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NINDS User Manual

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Quality of Life in

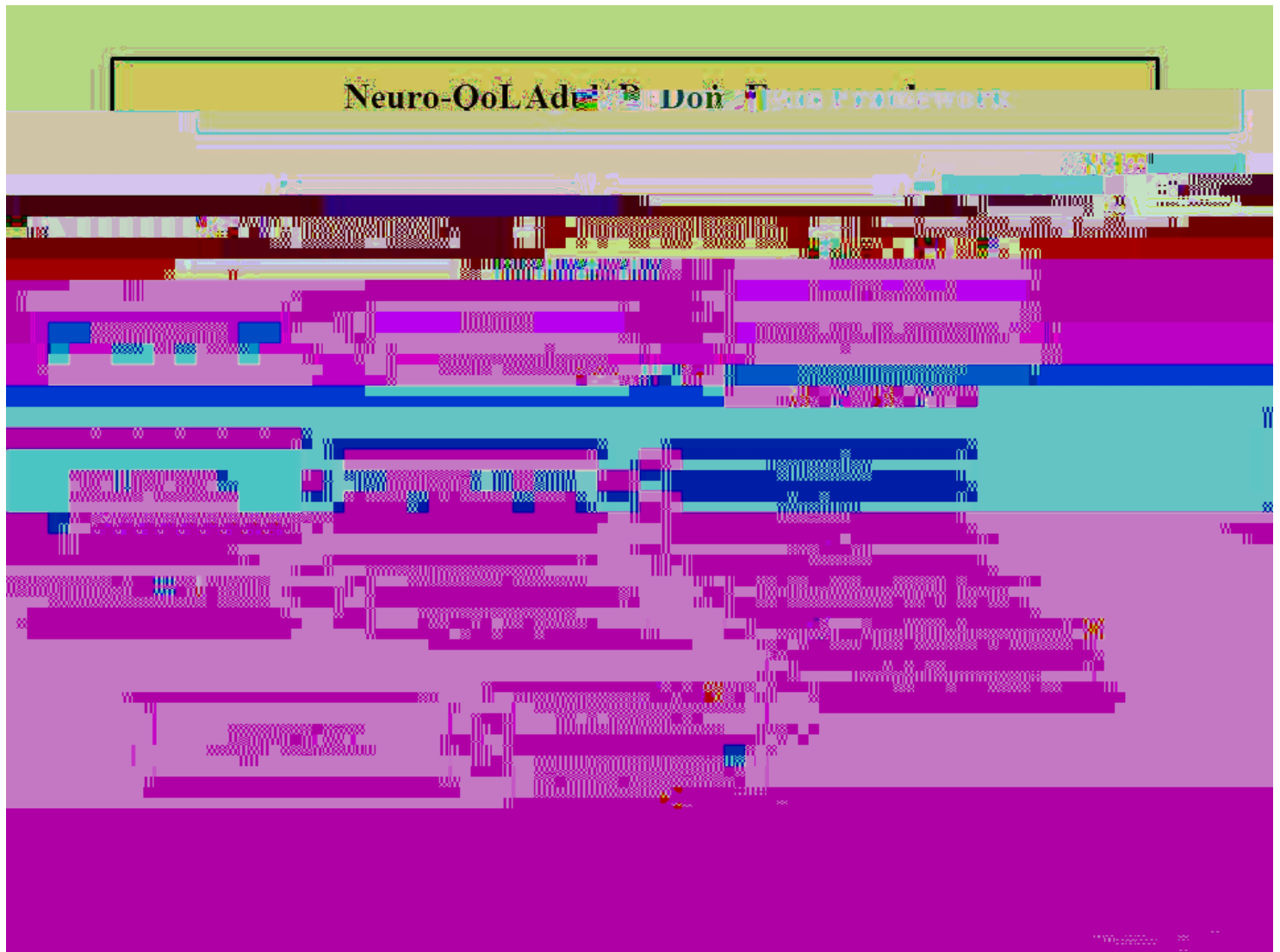
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| 2.1- Domain Definitions | |

1.0- What is Neuro-QoL?

