health and prevent LUTS

What is a prevention science approach?

- **What do prevention scientists do?**
 - Conduct etiologic studies to identify risk and protective factors
 - Develop and test prevention interventions aimed at modifying risk and protective factors
 - **Goal is to promote health and prevent major dysfunction *before* onset of a disease or disorder**
- **Prevention science applies a life course developmental perspective**
 - Dissemination of findings are expected to impact health promotion programs, practices, and policies, and in turn, the health of populations across the life course

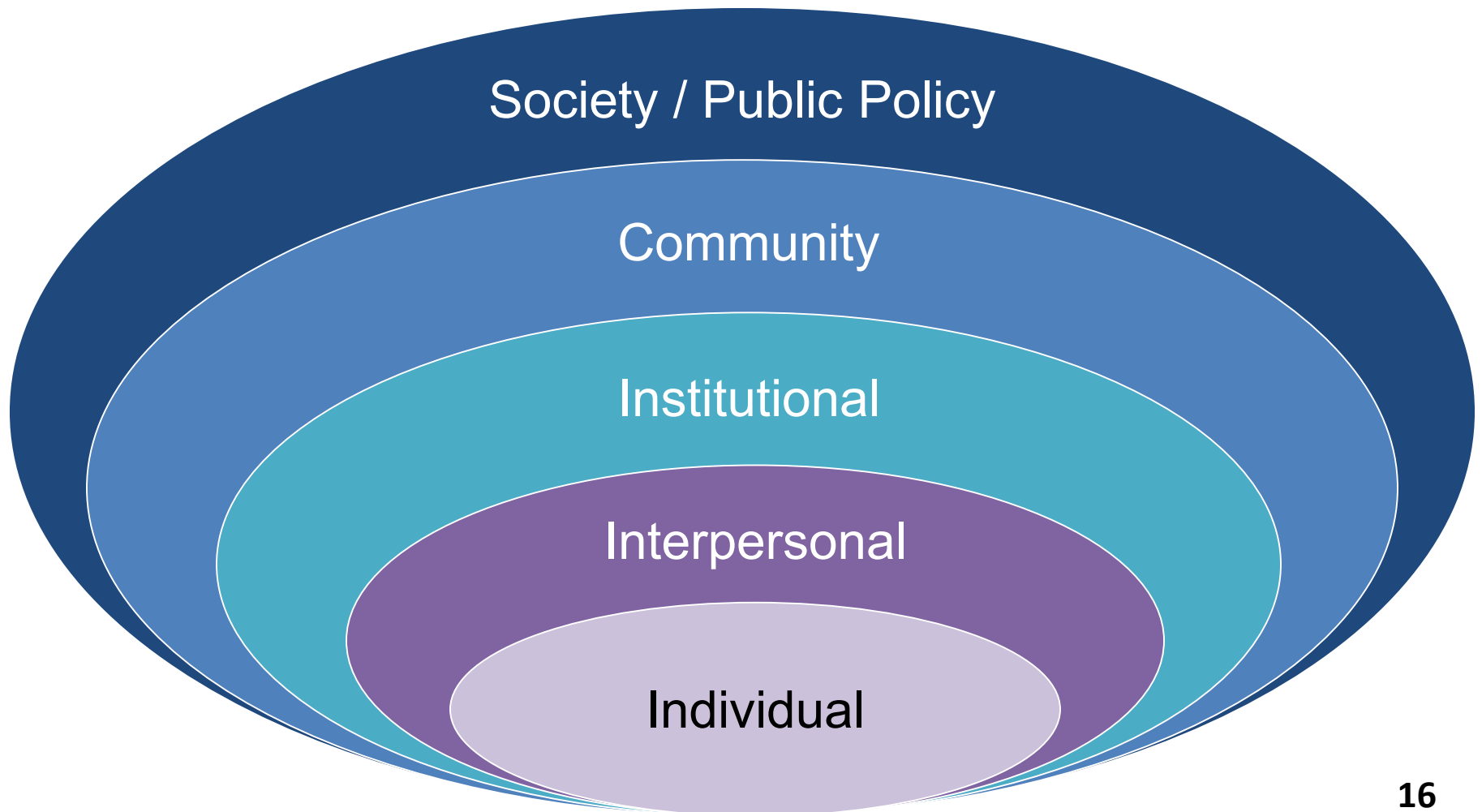
Social Ecological Model

- Interactions between social context and biology
- Health behaviors are determined by multiple factors outside of the individual
- Biologic, psychosocial, behavioral, cultural, environmental factors



Social Ecological Model

(McLeroy, Bibeau, Steckler, & Glanz, 1988)



Individual Level

- **Mind/Behavior**
 - Knowledge
 - Beliefs / Perceptions
 - Attitudes
 - Personality Traits
 - Behavior
- **Biological Systems**
 - Genetics
 - Physiology



Interpersonal Level

- **Interpersonal processes within primary groups may influence behavior**
- **Primary groups shape an individual's social identity, define an individual's role, and provide support to the individual**
 - Family
 - Friendship networks
 - Colleague / Peer networks
 - Intimate partners
 - Patient/provider relationship



Institutional Level

- **Organizational or institutional culture, informal structure, rules, regulations, and policies may promote or constrain specific behaviors**
- **Organizations and institutions have a formal identity and may be comprised of an individual's primary group members**

