NSFB 101: Getting Started with the National Survey of Fertility Barriers

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Introductions, Welcome, & Acknowledgements

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Oklahoma State University
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Theoretical Model and Measurement

Arthur L. Greil
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Why did we do a population based, longitudinal, telephone study of fertility/infertility that includes partners?
It was the most efficient way to answer compelling questions.

Greil’s (1997) critical review of past research on the social psychological impact of infertility showed the need for new data.
Needed:

- A representative sample
- Sufficient N of key racial/ethnic minority groups
- Partners
- Those who have not sought treatment
- Those who are economically deprived
- A longitudinal panel
- Observations before and after a problem
- Comparison groups (no infertility, no helpseeking)
- Recognition of the social construction of infertility
Feasibility Pilot Study

✓ Funding from the University of Nebraska in 2001

✓ 580 women ages 25 to 50 selected by random digit dialing (RDD) in the north central region of the United States and interviewed by telephone.
Emergent Issues

✓ Many women who are infertile by the medical definition do not see themselves as infertile.

✓ Qualitative interviews reveal that many women are “ok either way.”
NICHD: Infertility Pathways and Psychosocial Outcomes

Lynn White (PI)

Co-investigators:
Arthur (Larry) Greil, Mary Casey Jacob, David Johnson, Naomi Lacy, Julia McQuillan, Laurie Scheuble

Data Collection: 2003 - 2010
Specific Aims

✓ Test a general model of medical helpseeking applied to infertility.

✓ Identify the consequences of infertility for individual psychosocial outcomes, identities, and social relationships.
Specific Aims

✓ Assess prevalence of concerns about the ethics of assisted reproductive technologies, including the extent to which ethical concerns act as barriers to treatment.

✓ Provide a public use data set for researchers who are interested in issues of fertility, infertility, helpseeking, and well-being among adults.
NICHD funding to address needs

Unique Features

✓ probability sample
✓ Prospective, longitudinal, design
✓ Modular approach
✓ Special effort to include understudied groups
✓ Nation-wide
Biomedical Cues of Fecundity Impairment

Circumstantial Childlessness

Background Variables
- Racial/ethnic identification
- Gender
- Age
- Parity
- Socioeconomic status
- Relationship status
- Nativity

Perception of a Biomedical Fertility Problem (self-identification)

Cognitive Responses
- Assess the need for, barriers to, and benefits of behavioral responses
- Identity work

Behavioral Responses
- Health care utilization
- Self-care
- Non-medical helpseeking
- Alternative parenting routes

Behavioral Outcomes
- Birth of a child
- Adoption
- Gate-keeper rejection

Psychosocial Outcomes
- General distress
- Substance abuse
- Life satisfaction
- Marital (union) quality
- Satisfaction with social relationships
- Infertility-specific distress
- Childless-specific distress

Key Explanatory Concepts and Variables

Social Cues
- Perceived pressure for children
- Perceived stigma of infertility
- Network members’ experiences
- Social support for treatment
- State laws

Individual Cues
- Identity salience
- Valued goals
- Value of children
- Religiosity
- Fertility intentions & ideals
- Gender ideology

Temporal Cues
- Time perspective
- Life course

Enabling Conditions
- Resources
- Availability of treatment
- Social support
- Continuity of care

Predisposing Conditions
- Health
- Attitudes/knowledge about ART
- Medical locus of control
- Self-esteem

*For women with partners, partner values and couple congruence will also influence responses*
Conceptualizing Infertile women & couples outside of the medical setting

✓ Non-treatment seekers:
  ✓ Blurry distinctions, Diverse, Challenging to categorize
  ✓ Example: Meets the medical definition, does not report trying to conceive, Does not see herself as having a problem

✓ Need New categories:
  ✓ Subfecund with intent
  ✓ Subfecund without intent
  ✓ Relevant for distress and helpseeking
Studying infertility in the population

Need to situate infertility in a broader fertility framework
Proposed Renewal Grant

- Incorporate more measures relevant to fertility
- Extend study to end of reproductive years
- Allow more time for pathways to emerge
- Ability to use more sophisticated statistical techniques
Survey Design and Sample

✓ A Random Digit Dialing (RDD) telephone survey.
✓ Population was all women age 25-45 living in a household with a landline telephone in the contiguous United States.
✓ Included a supplemental sample in geographic areas with 40% or more minority populations.
✓ If more than one woman in the age range lived in the household one was selected at random to be interviewed.
Screening

✓ For women who:
  ✓ already had at least one child
  ✓ planned to have no more children
  ✓ had not had a fertility problem

✓ Only 1 in 5 (20%) were randomly selected for the full interview.
Interviewing the Partners

✓ All women who reported that they had a partner (either married or cohabiting) were asked if we could also interview their partner.

