



# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS





NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

!

"#\$%&'!%'(#!)#\*&#+&,  
%-'(#!./)!0#\$+&'1#2'!%-!3#+4'(!+25!361+2!)#&78\*#9!  
!  
%2!  
!

**Enhanced**

# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

## Enhanced Protections for Uses of Health Data: !

:!)'#; +859(\$!<6+ 1 # ; %&=-!-%&!> ) #\*%25+&,!. 9#9?!!-!@4#\*'&%28\*+44,!A%44#\*'#5!+25!B&+29 1 8''#5!3#+' (!0+'+  
!

### Table of Contents

!

B+C4#!%-!A%2'#2'9//////////	//////////	G
@J#*6'87#!) 6 1 1 +&, //	//////////	K
L2'&%56*'8%2 //	//////////	DD
M6&\$%9#!+25!) *%\$# //	//////////	DD
B#& 1 82%4%N, //	//////////	DD
<i>"Secondary Uses" of Health Data</i> //////////	//////////	DD
Ter	H	

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(\$!<&+ 1 # ; %&=!-%&!>) #\*%25+&,!. 9#9?!%~!@4#\*'&%2!+44,!A%44#\*'#5!+25!B&+29 1 8''#5!3#+4'(!0+'+  
!  
I/!OC9#&7+'8%29!+25! " #\*% 1 1 #25+'8%29!-%&!0+'+!

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(\$!<+ 1 # ; %&=-%&!> ) #\*%25+&, ! . 9#9?!% -!@#\*'%&2!+44, !A%4#\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+'+  
!

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(\$!<+ 1 # ; %&=-%&!>) #\*%25+&,!. 9#9?!%!@4#\*'&%2!+44,!A%44#\*'#5!+25!B&+29 1'8''#5!3#+4'(!0+'+  
!

%\$\$%&'628',!-%&!#--8\*8#2'+\*'#99!'%! 1 %&#!\*% 1 \$&# (#2987#!5+'!+25!\$%'#2'8+4!  
85#2'8-8\*+'8%2!%-!2# ; !%\$\$%&'628'8#9!-%&!8 1 \$&%7# 1 #2'!82!\*+&#!5#487#&, /!9

# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

## Enhanced Protections for Uses of Health Data: !

:!)'# ; +&59(8\$!<8+ 1 # ; %&=-!-%&!>) #\*%25+&, ! . 9#9?!%!@##\*%&2\*+4, !A%4##\*#5!+25!B&+29 1 8''#5!3#+4' (!0+' + !

o! <%&!&#+ ' 1 #2'F!\$+, 1 #2'F!+25! (#+4' ( \*+&#!%\$##+ '8%29!+9!5#-82#5!625#&! ( #! 3LM : : !M&87+\* , ! " 64#F!\*% 1 1 #2' #89!&+89#5! (#!8996#!' (+!' (#!+&#+!%-! > (#+4' ( \*+&#!%\$##+ '8%29?! ; +9!C&%+5!82!9\*%\$#!+25!2%!' ; #4!625#&9%'5/!L' ; +9! 2%'#5!' (+!'&69!' 1 + , !-+\*'%'&! 1 %&#! (#+784, !' (+2!4+ ; 9!+25!&#N64+'8%29! ; 8' (! &#9\$\*#!'!%182587856+49!+25!' (##&!\$887+\* , !\*%2\*#&29!+9!69#9!%-!5+'+! 1 %7#5! -6&' (#&!+ ; + , !-&% 1 !' (#!2#J69!%-!\*+&#!

!!

o! <%&!` 6+48' , ! 1 #+96&# 1 #2'F!&\$%&'82Nf!+25!8 1 \$&%7# 1 #2'!+\*'878'8#9F!' ( # ` 6#9'8%2! ; +9!&+89#5!+9!'%! ; ( #' ( #&! ( #!3LM : : !5#-828'8%2!%-! (#+4' ( \*+&#!%\$##+ '8%29! +\$5\$8#9/! " #78# ; 82N!' (89!5#-828'8%2!+25!\*%2985#&82N!'#9'8 1 %2, F!SAT 3 ) ! C#48#7#9!' (+!'\*6&&#2'!` 6+48' , !+\*'878'8#9!&# 1 +82! ; 8' (82!' (#!3LM : : !5#-828'8%2!%-! (#+4' ( \*+&#!%\$##+ '8%29!+25!' (+!'#2 (+2\*82N!'&+29\$+&#2\* , !+25!+\$5\$ , 82N!82'8&2+4! %7#&98N ('! 1 + , !+44+ , !+2 , !\*%2\*#&29/!