Neuro-QoL is a set of

Table 1: Adult Domain Framework



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Table 2: Pediatric Domain Framework

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Items were selected for inclusion in each domain through a multi-step, iterative process. Specifically, candidate items were reviewed to ensure relevance, translatability, clarity and comprehensive content coverage. The resulting sets of items (“item pools”)

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Table 4: Pediatric Domain Definitions

| / - " + * % 0 + 1 & ' () * + , ! | ' - . + , % + (, 2 ! |
|-----------------------------------|---|
| ' () * + , - ! | . (/ 0 + 1 2 1 (, ! , 3 4 5 6 3 , 2 ! 1 (7 8 4 9 ! : + + 0 * (6 2 ! 9 + 0 1 , + 7 ! , 4 ! : + 1 9 ! ; + < 6 < = ! : + 1 9 : 5 0 (+ 2 2 = ! : + + 0 * (6 2 ! 4 : ! / 1 (* > ? = ! 3 + 0 / 0 + 2 2 (+ 2 2 = ! @ 4 9 9 - ! 1 (7 ! 3 - / + 9 1 9 4 5 2 1 0 ! ; + < 6 < = ! , + (2 * 4 (= ! (+ 9 A 4 5 2 (+ 2 2 = ! 9 + 2 , 0 + 2 2 (+ 2 2 ? = ! |

2.2- Instrument Formats

Most Neuro-QoL instruments are calibrated item banks that can be administered

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2.3-

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field testing for item

item scores by 5, then dividing by 4. Then, subtract 5 from the total prorated sum, multiply by 100 and divide by 20. Thus, when 4 of 5 items were answered, the 0-100 score is computed algebraically as:

$$[(\text{Raw sum score} \times 5 / 4) - 5] \times 100 / 20$$

We do not recommend prorating in cases where fewer than 4 of 5 (or 6) questions (or fewer than 50% of the total number of questions for scales longer than 6 items) have been answered.

Table 6: Direction of Neuro-QoL Scores

| | Domains |
|---|---|
| High scores indicate <u>worse</u> (undesirable) self-reported health | Anxiety, Depression, Anger, Fatigue, Emotional and Behavioral Dyscontrol, Sleep Disturbance, Stigma, Pain |
| High scores indicate <u>better</u> (desirable) self-reported health | Upper Extremity Function – Fine Motor, ADL68Tm /TT3 1 Tf [(c ET Q q sc 36. |

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Table 7b: Adult Depression

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! Table 7d: Adult Upper Extremity Function – Fine Motor, ADL

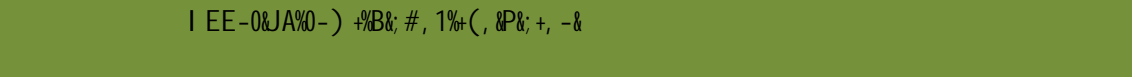
!  I EE-0&JA%0-) +%B&; #, 1%+(, &P&; +, -&

Table 7h: Adult Positive Affect and Well-Being

| / (2+%S-&! ..-1%&*, "&T -\$7=-+, 5&D7+%-) &?@(0%&; (0) & 4! "#\$%! | | | | | |
|---|----------|-------|------------|----------|------|
| V1@! >49+! | aEI>49+! | IC! | V1@! >49+! | aEI>49+! | IC! |
| f! | #W\$! | \$<f! | #\! | %W-\$! | "<&! |
| "Y! | \$Y<#! | #<\$! | #^! | %\<#! | "<&! |
| ""! | \$#<Y! | "<^! | #f! | %^<"! | "<&! |
| "#! | \$\$<\$! | "<W! | \$Y! | %f<Y! | "<&! |
| "\$! | \$\$<\$! | "<&! | \$"! | %f<f! | "<&! |

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Table 7I

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Table 7n

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Table 7r: Pediatric Cognitive Function

R(5, +%S-l; #, 1%+(, &67%-) &?@(0%

!

Table 7t: Pediatric Pain

Table 7u: Pediatric Anger

| | | |
|---|----------|-----|
| ! , 5-0&?@ (0%&; (0) ! 4/- "+*%0+1:! | | |
| V1@!>49+! | aE1>49+! | IC! |

Table 9: Adult Neuro-QoL Item Bank Calibration Sample T-Score Means and Standard Deviations, and Distributions by Percentile!

| X%-) &=*, >! | 3&&%-) 2! | Y! | K-*, ! | ?' ! | /W! | /8N! | /CW! | /WN! | /9W! | /DN! | /DW! |
|-------------------------|-----------|-------|---------|--------|---------|----------|---------|---------|----------|--------|---------|
| ' ()*+, -! | #''! | &"\$! | %^<f\$! | f<>%^! | \$Y<f^! | \$W<Y''! | %#<##! | %^<f\$! | &W<''''! | WY<f%! | W\$<'W! |
| B+/9+22*4 (! H1,*65+ | #%! | &"\$! | %\<W^! | f<Yf! | \$#<^^! | \$#<^^! | %''<&^! | %\<%\! | &%<W! | WY<YY! | W#<YW! |

6.2- Item Statistics

Item-level statistics were calculated for all Neuro-QoL items, including the frequency of endorsement for each response category as well as the mean score and standard deviation, alpha reliability, adjusted alpha reliability, item total correlation, and adjusted item total correlations.