✓ Both male and female (lesbian) partners were selected to be interviewed.

✓ The interview schedules for male and female partners were somewhat different.
Interviewing the Partners

✓ Not all available partners were selected to be interviewed.
  ✓ For main respondents who had experienced a biomedical barrier to fertility; already had biological children; and did not intend to have any more children only a random 20% of these women’s partners were selected for the interview.
  ✓ For main respondents who had not experienced a biomedical barrier to fertility; already had biological children; and did not intend to have any more children only 10% of the partners were selected.
  ✓ Analysis of the partner data requires the use of weights that adjust for this disproportionate sampling.
Calling and Contact Procedures

✓ The RDD sample numbers were purchases from a national sampling firm.
✓ Addresses when available were included and used to mail a pre-notification letter with a small incentive ($2 or $1 bill).
✓ A CATI system was used to conduct the interview.
✓ Interviews were conducted by the Penn State Survey Research Center and the University of Nebraska Bureau of Sociological Research.
Calling and Contact Procedures

✓ Sampled numbers were called 25 or more times until resolved.
✓ Refusal conversions were attempted for most refusals.
Response Rate and Non-response Bias Analysis

✓ Response rates (AAPOR RR4)
  ✓ Screener 53.7%
  ✓ Main interview 37.2%
  ✓ Partner interview 47%

✓ These were similar to response rates obtained in the last decade in RDD national interview surveys.

✓ In today’s current low response rate climate, assessment of possible response bias is critical
Response Rate and Non-response Bias Analysis

✓ Compared demographics with CPS data from the same time period. Of 34 demographic comparisons, 22 were within + or – 1.5 percent.

✓ Largest difference was educational attainment.

✓ Compared fertility and infertility related items with the most recent National Survey of Family Growth (NSFG) estimates.
  ✓ 16.2% of the women in the NSFG had talked to a doctor about pregnancy help compared to 15.6% in the NSFB.
  ✓ Estimates of impaired fecundity using NSFB definitions (NSFG = 15.5%, NSFB = 19.6%).
  ✓ In the NSFG, 83.4% had ever been pregnant compared to 85.3% in the NSFB.
Planned Missing Design

✓ Twenty-two of the Scales in the survey were measured using a planned missing (PM) design.
✓ Reduced the length of the interview and respondent burden.
✓ Most respondents were asked 2/3rds of the items in a scale. A small percent got all items.
✓ Each scale was divided into three parts (A, B, C) and based on a random number one of these parts was not included in that interview.
✓ Some items in some scales were selected to be always included.
Weights

✓ Weights were developed to adjust for design and non-response.
✓ Distributions of demographic variables in the 2005 CPS were used as the population estimates in the development of the weights.
✓ After adjustment for design (disproportionate sampling) a raking method was used to produce the post-stratification weights.
✓ The demographic characteristics used were age, educational attainment, marital status, metropolitan residence, region of the country, and race/ethnicity.
Weights

✓ For the main sample two final weights are included
  ✓ Fwate  Final weight which sums to sample size
  ✓ Fpwate  Final weight which sums to population size

✓ A partner weight was also created to adjust for the disproportionate sampling of partners.
Planned Missing Skips: Imputation