- Schools
- Worksites
- Churches
- Clinics



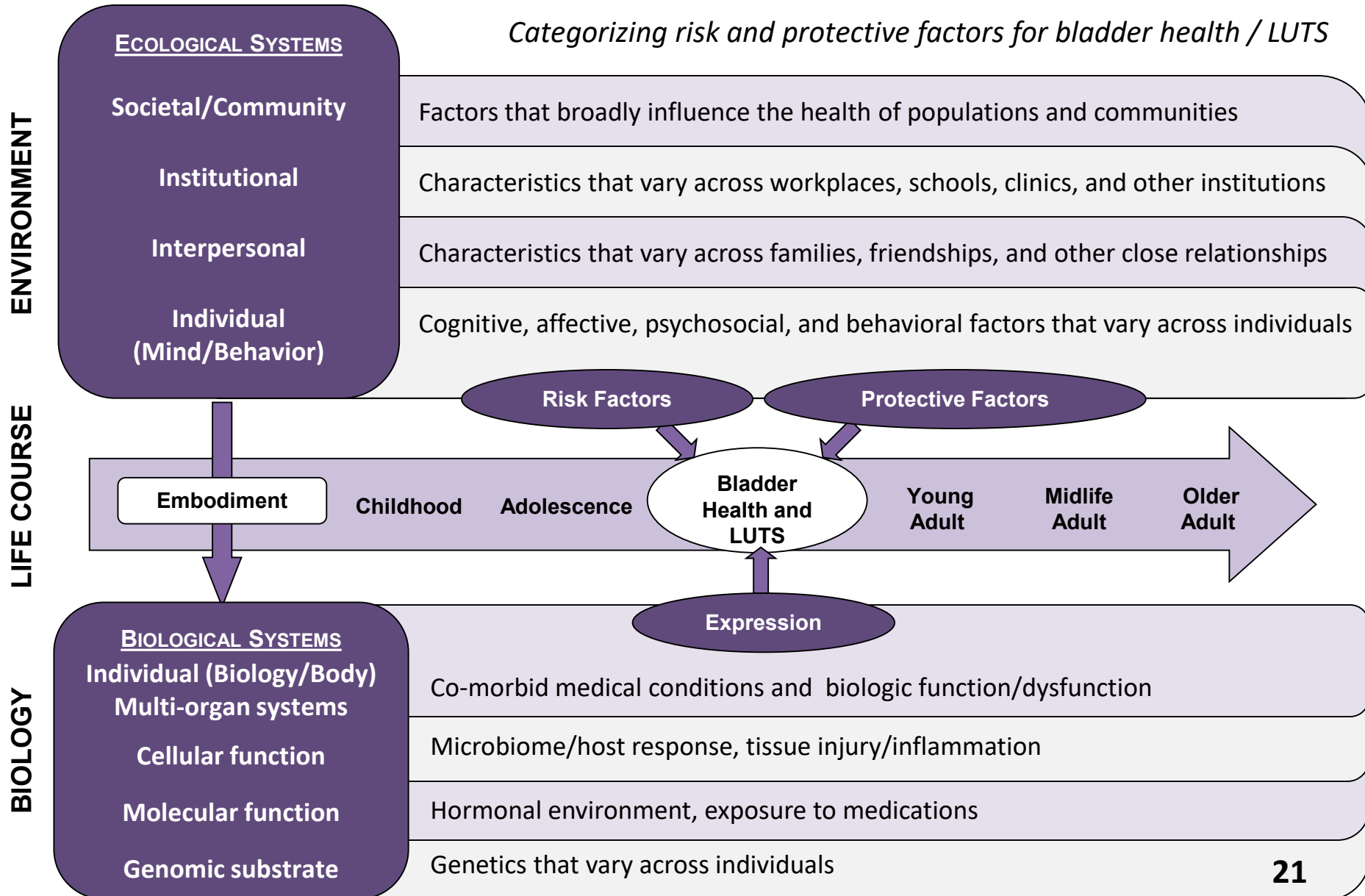
Community/Societal Level

- **Extended social networks and their norms, whether formal or informal, may influence behavior**
- **Communities may be comprised of individuals, primary groups, and organizations/institutions**
- **Local, state, and federal policies and laws may regulate or support healthy behavior**