Using MULTILOG and other software as needed, the following information was calculated within an Item Response Theory framework when sample size was greater than 500: 1) item fit indices, $S-X^2$ and $S-G^2$ statistics developed by Orlando & Thissen; 2) exhibition of differential item function on conditions of gender, age, education and diagnosis; 3) item information

7.0- Appendix- User Manual Version 1.0

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NINDS User Manual!

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Quality of Life in Neurological Disorders (Neuro-QOL) Measures

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Version 1.0

September 2010

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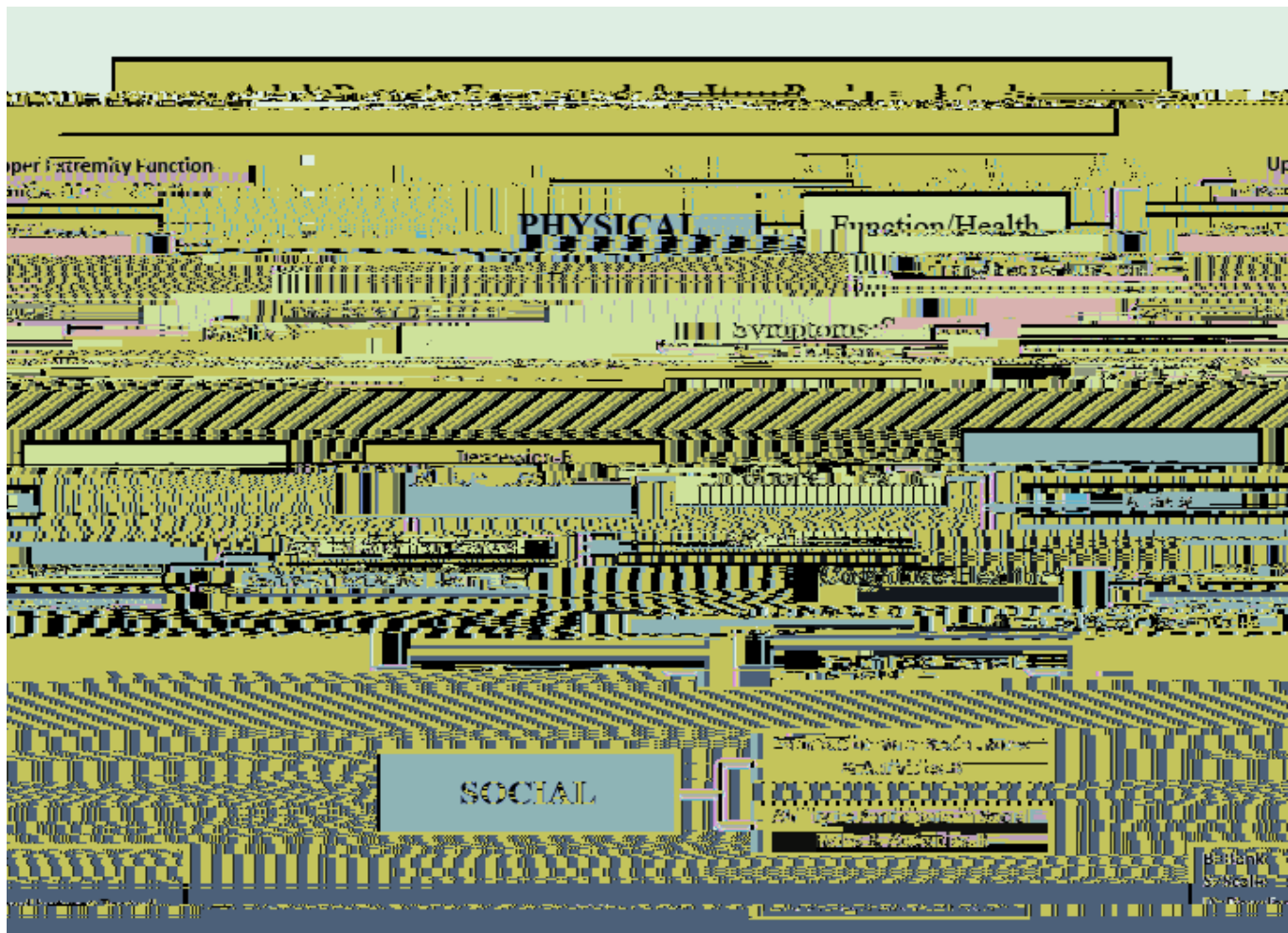
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1.0- What is Neuro-QOL?

