

### **Pain Questions**

- Do you have frequent pain?
- Do you use medication for pain?
- *If yes:* In the past 3 months, how often did you have pain? Some days, most days, or every day?
- Thinking about the last time you had pain, how long did the pain last? Some of the day, most of the day, or all of the day?

### **Pain Questions**

Thinking about the last time you had pain, how much pain did you have, a little, a lot, or somewhere in between a little and a lot?

*If somewhere in between:* Would you say the amount of pain was closer to a little, closer to a lot, or exactly in the middle? Thinking about the last time you had pain, was the pain worse than usual, better than usual, or about the same as usual?

#### **Medication questions**

- Respondents varied in what they counted as pain medication
- Some respondents asked what they should count
- Interpretations:
  - Western vs. traditional or alternative medicine
  - Over-the-counter vs. prescription
  - Ointments vs. ingested tablets

### Frequency Questions

- Interpretations
  - Multiple types of physical pain:
    - long term injury, "usual pain," back pain from chair, disease-related, sore muscles from overwork, rash
  - Two cases mentioned emotional pain
  - Many different parts of the body: back, knees, eye, hand, kidneys, toothache, headache, common cold

### Frequency Questions

- Interpretations
  - Some respondents asked what this meant and how was this different from chronic or constant pain
  - Interpretations of frequent appeared to vary
     Examples: Constant, Everyday, Every week, Every time it rains

#### **Frequency Questions**

 Variation among respondents regarding whether or not they report their pain

(the question is not consistently screening respondents into the pain section)

- Variation appears to relate to:
  - R's interpretation of 'frequent'
  - R's belief in whether the pain warrants being reported
  - Whether R believes their pain is 'usual' and whether R believes the question is asking about 'usual pain'
  - Whether R believed their pain was intense enough to report

#### **How Long Question**

- Little information; difficult to make solid conclusions
- Some respondents are not considering 'the last time'
- Some evidence Rs have difficulty estimating how long the pain lasted
- Possibility that response categories are not clearly distinct to Rs

#### How Much Question

- Little information; difficult to make solid conclusions
- Unlike previous question, there is some evidence that Rs understand the response categories as a scale
- No evidence that 'somewhere in between a little and a lot' is a problem

Thinking about the last time-- how often did you have pain

• Not enough information

#### Thinking about the last time—how long did the pain last

- Little information; difficult to make solid conclusions
- Possible difficulty for Rs to compare episodes and think in trends, especially if pain is not discrete

### Summary of Pain Cognitive Findings

- Lack of evidence limits understanding of response process
- Interpretive variation (which may be related to sociocultural factors)
- Frequency question is problematic for screening Rs into the domain
- Use of pain medication is problematic

### Revisions for Field Test Questionnaire

Lack of information: use field test to fill in gaps

Interpretive variation: use field test to examine comparability

<u>Screener question</u>: added an additional question for screening

Pain medication: eliminated

### Pain Field Test

**Screener Questions** 

Do you have frequent pain?

In the past 3 months, how often did you have pain? Never, Some days, Most days, Every day?

### Pain Field Test

Thinking about the last time you had pain, how long did the pain last? Some of the day, Most of the day, All of the day?

Thinking about the last time you had pain, how much pain did you have? A little, A lot, Somewhere in between a little and a lot?

Would you say the amount of pain was closer to a little, closer to a lot, or exactly in the middle?

### Pain Field Test

Please tell me which of the following statements, if any, describe your pain.

- 1. It is constantly present.
- 2. Sometimes I'm in a lot of pain and sometimes it's not so bad.
- 3. Sometimes it is unbearable and excruciating.
- 4. When I get my mind on other things, I am not aware of the pain.
- 5. Medication can take my pain away completely.
- 6. My pain is because of work.
- 7. My pain is because of exercise.

#### Field Test Data: Maldives and Sri Lanka Percent reporting pain (first 2 questions)



Last 3 month – how often

#### Field Test Data: Sri Lanka and Maldives Intensity of pain – the last time



#### Field Test Data

#### Maldives and Sri Lanka: first 2 Questions

#### Do you have frequent pain?

In the past 3 months, how often do you have pain?

	Yes	No
Never	26	1,089
Some days	459	70
Most days	166	2
Everyday	204	5

n=2,021

#### Field Test Data: Maldives and Sri Lanka

Intensity of pain reported by those respondents answering 'no' to frequent pain

	Maldives	Sri Lanka
Little	23	17
Between	8	2
A lot	17	6

#### Field Test Data: Sri Lanka and Maldives





#### Field Test Data: Maldives How often by Pain Characterization





### **Fatigue Questions**

Do you have frequent feelings of being tired?

In the past 3 months, how often did you feel tired? Some days, most days, or every day?

Thinking about the last time you felt tired, how long did the tiredness last? Some of the day, most of the day, or all of the day?

### **Fatigue Questions**

Thinking about the last time you felt tired, how would you describe the level of tiredness? Mild, moderate or severe?

Thinking about the last time you felt tired, was the tiredness worse than usual, better than usual, or about the same as usual?