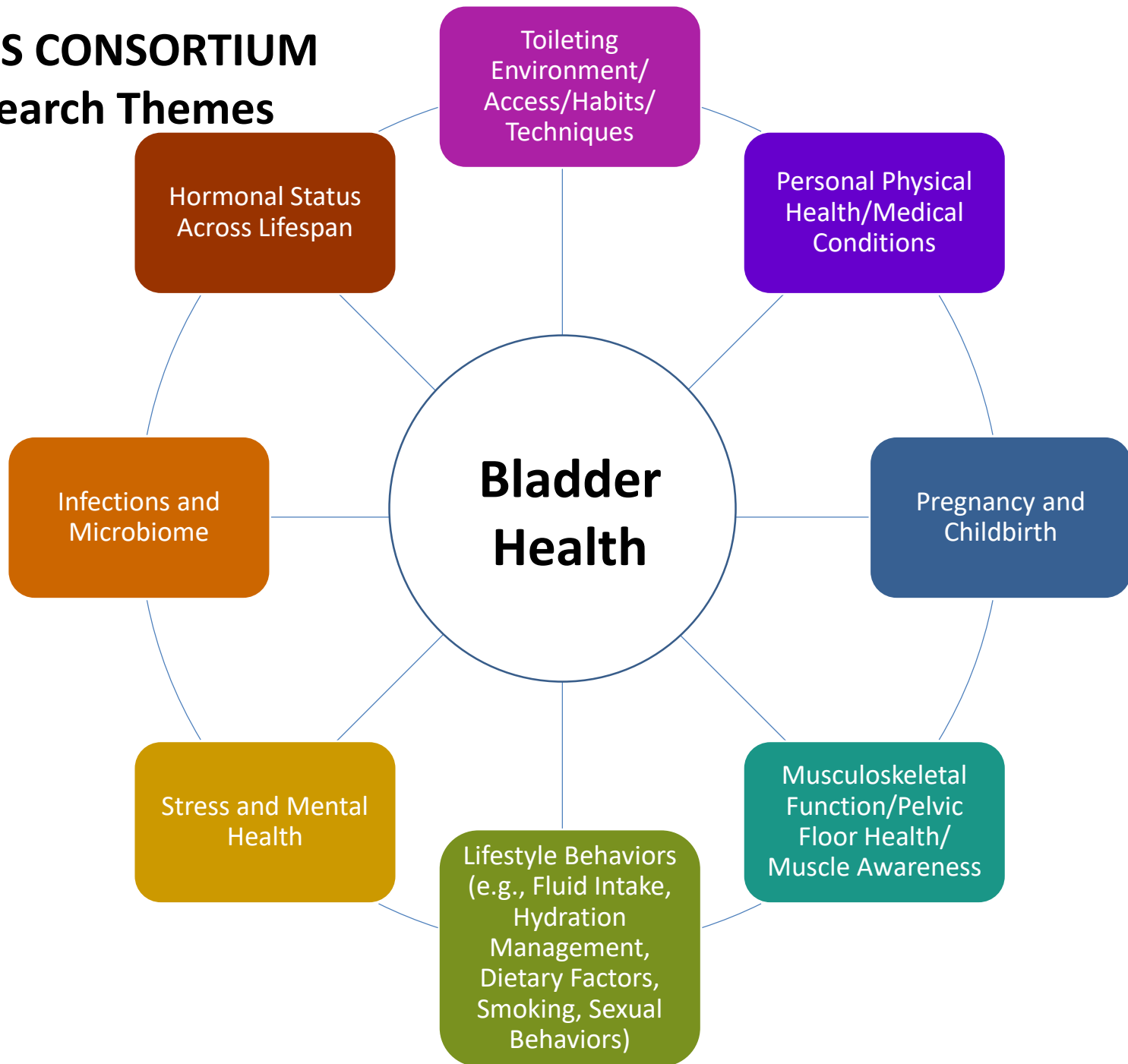
Working PLUS Conceptual Framework

Adapted from Thomas Glass and Matthew McAtee (Social Science & Medicine, 2006)

Categorizing risk and protective factors for bladder health / LUTS



PLUS CONSORTIUM Research Themes



Gaps- some examples

- **Toileting environment – Access to toilets**
 - School (students and teachers)
 - Workplace via occupation
 - Public spaces
- **Musculoskeletal Function**
 - Low back pain
 - Prior lumbar/sacral surgery
- **Stress and Mental Health**
 - Anxiety
 - Children/adolescents

What is bladder health?

**“In modern medicine, we have a
name for everything, but a cure for
nothing.”**

Charles F. Glassman

Definitions – LUTS Terminology



Definitions – Measurement of LUTS



Current uses of “bladder health”

Urology Care FOUNDATION
The Official Foundation of the American Urological Association

Home > Media Center > Bladder Health Month 2016

Bladder Health Month 2016

Urology Care FOUNDATION
Take Control of Your Bladder Health
NOVEMBER IS BLADDER HEALTH MONTH

November is Bladder Health Month

This month serves as a reminder to get the facts about common bladder health problems and to take an active role in your health. During November, the Urology Care Foundation will highlight a different bladder health theme and related resources.

- Week 1 Theme: Incontinence, OAB and SUI**
November 1-5
- Week 2 Theme: Nocturia and Bedwetting**
November 6 - 12
- Week 3 Theme: Bladder Cancer**
November 13 - 19
- Week 4 Theme: Bladder Infection/Urinary Tract Infection (UTI)**
November 20 - 26
- Week 5 Theme: Interstitial Cystitis (IC) and Neurogenic Bladder**
November 27 - 30

Bladder Conditions

- Bladder Cancer
- Overactive Bladder (OAB)
- Stress Urinary Incontinence (SUI)
- Urinary Incontinence
- Urinary Tract Infections in Adults
- Urinary Tract Infections in Children
- Interstitial Cystitis
- Bed-Wetting (Enuresis)
- Neurogenic Bladder
- Bladder Exstrophy
- Bladder Fistula
- Bladder Prolapse (Cystocele)
- Bladder Trauma
- Cystometry
- Cystoscopy
- Contrast and Radionuclide Cystography
- Urinary Diversion