20 Scales Imputed for main R only

- Importance of Parenthood (Q2a-Q2e, excluding Q2b)
- Life Satisfaction (Q8a-Q8d)
- Medical Locus Scale (Q8e-Q8j)
- Treatment Series (Q36b-Q36o)
- Depression Series (Q39a-Q39i, excluding Q39d, Q39h)
- Positive Attitude Series (Q39d, Q39h)
- Attitudes About Getting Pregnant Series (Q43a-Q43d, deleted Q43b)
- Attitudes About Possibility of Getting Pregnant (Passive) Series (Q44a, Q44c)
- Childlessness Social Distress Series (Q45a-Q45e)
- Feelings About Being Childless Series (Negative) (Q46a-Q46i, excluding Q46d, Q46h)
- Feelings About Being Childless Series (Positive) (Q46d, Q46h)
- Social Support Scale (Q48a-Q48d)
- CESD Scale (Q54a-Q54j)
- Medical Science and Pregnancy Scale (Q60a-Q60c)
- Stigma Scale (Q60d-Q60f)
- Ethics Scale (Q61a-Q61f)
- Ethics of Multiple Pregnancy Series (Q62, Q62a)
- Self Esteem Scale (Q63a-Q63c)
- Religiosity Scale (Q79-Q82)
- Economic Hardship Scale (Q87a-Q87c)
Planned Missing Skips: Imputation

✓ Respondents divided into five mutually exclusive groups

✓ Groups based eligibility criteria for specific scales

✓ A separate imputation model was constructed for each group
Planned Missing Skips: Imputation

✓ Single imputation in Stata ICE (Royston 2005)

✓ Fully Normal (FN) assumption (Rubin 1987)

✓ Imputed values rounded based on calibration (Yucel, He & Zaslavsky 2008)
Example of Imputed Variable

✓ q84a
  ✓ label: [CESD1] Was bothered by things usually don’t bother me
  ✓ raw, non-imputed version

✓ flagq54a
  ✓ label: 1 if q54a missing, 0 otherwise
  ✓ dummy variable indicating missingness

✓ q54a_i
  ✓ label: IMPUTED [CESD1]: Was bothered by things usually don’t bother me
  ✓ imputed version
References


Technical Issues

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Concepts and Measures

Julia McQuillan
University of Nebraska - Lincoln
Fertility (reproductive) Barriers

1. Infertility (Subfecundity) with intent
2. Infertility (subfecundity) without intent
3. Surgery regret
4. Other health problems
5. Miscarriage
6. Situational barriers (<> 35)
7. Meet infertility criteria, hoping not to conceive
8. (compared to no barrier)
### Examples of Syntax that goes into creating “subfecund with intent” and “subfecund without intent”