Neuro-QOL is a set of self-report measures that assesses

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Table 1: Adult Domain Framework



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Table 2: Pediatric Domain Framework

Items were selected for inclusion in each domain through a multi-step, iterative process whereby candidate items were reviewed to ensure relevance, translatability, clarity and comprehensive content coverage. The resultant sets of items (item pools) underwent

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2.0- Available Neuro-QOL Instruments

2.1- Domain Definitions

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! " # \$ % & ' () * + , !

' - . + , % & (, !

1 1 , * 2 : 1 > , * 4 (! @ * , 3 ! ! 4 > * 1 0 ! V 4 0 + 2 ! 1 1 , * 2 : 1 > , * 4 (! @ * , 3
1 (7 ! ' > , * A * , * + 2 !

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| | |
|-----------------------------------|----------------------|
| / - " + * % 0 + 1 & ' () * + , ! | ' - . + , % + (, 2! |
|-----------------------------------|----------------------|

' / / 0 * + 7 ! 0 4 6 (* , * 4 (! E ! e + (+ 9 1 0 ! P + 9 > + * A + 7 !
0 4 (> + 9 (2 !

&

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2.2- Instrument Formats

Most Neuro-QOL instruments are calibrated item banks that can be administered as a computerized adaptive

4.5- Item Content

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Table 6: Direction of

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Table 7b: Adult Depression

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| |
|------------------------------------|
| ' -E0-22+(, &67+%-) &?@(0%&; (0) ! |
|------------------------------------|

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Table 7c: Adult Fatigue

| ; *%+5# - &67+%-) &?@(0%&; (0) ! ! 4! "#\$%:! | | | | | |
|---|----------|------|------------|----------|------|
| V1@! >49+! | aE >49+! | IC! | V1@! >49+! | aE >49+! | IC! |
| ^! | #f<&! | %<#! | #&! | &#<\$! | "<\! |
| f! | \$%<"! | #<\! | #W! | &\$<\$! | "<\! |
| "Y! | \$W<&! | #<#! | #\! | &%<#! | "<\! |
| "#! | \$f<&! | "<f! | #f! | &W<&! | "<^! |
| "\$! | %Y<\! | "<^! | \$nC\$c3. | | |

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Table 7d: Adult Upper Extremity Function – Fine Motor, ADL

I EE-0&JA%0-) +%B&; #, 1%+(, &P&; +, -&

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Table 7f: Adult Applied Cognition – Executive Function

! EE\$+- "

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Table

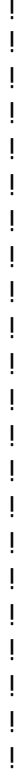
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Table 7i: Adult Positive Affect and Well-Being

| / (2+%S- &! ..-1%&* , "&T -\$\$7=-+, 5& D7+%-) &?@(0%&; (0) & 4! "#\$%:! | | | | | |
|---|----------|-------|------------|----------|-----|
| V1@!!>49+! | aEI>49+! | IC! | V1@!!>49+! | aEI>49+! | IC! |
| f! | #W<\$! | \$<f! | #\! | %W<\$! | "&! |
| "Y! | \$Y<#! | #<\$! | #^! | %\<#! | "<! |

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Table 7j: Adult Sleep Disturbance



For version 1.0 instruments only. Version 2.0 instrument users should refer to the v2.0 scoring tables.