"Bladder Friendly" Recipes

Turkey Minestrone Soup

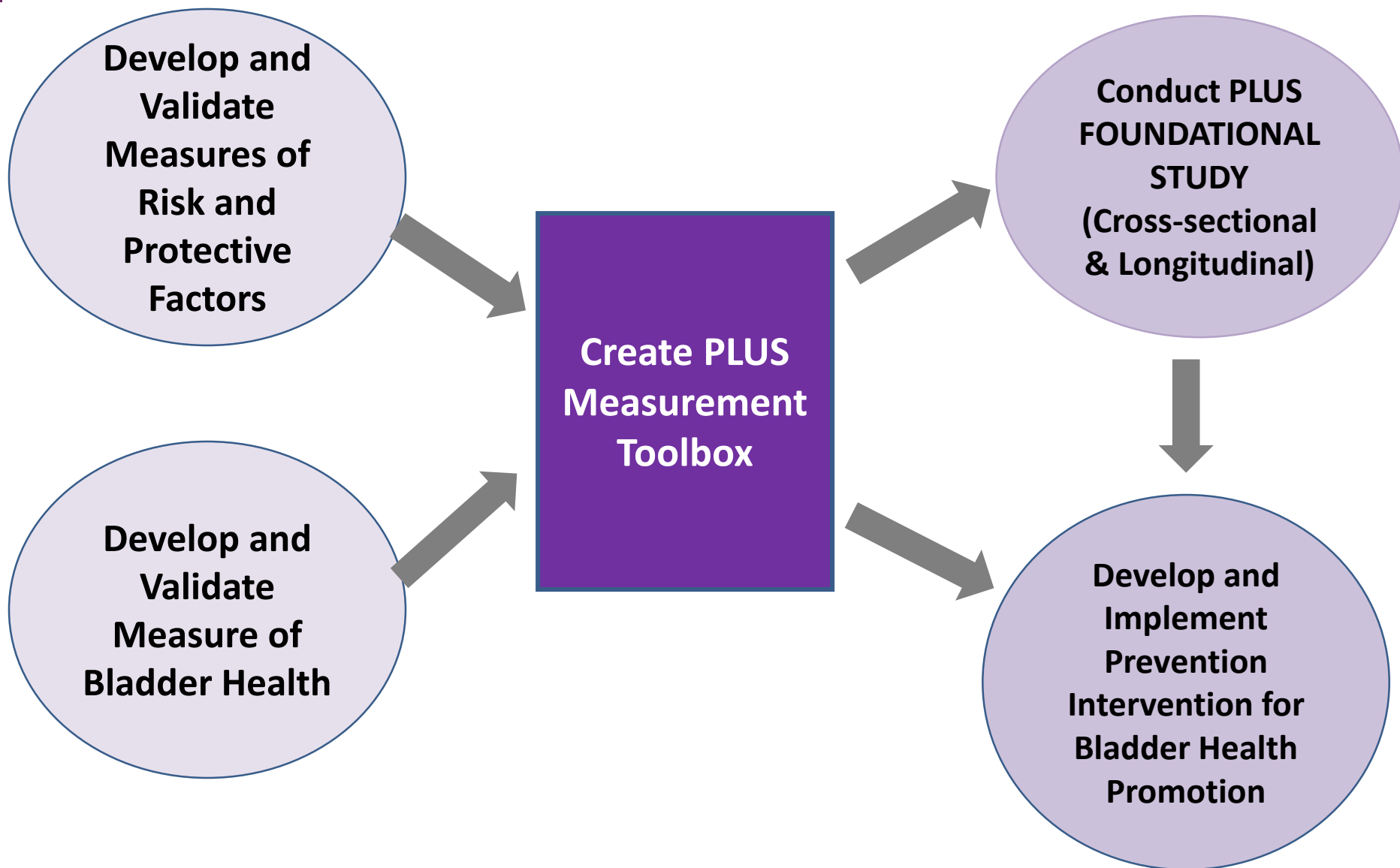
Definitions – Why Bladder Health?

- While there are effective treatment options for LUTS, *few* prevention programs studied
 - In part due to no definition of Bladder Health
- A standardized Bladder Health definition can aid in identifying:
 - **factors to promote health**
 - **factors to modify to prevent LUTS**

Bladder Health: More than the absence of LUTS

- **Working definition**
 - *A complete state of physical, mental, and social well-being related to bladder function, and not merely the absence of LUTS*
 - *Function that permits daily activities, adapts to short term physical or environmental stressors, and allows optimal well-being (e.g. travel, exercise, social, occupational activities)*
- **Functions of the bladder**
 - Storage
 - Emptying
 - *NEW Bioregulatory (protection from infection, inflammation, etc.)
- **QoL/functional status**
 - Function does not impact activities on a routine basis, is adaptable to short term physical or environmental stressors, and allows optimal well-being (e.g. travel, exercise, social, occupational activities)

Next Steps-The Map



Bladder Health Measurement Roadmap

What components should we include?