| Syntax Description                                                                                      | Code                                                                                           | Example Code                                                                                           |
|-------------------------------------------------------------------------------------------------------|                                                                                                | -------------------------------------------------------------------------------------------------------|
| Pregnancies after breastfeeding previous child.                                                       | recode q9c2a1_2 (5=0) (else=copy) into bf2nd.                                                 | recode q9c2a1_2 (5=0) (else=copy) into bf2nd.                                                     |
|                                                                                                      | recode q9c2a1_3 (5=0) (else=copy) into bf3nd.                                                 |                                                                                                      |
|                                                                                                      | recode q9c2a1_4 (5=0) (else=copy) into bf4nd.                                                 |                                                                                                      |
|                                                                                                      | recode q9c2a1_5 (5=0) (else=copy) into bf5nd.                                                 |                                                                                                      |
|                                                                                                      | recode q9c2a1_6 (5=0) (else=copy) into bf6nd.                                                 |                                                                                                      |
|                                                                                                      | recode q9c2a1_7 (5=0) (else=copy) into bf7nd.                                                 |                                                                                                      |
|                                                                                                      | recode q9c2a1_8 (5=0) (else=copy) into bf8nd.                                                 |                                                                                                      |
|                                                                                                      | recode q9c2a1_9 (5=0) (else=copy) into bf9nd.                                                 |                                                                                                      |
|                                                                                                      | recode q9c2a1_0 (5=0) (else=copy) into bf10nd.                                                |                                                                                                      |
|                                                                                                      | execute.                                                                                       |                                                                                                      |
|                                                                                                      |                                                                                                 |                                                                                                      |
| Pregnancies from trying.                                                                              | recode q9c2 (1=1) (2 thru 4 = 0) (else=copy) into trypreg1.                                   | recode q9c2 (1=1) (2 thru 4 = 0) (else=copy) into trypreg1.                                        |
|                                                                                                      | recode q9c2_2 (1=1) (2 thru 4 = 0) (else=copy) into trypreg2.                                 | recode q9c2_2 (1=1) (2 thru 4 = 0) (else=copy) into trypreg2.                                     |
|                                                                                                      | recode q9c2_3 (1=1) (2 thru 4 = 0) (else=copy) into trypreg3.                                 | recode q9c2_3 (1=1) (2 thru 4 = 0) (else=copy) into trypreg3.                                     |
|                                                                                                      | recode q9c2_4 (1=1) (2 thru 4 = 0) (else=copy) into trypreg4.                                 | recode q9c2_4 (1=1) (2 thru 4 = 0) (else=copy) into trypreg4.                                     |
|                                                                                                      | recode q9c2_5 (1=1) (2 thru 4 = 0) (else=copy) into trypreg5.                                 | recode q9c2_5 (1=1) (2 thru 4 = 0) (else=copy) into trypreg5.                                     |
|                                                                                                      | recode q9c2_6 (1=1) (2 thru 4 = 0) (else=copy) into trypreg6.                                 | recode q9c2_6 (1=1) (2 thru 4 = 0) (else=copy) into trypreg6.                                     |
|                                                                                                      | recode q9c2_7 (1=1) (2 thru 4 = 0) (else=copy) into trypreg7.                                 | recode q9c2_7 (1=1) (2 thru 4 = 0) (else=copy) into trypreg7.                                     |
|                                                                                                      | recode q9c2_8 (1=1) (2 thru 4 = 0) (else=copy) into trypreg8.                                 | recode q9c2_8 (1=1) (2 thru 4 = 0) (else=copy) into trypreg8.                                     |
|                                                                                                      | recode q9c2_9 (1=1) (2 thru 4 = 0) (else=copy) into trypreg9.                                 | recode q9c2_9 (1=1) (2 thru 4 = 0) (else=copy) into trypreg9.                                     |
|                                                                                                      | recode q9c2_10 (1=1) (2 thru 4 = 0) (else=copy) into trypreg10.                                | recode q9c2_10 (1=1) (2 thru 4 = 0) (else=copy) into trypreg10.                                   |
|                                                                                                      |                                                                                                 |                                                                                                      |
| Worlds of waiting.                                                                                   | recode q9c2a (1=0) (2 thru 4 = 1) (else=copy) into longt1p.                                  | recode q9c2a (1=0) (2 thru 4 = 1) (else=copy) into longt1p.                                       |
|                                                                                                      | recode q9c2a_2 (1=0) (2 thru 4 = 1) (else=copy) into longt2p.                                 | recode q9c2a_2 (1=0) (2 thru 4 = 1) (else=copy) into longt2p.                                     |
|                                                                                                      | recode q9c2a_3 (1=0) (2 thru 4 = 1) (else=copy) into longt3p.                                 | recode q9c2a_3 (1=0) (2 thru 4 = 1) (else=copy) into longt3p.                                     |
|                                                                                                      | recode q9c2a_4 (1=0) (2 thru 4 = 1) (else=copy) into longt4p.                                 | recode q9c2a_4 (1=0) (2 thru 4 = 1) (else=copy) into longt4p.                                     |
|                                                                                                      | recode q9c2a_5 (1=0) (2 thru 4 = 1) (else=copy) into longt5p.                                 | recode q9c2a_5 (1=0) (2 thru 4 = 1) (else=copy) into longt5p.                                     |
|                                                                                                      | recode q9c2a_6 (1=0) (2 thru 4 = 1) (else=copy) into longt6p.                                 | recode q9c2a_6 (1=0) (2 thru 4 = 1) (else=copy) into longt6p.                                     |
|                                                                                                      | recode q9c2a_7 (1=0) (2 thru 4 = 1) (else=copy) into longt7p.                                 | recode q9c2a_7 (1=0) (2 thru 4 = 1) (else=copy) into longt7p.                                     |
|                                                                                                      | recode q9c2a_8 (1=0) (2 thru 4 = 1) (else=copy) into longt8p.                                 | recode q9c2a_8 (1=0) (2 thru 4 = 1) (else=copy) into longt8p.                                     |
|                                                                                                      | recode q9c2a_9 (1=0) (2 thru 4 = 1) (else=copy) into longt9p.                                 | recode q9c2a_9 (1=0) (2 thru 4 = 1) (else=copy) into longt9p.                                     |
|                                                                                                      | recode q9c2a_10 (1=0) (2 thru 4 = 1) (else=copy) into longt10p.                                | recode q9c2a_10 (1=0) (2 thru 4 = 1) (else=copy) into longt10p.                                   |
|                                                                                                      |                                                                                                 |                                                                                                      |
| Count triedpregN = trypreg1 trypreg2 trypreg3 trypreg4 trypreg5 trypreg6 trypreg7 trypreg8 trypreg9 trypreg10. | count longwaitN =q9c2a q9c2a_2 q9c2a_3 q9c2a_4 q9c2a_5 q9c2a_6 q9c2a_7 q9c2a_8 q9c2a_9 q9c2a_10 (2 thru 4). | count longwaitN = q9c2a q9c2a_2 q9c2a_3 q9c2a_4 q9c2a_5 q9c2a_6 q9c2a_7 q9c2a_8 q9c2a_9 q9c2a_10 (2 thru 4). |
|                                                                                                      | recode triedpregN (0=0) (1 thru hi = 1) into triedpregDUM.                                    | recode longwaitN (0=0) (1 thru hi = 1) into longwaitDUM.                                         |
|                                                                                                      |                                                                                                 |                                                                                                      |
| **checked to see if wanted a child during episode, excluded if did not.**                             | compute notwantkid = 0.                                                                       | compute notwantkid = 0.                                                                         |
|                                                                                                      | if q24c = 2 notwantkid = 1.                                                                     | if q24c = 2 notwantkid = 1.                                                                       |
|                                                                                                      | compute sub_int=0.                                                                             | compute sub_int=0.                                                                               |
|                                                                                                      | if ((longtry=1 or tried=1) and notwantkid=0 ) sub_int=1.                                       | if ((longwait=1 or couldve=1) and notwantkid=0) sub_int=1.                                       |
|                                                                                                      | compute sub_noint=0.                                                                           | compute sub_noint=0.                                                                            |
|                                                                                                      | if sub_int=0 and sub_noint=1 sub_nointO=1.                                                      | if sub_int=0 and sub_noint=1 sub_nointO=1.                                                      |
|                                                                                                      |                                                                                                 |                                                                                                      |
Examples of NSFB Measures