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Table 7k: Adult Ability to

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Table 7I: Adult Satisfaction w/Social Roles and Activities

| ?*%+2.*1%+(, &O<?(1+*\$&V(\$-2&*, " &! 1%+S+%+-2&67+%-) &?@(0%&; (0) ! &A! "#\$%! | | | | | |
|--|----------|------|------------|----------|-------|
| V1@! >49+! | aE >49+! | IC! | V1@! >49+! | aE >49+! | IC! |
| ^! | #^<%! | %<'! | #&! | %"\$<#! | "<\$! |

Appendix –

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Table 7o: Pediatric Depression

| ' -E0-22+(, &67+%-) &?@(0%&; (0) ! 4/-"+*%0+1:! | | | |
|--|----------|-----|------|
| V1@!>49+! | aEI>49+! | IC! | V1@! |

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Table 7r: Pediatric Applied Cognition-General Concerns

| ! EE\$+- " &R (5, +%(, 7[-, -0*\$&R (, 1-0, 2&67+%-) &?@(0%&; (0) ! ! | | | | | |
|--|----------|--------|------------|----------|-------|
| 4/- "+*%0+1:! | | | | | |
| V1@! >49+! | aE >49+! | IC! | V1@! >49+! | aE >49+! | IC! |
| ^! | #%<#! | %<\$! | #&! | %&<\$! | #<\! |
| f! | #\<f! | \$<&! | #W! | %W<#! | #<\! |
| "Y! | #f<f! | \$<\$! | #\! | %\<"! | #<\! |
| ""! | \$"<&! | \$<"! | #^! | %^<Y! | #<\! |
| "#! | \$#<f! | \$<Y! | #f! | %^<f! | #<^! |
| "\$! | \$%<"! | #<f! | \$Y! | %f<f! | #<^! |
| "%! | \$&<\$! | #<^! | \$"! | &Y<f! | #<^! |
| "&! | \$W<\$! | #<^! | \$#! | &#<Y! | #<f! |
| "W! | \$\<\$! | #<\! | \$ \$! | &\$<"! | #<f! |
| "\! | \$^<\$! | #<\! | \$%! | &%<\$! | \$<Y! |
| "^! | \$f<#! | #<\! | \$&! | &&<W! | \$<Y! |
| "f! | %Y<"! | #<\! | \$W! | &\<Y! | \$<#! |

! For version 1.0 instruments only. Version 2.0 instrument users should refer to the v2.0 scoring tables.

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6.0- Instrument Statistics

Descriptive statistics were calculated for the Neuro-QOL measures. The following section provides summary information for each instrument including the overall calibration sample size, alpha reliability, error and reliability at various scale (T) scores, and raw and scale (T) scores for different percentiles. All item banks were calibrated using the Graded Response Model.

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Table 10: P+7*1,9*>2!_+594EbMLIZ,+D!R1(G!l,1(7197!C9949!1(7!V+0*1F*0*,-!F-laE2>49+2!

| X%-) &=* , >! | Y! | ! | Z7?1 (0-2! | | | | | | | | |
|------------------------|-------|--------------|------------|--------|--------|--------|-------|-------|--------|--------|--------|
| | | | 8N! | CN! | UN! | FN! | WN! | GN! | 9N! | 6N! | DN! |
| ' / /0*+7!046(*,*4(!]! | "\"! | IC! | ^<f! | &<%! | #<#! | #<Y! | #<"! | #<#! | &<#! | ^<f! | f<f! |
| | | V+0*1F*0*,-! | Y<#Y! | Y<\!"! | Y<F%! | Y<FW! | Y<FW! | Y<F%! | Y<\\$! | Y<##! | Y<Y\$! |
| ' ()*+,-! | &"\$! | IC! | "Y<Y! | f<\! | ^<"! | \$<^! | "<%! | "<\$! | "<\$! | #<W! | \<"! |
| | | V+0*1F*0*,-! | Y<Y"! | Y<YW! | Y<\$&! | Y<^W! | Y<F^! | Y<F^! | Y<F^! | Y<F\$! | Y<&Y! |
| B+/9+22*4(! | &"\$! | IC! | f<^! | ^<f! | W\$! | \$<Y! | "<\$! | "<%! | "<\$! | \$<Y! | \<f! |
| | | V+0*1F*0*,-! | Y<Y%! | Y<#"! | Y<W"! | Y<F"! | Y<F^! | Y<F^! | Y<F^! | Y<F"! | Y<\$^! |
| H1,*65+! | "\"! | IC! | f<^! | ^<#! | &<#! | \$<%! | #<#! | #<\$! | #<%! | \$<"! | W<Y! |
| | | V+0*1F*0*,-! | Y<Y&! | Y<#^! | Y<\Y! | Y<^!^! | Y<F%! | Y<F&! | Y<F%! | Y<FY! | Y<W%! |

6.2- Item Statistics

Item-level statisti