Determine
Components of
Bladder Health

Conceptualize
Bladder Health

Bladder Health Measurement Roadmap

Develop and Validate
Measure of Bladder
Health

Select/Develop
Measurement
Approach

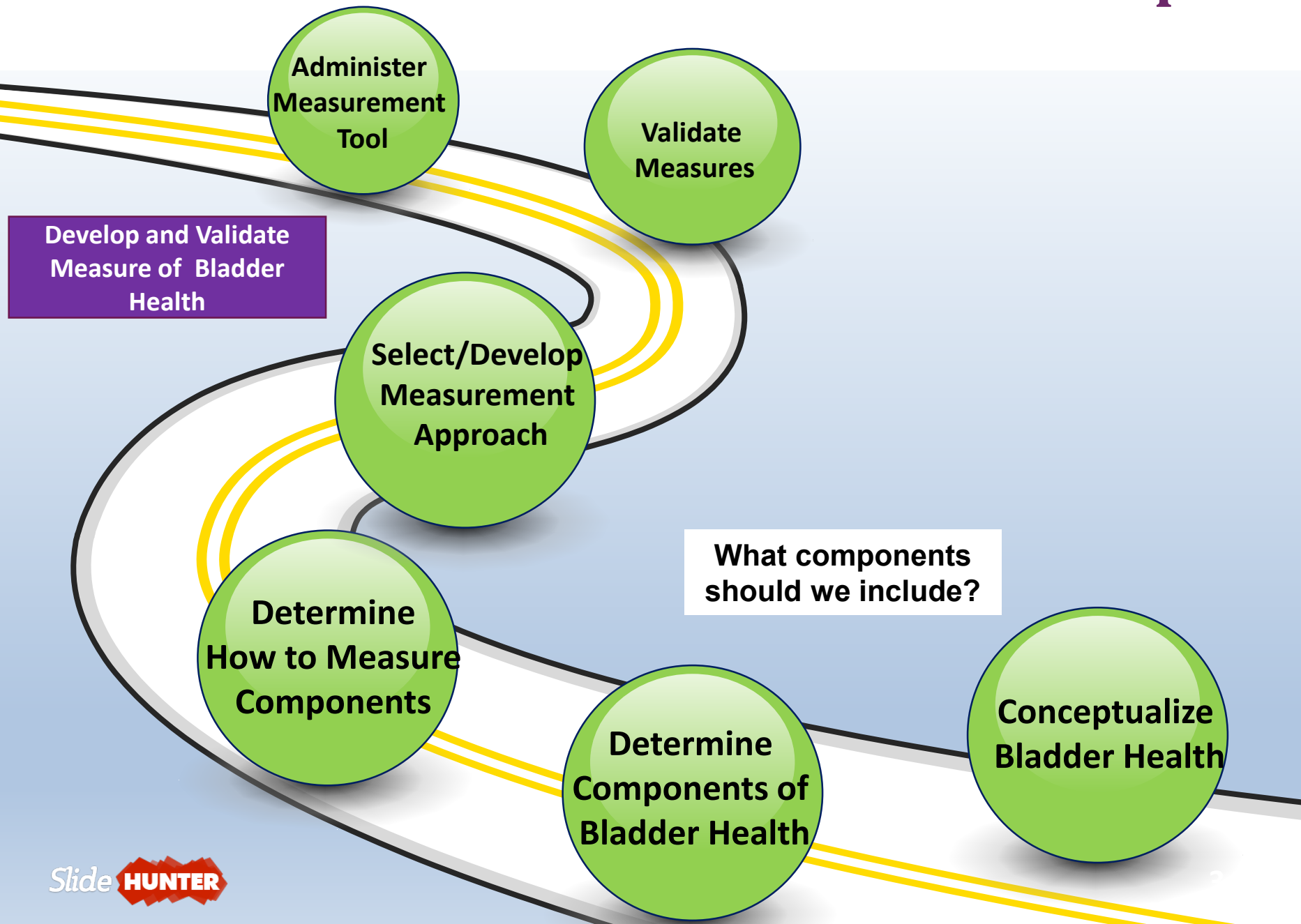
Determine
How to Measure
Components

What components
should we include?

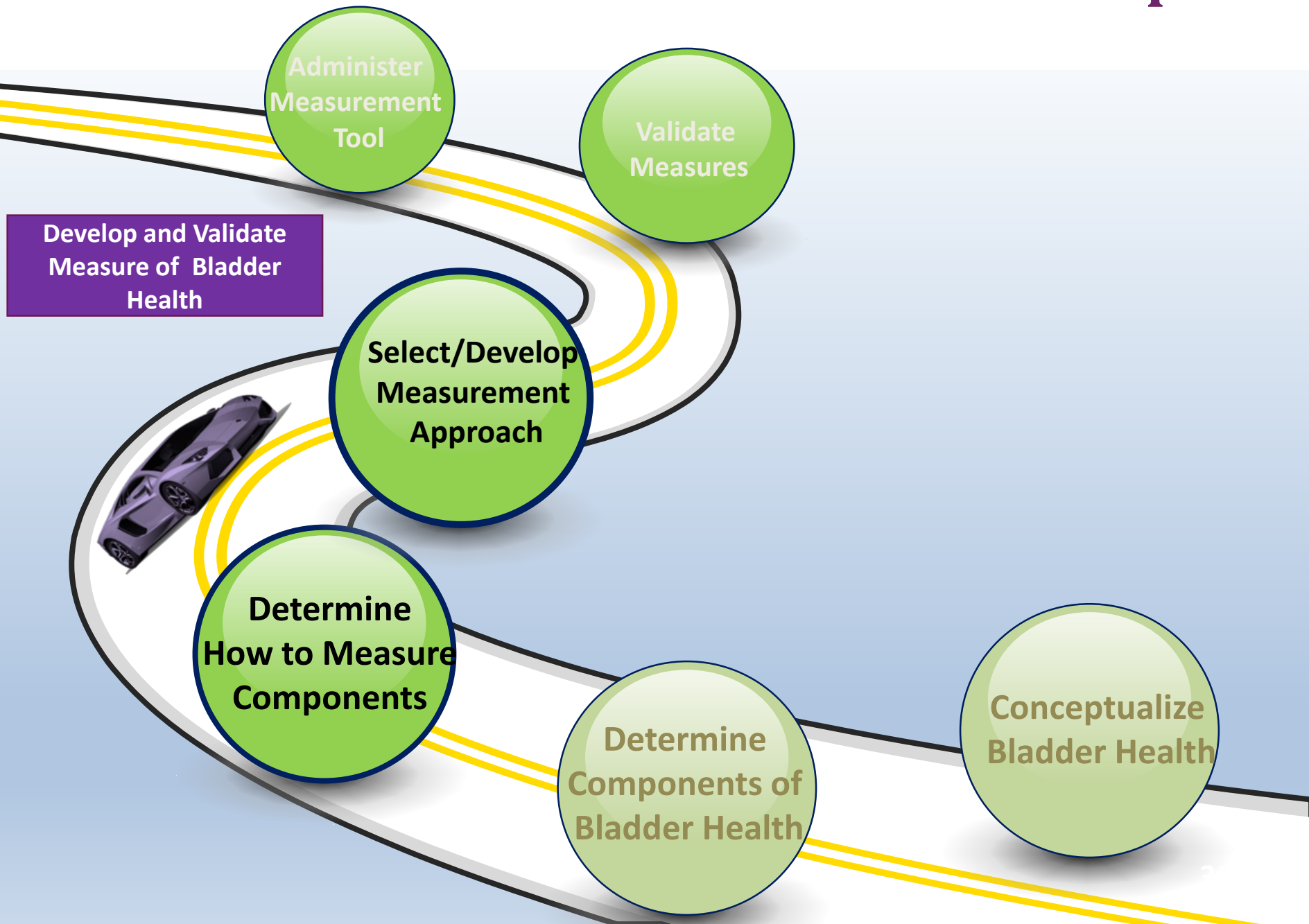
Determine
Components of
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Conceptualize
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Bladder Health Measurement Roadmap