Perception of a biomedical fertility problem

Q26 Do you think of yourself as someone who has, has had or might have trouble getting pregnant?
Q26a Do you think of yourself as someone who has or has had fertility problems?

Attitude towards pregnancy now:

Q24c What was your attitude toward getting pregnant at that time? Were you hoping to get pregnant, hoping NOT to get pregnant, or would it have been okay either way?

Attitude towards pregnancy in the past (Q44 for the future)

Q43 I'm going to read you a list of attitudes toward pregnancy. For each, I'd like you to tell me whether you strongly agree, agree, disagree, or strongly disagree.
Q43a I thought I would get pregnant when the time was right.
Q43c I thought if it's God's will, I would get pregnant.
Q43d I worried that I might not be able to get pregnant without medical treatment.
Stages in Medical Helpseeking for Infertility

0. Meet Criteria for Infertility

1. Consider medical help
   - Q27

2. Talk to a doctor
   - Q29

3. Get medical tests
   - Q30

4. Get basic treatment
   - Q31

5. Get ART
   - Q31a
### Examples

<table>
<thead>
<tr>
<th>Non-medical or alternative help seeking actions for fertility problems</th>
<th>Q32c to Q35b</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approaches to educate self about ways to have a baby</td>
<td>Q37 - Q38</td>
</tr>
<tr>
<td>Adoption</td>
<td>Q13</td>
</tr>
<tr>
<td>Fertility specific distress</td>
<td>Q39</td>
</tr>
<tr>
<td>Childlessness Specific distress</td>
<td>Q40</td>
</tr>
</tbody>
</table>
## Examples