### Fatigue Findings

### Frequent question

- Types of fatigue described
  - A lot of physical activity
  - Pain-related
  - Lack of sleep (new baby, anxiety)
  - Side effect from medication
  - Season-related
  - Usual/expected tired
- Some Rs asked for clarification: usual vs. another reason

### Fatigue Findings

#### Frequency Questions

- Factors relation to whether fatigue is reported
  - R's interpretation of 'frequent'
  - R's belief in whether the tiredness warrants reporting
  - Whether R believes their fatigue is 'usual' and whether R believes the question is asking about 'usual tiredness'
- Some Rs answers appear to contradict their 'story';
   Not always clear why they answered the way that they did;

### **Fatigue Findings**

**Remaining Questions** 

• Not enough information to draw conclusions

### Summary of Fatigue Cognitive Findings

Lack of solid understanding

Interpretive variation (which may be related to socio-cultural factors)

 Frequency question is problematic for screening Rs into the domain

### Revisions for Field Test Questionnaire

# <u>Lack of information</u>: use field test to fill in gaps

Interpretive variation: use field test to examine comparability

Screener question: revised

### Fatigue Field Test

In the past 3 months, how often did you feel very tired or exhausted? Never, Some days, Most days, Every day

Thinking about the last time you felt very tired or exhausted, how long did it last?

Thinking about the last time you felt this way, how would you describe the level of tiredness? A little, A lot, Somewhere in between a little and a lot

Would you say it was closer to a little, closer to a lot, or exactly in the middle?

### Fatigue Field Test

Is your tiredness the result of any of the following?
Too much work or exercise?
Not getting enough sleep?
A physical or health-related problem?
Something else? (specify: )

Field Test Data: Maldives and Sri Lanka Percent reporting fatigue



Field Test Data: Sri Lanka and Maldives Reasons for reported fatigue by country





#### Field Test Data: Maldives Reasons for fatigue by frequency of fatigue

#### Some days Most days Everyday



### Field Test Data Maldives and Sri Lanka: Fatigue

# In the past 3 months, how often did you feel tired or exhausted?

Thinking about the last time you felt very tired or exhausted, how long did it last?

		Never	Some days	Most days	Every day	
g	Some of the day	0	257	23	25	66.2%
	Most of the day	0	47	15	13	16.3%
	All of the day	0	34	17	30	17.6%
		0.0%	73.3%	11.9%	14.8%	461

### Field Test Data Maldives and Sri Lanka: Fatigue

# In the past 3 months, how often did you feel tired or exhausted?

Thinking about the last time you		Never	Some days	Most days	Every day	
felt this way, how would you	A little	0	192	15	23	49.8%
describe the level of tiredness?	Some- where in between	0	72	15	9	29.4%
	A lot	0	76	25	35	20.8%
		0.0%	73.6%	11.9%	14.5%	462
### Field Test Data Maldives and Sri Lanka: Fatigue

Thinking about the last time you felt very tired or exhausted, how long did it last?

Thinking about Most of All of Some of the day the day the day the last time you felt this way, how A little 193 23 10 49.3% would you describe the Some-29.7% 67 17 12 level of where in between tiredness? A lot 43 34 59 21.0% 66.2% 16.2% 17.6% 458

## COMMUNICATION

## **Communication Questions**

Using your usual language, do you have difficulty communicating, for example understanding or being understood?

Do people have difficulty understanding you when you speak?

*If Yes:* Do you use any of these forms of communication?

a. sign language? b. hand writing? c. typed or text messages? d. communication or picture board or cards? e. computer assisted communication device? f. an interpreter? g. other? (specify: \_\_\_\_\_)

# **Communication Findings**

- Interpretations
  - Physical problem with mouth or tongue
  - Hearing-related
  - Interpersonal difficulties: shy, talk-too-fast, parent/spouse won't listen
  - Language differences: speak different dialect, speak different language

(particular problem for multi-language contexts)

#### **Cognitive Interview Data:**

#### Basis for communication difficulty reports

30 25 20 15 10 5 0 Cognition Physical Hearing General Social Clarify Missing Language

n=92

#### Cognitive Interview Data: Breakdown of the 'social' theme



### Cognitive Interview Data Thematic differences by gender



#### Cognitive Interview Data: Thematic differences by country



# Summary of Communication Cognitive Findings

Interpretation variation

## **Revisions for Field Test Questionnaire**

Interpretation variation: add follow-up probe to better understand interpretations

## **Communication Field Test**

Using your usual language, do you have difficulty communicating, for example understanding or being understood?

Do people have difficulty understanding you when you speak?

Is this difficulty:

Because you sometimes feel shy or have trouble expressing yourself?

Because of a physical problem with your mouth or tongue? Because you need to understand other languages or different ways of speaking?

Because you sometimes talk too fast?

Because you have trouble hearing?

# **Communication Field Test**

What is your difficulty related to? Interviewer: Record answer

Do you use sign language?

#### Field Test Data Maldives and Sri Lanka: Screening Questions

Using your usual language, do you have difficulty communicating, for example understanding or being understood?

Do people have difficulty understanding you when you speak?

	None	Some	A lot	Can't	
None	1919	35	4	0	96.1%
Some	27	30	3	2	3%
A lot	3	1	12	1	.8%
Can't	0	0	0	1	.1%
	95.6%	3.2%	.9%	.1%	2,038

### 31 Problematic Cases: Following questions



### **Field Test Data**

Reasons for reported communication difficulty (ss)



### Field Test Data Reasons for reported difficulty by country



## Kazakhstan's Experiences