Bladder Health Measurement Roadmap



Study of Habits, Attitudes, Realities and Experiences (SHARE)

- **Purpose:** To explore women and girls' experiences, perceptions, knowledge, and behaviors related to bladder health across the life course and to inform development of a **Bladder Health Instrument**
- **44 Focus groups across 7 PLUS sites, 6 in Spanish**
- **360 Community dwelling women and adolescents**
- **Life Course Approach**
 - Early adolescents 11-14
 - Adolescents 15-17
 - Young adult women 18-25
 - Adult women 26-44
 - Middle aged women 45-64
 - Older women 65+
- **Diversity: Racial, Ethnic, Geographic**

Study of Habits, Attitudes, Realities and Experiences (SHARE)

- **Coding & Multilevel Content Analysis**
- **Interpretation <-> Community Engagement <-> Feedback**
- **Prioritized topics:**

Terminology & Lay Discourse: Exploring lay discourse about bladder health and function

Bladder Monitoring: The social processes of monitoring bladder behavior across social ecologies and throughout the life course

Bladder Navigation: Female adult and adolescent experiences accessing toilets in public spaces, workplaces and schools

Healthy Bladder: Women's and adolescents perceptions of healthy bladder

plus ⁺ “I Don’t Know Anyone Who Pees on Themselves on Purpose:” Exploring Women’s and Adolescents’ Lay Discourse about Bladder Health and Function

Beverly R Williams¹, Jesse Nodora², Diane K Newman³, Lisa Kane Low⁴, Aimee S James⁵, Deepa R Camenga⁶, Jeni Hebert-Beirne⁷, Sonya S Brady⁸, Cecilia T Hardacker⁷, Kathryn L Burgio¹
¹University of Alabama at Birmingham, ²University of California at San Diego, ³University of Pennsylvania, ⁴University of Michigan, ⁵Washington University at St. Louis, ⁶Yale University, ⁷University of Illinois at Chicago/Loyola, ⁸University of Minnesota, For The Prevention of Lower Tract Symptoms (PLUS) Research Consortium

Background and Objectives

Background
 Research about lay terminology and discourse can provide insight into women’s and adolescents’ perspectives on bladder health and function. Lay language for bladder function and urinary symptoms often does not coincide with scientific medical terminology. The lay public does not have a recognized shared repository of terminology or a common arena for discourse about bladder health. There is a need to develop a consensus on terminology for bladder function to facilitate lay-medical conversations and to inform public health initiatives.

Objectives:
 1. To characterize the attributes of lay language and terminology

Methods



- Experiences (SHARE)
- Focus groups conducted to explore adolescents’ and women’s experiences, perceptions, beliefs, knowledge, and behaviors about bladder health/function
 - 44 focus groups conducted across 7 research centers
 - 360 adolescents and women
 - Diverse in race, ethnicity (Spanish speaking) and urban vs. rural
 - Six age categories: 11-14, 15-17, 18-25, 26-44.

Data Analysis & Interpretation

- Focus group sessions conducted by trained moderators
- Semi-structured guide based on the PLUS conceptual framework
- Sessions audio-recorded, transcribed, and entered into Dedoose
- Field note scribe observed the sessions for nonverbal communication, group dynamics, and articulating emerging insights.
- Multilevel content analysis conducted by trained coders using deductive approach to develop code book.
- 4-member transdisciplinary interpretation team used inductive approach for data interpretation of the “lay terminology” code
- Multiple cycles of data immersion and consensus building
- Insights validated by 11-member community engagement panel comprised of adolescents and women and

Results

Lay Terminology: A Repertoire of Terms
 Lay expressions for bladder reflect a cumulative and generational process associated with developmentally-related exposures.

Across age, race, ethnic and urban/rural categories, adolescents and women have a repertoire of terms for bladder function in general, and passing urine, in particular.

- Informal functional terms such as “pee,” “piss” and “whiz”
- Formal terms such as “void” and “urinate” (not often used)
- Polite euphemistic terms as “using/going to the ladies room” or “being excused”
- Cultural and regional metaphors and idioms such as “paying the water bill” or “throwing the waters.”

Lay Terminology: Social-Historical Contexts
 Lay terminology is embedded in a social-historical context, with terms coming in and out of vogue due to changing social norms, practices, and sensibilities.