<table>
<thead>
<tr>
<th>Category</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived barriers to treatment</td>
<td>Q36</td>
</tr>
<tr>
<td>Attitudes towards medical science of infertility</td>
<td>Q60 a-c</td>
</tr>
<tr>
<td>Perceived Stigma of infertility</td>
<td>Q60 d,e,f</td>
</tr>
<tr>
<td>Importance of Motherhood/Fatherhood</td>
<td>Q1a, Q2a-c</td>
</tr>
</tbody>
</table>

Cautions

Always check Ns

✓ Efficiency essential therefore items were removed if unnecessary or they were not working (e.g. no Q28, Q17 ceased after ~900 cases)
✓ Many complicated skip patterns
✓ “Cohabiting” – requires 3 variables
✓ Hard to generalize about men – only have those in relationships with women
Additional Information

✔ Open ended comments available for many variables

✔ There are dates for most episodes/events

✔ Race/ethnicity: possible select multiple categories
Next:
Skip Patterns, Modules, Wave 2

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Things to Consider and Why

✓ Always check the $n$ on variables of interest.
  ✓ Very quickly get to small number of cases.
  ✓ How are they missing within context of series?
✓ Economic constraints and respondent burden necessitated skip patterns or modules
  ✓ Internally calculated variables
✓ Changes in instrument implemented during Wave 1 data collection (e.g., q17, $n \sim 960$)
Partnered or Not

✓ Using scr1 and scr1a
  ✓ Single
  ✓ Married
  ✓ Heterosexual cohabitation
  ✓ Lesbian partnership

✓ Some items specific to partner status:
  ✓ Partner surgery (q22-q22f1)
  ✓ Helpseeking related to social support of partner (e.g., q32b2)
  ✓ Single or lesbian helpseeking (q27a-27f)
Helpseeking

✓ Self-identified barrier
✓ Survey-identified barrier
  ✓ Subfecundity (q32-q39 series)
  ✓ Long waiting
  ✓ Long trying
  ✓ Breastfeeding
  ✓ Intent
✓ Biomedical barrier (q32-q39 series)
  ✓ Surgically sterile (with regret)
  ✓ Other medical conditions (such as endometriosis)
✓ Miscarriage or still birth only (q120-q122f1)
As expected of Everyone

✓ Socio-Demographics
  ✓ Age (birth year at Wave 2)
  ✓ Relationship status
  ✓ Education
  ✓ Income

✓ Pregnancy history

✓ Importance of motherhood

✓ Physical health and well-being (e.g., CES-D, substance use, life satisfaction)

✓ Health and health care, including ethics of ART
Preview: Wave 2
Data Collection

✓ Wrapping up
✓ Focal (female) completes
  ✓ 1962 of 3709 by phone
  ✓ 100+ in mail surveys
✓ Male partner completes
✓ 741 of 1165
21st-Century Challenges in Longitudinal Data Collection

✓ We did not intend to track everyone.
✓ Specialized population
✓ Structural and social changes
  ✓ Cell phone usage
  ✓ Immigration policies
  ✓ Economic recession
✓ Experiments to overcome attrition
  ✓ Incentive (advance and promised)
  ✓ Nonresponse survey (mode/length)
  ✓ Attrition attitudes
Context for Wave 2

✓ Pregnancies
✓ Reproductive barriers
✓ Helpseeking
✓ All framed as change since their last interview (date given or about 3 years ago).
New Questions

✓ Gender ideology questions
  ✓ I see nothing wrong with giving a little boy a doll to play with. (genat3)
  ✓ Female bosses are harder to work for than male bosses. (genat5)

✓ Couple & partner fertility intentions
  ✓ Have you and your partner ever discussed the number of children you would like to have? (q12b)

✓ Adoption questions expanded
  ✓ International/domestic; out of fosterage

✓ Doctor questions added
  ✓ Race and gender
Always available at . . .

Simple Online Data Archive for POPulation Studies
At PennState

http://sodapop.pop.psu.edu/data-collections/nsfb

In Stata, SAS, SPSS formats
Individual variables possible too
Finally...

✓ Please ask folks to download from Soda Pop
✓ We are submitting a grant for a 3rd wave to focus on the transition to menopause and post reproductive years
✓ Happy to have feedback/comments on the grant
✓ Ideas for additional concepts or measures?
Thank you

Q&A
Break
Brainstorming I
Break/Transition
Brainstorming II