- *My mother-in-law used to always say ‘I got to go to the little girl’s room.’ . . . What about when mothers used to say they’re going to powder their nose? . . . You don’t hear that much anymore.*
 - *Growing up, no one ever said I have to pee. That’s a more modern thing.*
- Our community engagement panel pointed out recent shifts in lay reflect technological innovations, popular culture and social media. Examples include,
- texting “BRB” for “be right back” or “bathroom break”
 - using a faucet emoji to indicate one’s intent to pass urine

Results

Lay Terminology: Interpersonal and Situational Contexts

The interpersonal context and social setting dictates terminology. In personal, close-knit social groups such as family and friends, informal terms are common. In impersonal, loosely-knit task oriented groups such as schools and workplaces, the use of formal, polite terminology is preferred.

- *I think if I’m with my family or closer friends, then I’ll be like, ‘hey, I got to pee,’ like casual. But if I’m asking a teacher, then I’ll just say, ‘can I, may I use the restroom?’*
- *It depends on who you’re with, you know? It’s girls night, we’re all setting around saying ‘I gotta go piss, you know? It is vulgar in here [focus group setting].*
- *If I’m talking to the kids, it’s just I gotta pee really bad, That would be our everyday language. . . when you have children, you still focus on the smaller words.*

Lay Terminology: Emotional Salience (Affective Valence)

Lay terminology for bladder function can evoke emotions ranging from comfort to unease. Terms with positive affective valence may be used intentionally by adults during childrearing to provide a reassuring toileting experience.

- *If you’re around children, it depends on what you say how children relate to going to the bathroom. . .*
- *As a new parent, I constantly think of what terminology am I saying because that’s what this person is going to learn. I want my son to feel comfortable . . . So then it’s not something I have to be embarrassed about.*

Expressive terminology for bladder function can elicit negative feelings

- *I always say I have to go to the restroom, and I have a friend that she says ‘I need to pee,’ in front of me. It’s so weird you’re telling me. For me, it doesn’t sound good.*
- *Boys, I know boys be like ‘I got to take a piss’ . . . Ooohhh (cringes) Yeah, that’s so nasty. . . . I hate when boys say (that).*
- *Sometimes I’ll say it out loud, like what I have to do. Some people with be like, they share their business too much, So you just gotta keep it to yourself.*

Lay Discourse: Family and Friend Narratives

Conversations about bladder function occur predominantly among family and friends and typically take the form of storytelling, anecdotes and cautionary tales.

- *My mother-in-law talked more in my younger adult year, telling me about what she was experiencing, and that’s when I became more alert. She said, ‘hey, as you grow older. . . When you laugh, you tinkle, when you sneeze you tinkle.’*
- *We have been struggling from generation to generation since my grandmother, my great-grandmother, also my mother with bladder problems. . . For that reason, the bladder for us, has not been taboo. That is talked about in the whole family because it has been circulating in the family.*
- *My mother used to tell me. . . “the queen never misses an opportunity.” Whenever there’s an opportunity to pee, you take it because keeping things coming out is good.*
- *This friend group of mine, whenever we go out drinking, it’s like ‘don’t break the seal.’ Because as soon as you break the seal, you’re just going to have to keep going back to the bathroom.*

Results

Lay Terminology: Finding the Words

Women and adolescents often had difficulty finding the words to talk about bladder function, trying to describe rather than name bladder experiences.

- *It’s [urgency] not like pain, but you could feel like it’s something there, I guess, like I don’t know like kind of like I can’t really describe it right now.*
- *I get pain like on the side if I hold it too long. . . Not an excruciating pain, kind of like a desire, like a small little hip bruise or something, just a small slight pain.*
- *It really is uncomfortable when you really hold it, it’s like cramps. It’s like a cramp.*

Lay Discourse: Normalizing and Minimizing

Lay discourse can normalize, trivialize, humiliate, & stigmatize bladder issues.

- *You teach the kids to say I had an accident. So we joke with my mother because she has accidents as well.*
- *I was running in the house while having to go to the bathroom. I was running down my steps. . . like pee coming down. It’s like oh, no, no, no. It’s your yeah. It’s like oops, I peed on myself, or I had an accident, or oh geez. Let’s not say anything to anybody (laughter).*
- *What do you call it when you wake up at night to go to the bathroom? Ahh, tinkle, tinkle little star.*
- *I had a case of the night pees last night three times. . . It doesn’t happen often but it does, there it is the night pees.*
- *She (roommate) had an accident. . . She was like ‘I was asleep, I had a pee dream.*

Conclusions

Lay discourse and terminology for bladder health and function:

- is shaped by historical and life course influences
- influenced by contemporary norms and practices
- embedded in social and interpersonal contexts
- illustrates a preference for diminishing emotional impact and culpability
- reveals an underlying social process of definitional discordance between medical and lay views.

Rely heavily on personal anecdotes shared with family and friends.

Do not exhibit language for translating stories of personal troubles into issues of public health.

Public health educational programs can foster bladder health literacy by targeting family-peer networks; integrating lay perspectives; messaging about health-promoting behaviors rather than clinical conditions.

Contact: Beverly Rosa Williams, PhD:
 Beverlywilliams@uabmc.edu

Innovative Bladder Health Measurement

- **Developing a smartphone bladder application for discovery & dissemination of information**
 - Assess behaviors, adaptations, bladder measures, risk/protective factors
 - Utilize ecological momentary assessment (EMA) so events are recorded close in time to experience

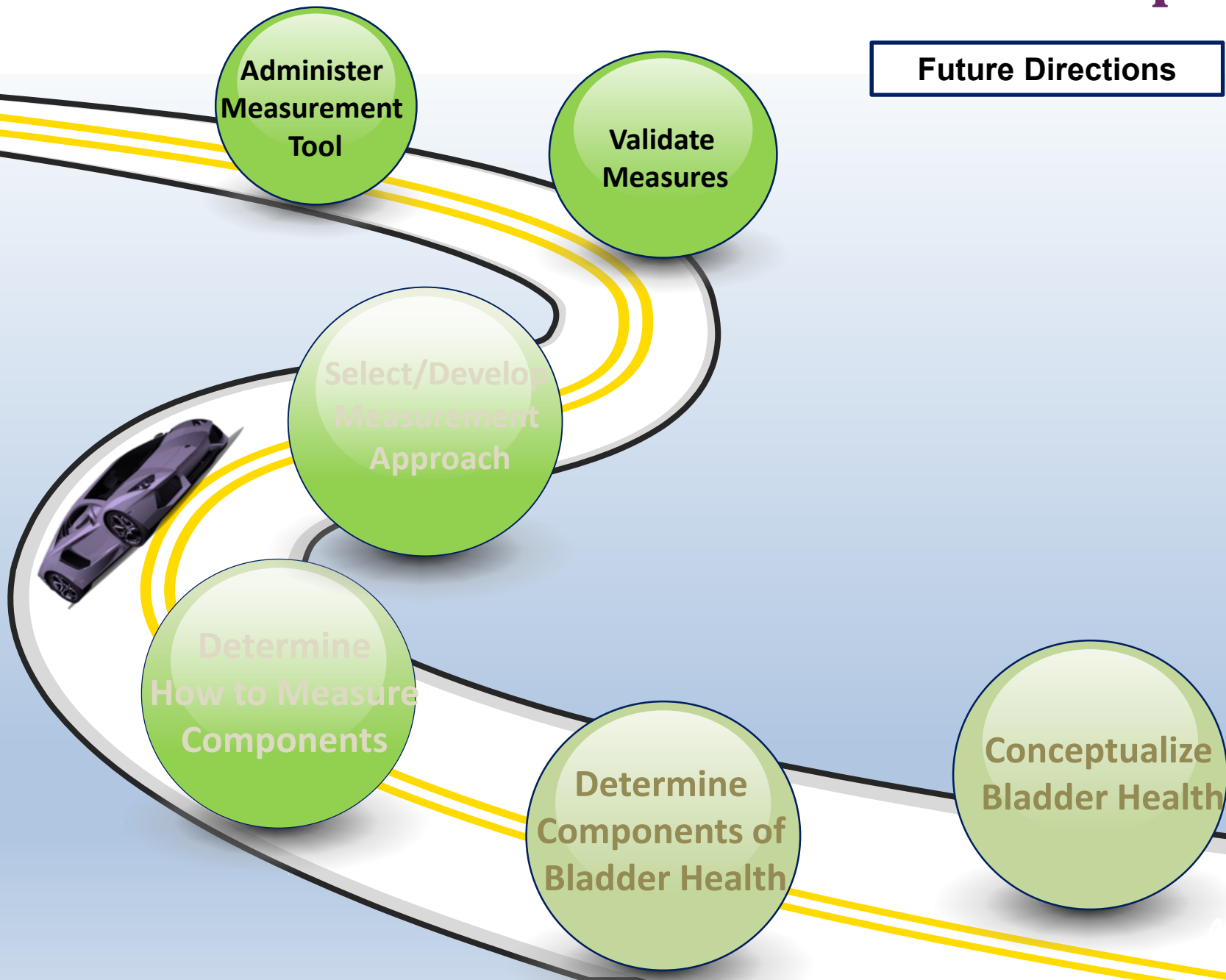


Clarification of Language, Evaluation And Refinement of questions

- **Develop instrument to measure bladder health components**
 - Storage, emptying, bioregulatory, QoL/functional
- **Identified existing items and developed novel questions**
- **Cognitive evaluation**

Bladder Health Measurement Roadmap

Future Directions



Validation of Bladder Health Instrument for Evaluation in Women (VIEW)

- **Develop and establish internal and external validity of a bladder health instrument (BHI) for use in:**
 - Population-based research
 - Clinical research population
 - Post-partum population

Link to ClinicalTrials.gov site:

<https://clinicaltrials.gov/ct2/show/NCT04016298?term=VIEW%2C+Luts&rank=1>

Large observational study of bladder health

- **Determine distribution of bladder health in a national representative sample**
- Use in person visits recruited through regional sampling around our 7 research centers for physical assessments and laboratory assessment
- **Obtain the necessary information to plan future interventions to promote bladder health and prevent LUTS**

Observational Study Aims

- 1. Determine the distribution of bladder health (BH) status.**
- 2. Identify BH trajectories over time and across the life-course.**
- 3. Determine the distributions of knowledge, attitudes, beliefs; and toileting behaviors.**

Observational Study Aims

- 4. Evaluate associations of various candidate risk and protective factors with BH at baseline (based on surveys, clinical assessments and biological specimens, as appropriate).**
- 5. Evaluate associations of various candidate risk and protective factors with changes in BH over time.**

Planned Impact

- **Development and testing of evidence-based prevention interventions**
 - Broad dissemination to the public
 - Integration into health care systems
 - Shaping of health-promoting policies within schools, workplaces, public spaces, and public health agencies
- **Promoting the overall well-being of girls and women**