!

o! <%&!&#9#+&\* (F!8'! ; +9!%C9#&7#5!' (+!' ( #&#! ; #&#!7+88+'8%29!+ 1 %2N!-#5#&+4! +N#2\* , !&#N64+'8%29!' (+!' ; %645!C#2#-8'!-&% 1 ! ( +& 1 %28P+'8%2!/B (###! ; +9!+49%! \*%2\*#&2!#J\$&#99#5!' (+!'!+9!` 6+48' , !+\*'878'8#9!+&#!C#\*% 1 82N! 1 %&#! 9%\$ (89'8\*+'#5F!9% 1 #! 1 + , !C#1#7%4782N!82'!&#9#+&\* (F!\$%'#2'8+44, ! ; 8' (%6'!' ( #! \$&%\*#\* '8%29!+--%&5#5!C , !&#9#+&\* (!%2! (6 1 +2!96C/#\*!'&#N64+'8%29!/B (#!2##5!'%! 589'82N689 (!C# ; ##2!` 6+48' , !+25!&#9#+&\* (!+25!'%!+\$&%\$&8+'#4 , !9 ( # \$ ( #&5! ` 6+48' , !82'!&#9#+&\* (! ; +9!5#9\*88C#5/!

!

o! . 9#!%-! (#+4' (!5+'+!827%4782N! 1 %2#'+&, !#J\* (+2N#! ; +9!85#2'8-8#5!+9!+2! 82\*#&+982N!\*%2\*#&2!/ e (84#!' (###!+&#!829'+2\*#9! ; (###! 1 %2#'+&, !#J\* (+2N#!-%&! (#+4' (!5+'+!89!+\$&%\$&8+'#F!' (###!+&#!69#9!' (+!' 1 + , !&#964'!82! (+ 1 F!96\* (!+9! ; ( #2!82587856+49! 1 + , !2%'!+2'8\*8\$+ #!+!69#!+25!+9!+!&#964'!&#56\*#!' ( #8&'&69'! 82!' (##&!\$&%785#&9F!'%&! ; ( #2!' (###!89!6256#!82-46#2\*#!%7#&! (#+4' ( \*+&#! 5#\*898%29!+9!+!&#964'!%-!+!69#F!'%&! ; ( #2!\$&%\*#\*#5! (#+4' (!82-%& 1 +'8%2!89!2%'! \$&%\$&#4 , !5#]85#2'8-8#5!+25!89!69#5!'%! +&N#! 1 +&=#'82N!'!%182587856+49/!

### Guiding Principles

SAT 3 )!5#7#4%\$9!N68582N!\$882\*8\$4#9!'!#296&#!8'9!&#\*% 1 1 #25+'8%29!+&#!\*%2989'2'! ; 8' ( ! ' (#!'9'8 1 %2, ! (#+&5!+25!8'9!' +9=!/SAT 3 ) !5#7#4%\$5!' (#!-%44% ; 82N!N68582N!\$882\*8\$4#9!'%! #7+46+'#!#+\* (!&#\*% 1 1 #25+'8%29!-%&!#2 (+2\*#5!\$&%\*#\* '8%29!-%&!69#9!%-! (#+4' (!5+'+!82!48N ('! %-!2# ; !#\* (2%4%N8#9!/SAT 3 ) !&#\*% 1 1 #25+'8%29!-%&!\$&%\*#\* '8%29! ; 844\_!!

D/! 1 +82'+82!%&!9'&#2N' ( #2!82587856+49! (#+4' (!82-%& 1 +'8%2!\$887+\* , !

G/! #2+C#4!8 1 \$&%7# 1 #2'9!82!' (#! (#+4' (!%-! : 1 #88\*+29!+25!' (#! (#+4' ( \*+&#!5#487#&, ! 9, 9' # 1 !%-!' (#!S+'8%2!

Q/! -+\*848+'#!69#9!%-!#4#\*'8%28\*! (#+4' (!82-%& 1 +'8%2!

K/! 82\*#&+9#!' (#!\*4+88' , !+25!628-%& 1 !625#&9'+2582N!%-!4+ ; 9!+25!&#N64+'8%29!\$&#+8282N! '%!\$887+\* , !+25!9#\*688' , !%-! (#+4' (!82-%& 1 +'8%2!



**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(\$!<&+ 1 # ; %&=-%&!>) #\*%25+&,!. 9#9?!%-!@4#\*'&%2!+4, !A%4#\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+'+

!

W/! C6&45!6\$%2!#J89'82N!4#N894+'8%2!+25!&#N64+'8%29! ; (#2#7#&!\$%99&C4#!!

!

Z/! 2%'!&#964'!82!6256#!+5 1 8289'&+'87#!C6&5#2!

!

***Recommendations***

***In making its recommendations, NCVHS observes that currently, the health industry relies upon the HIPAA construct of covered entities and business associates: r0 12 72.00001 10.siness***

**NATIONAL**

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'#; +&59(\$!<+ 1 # ; %&=-%&!>) #\*%25+&,!. 9#9?!%~!@4#\*'&%2!+4, !A%4#\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+'+  
!

C/! 33)!

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATIS**

# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

## Enhanced Protections for Uses of Health Data: !

:!)'# ; +&59(8\$!<&+ 1 # ; %&=-!-%&!>) #\*%25+&, ! . 9#9?!%~!@##\*!&%28\*+4, !A%4##\*#5!+25!B&+29 1 8''#5!3#++! (!0+ '+ !

## Introduction

### Purpose and Scope

! : '!&+29-%& 1 + '8%2!82! (#+4' (!+25! (#+4' (!\* +&#!89!C#82N!#2+C4#5!C, ! (#+4' (!82-%& 1 + '8%2! '#\* (2%4%N, !X3LBY!A4828\*+44, !88\* (!82-%& 1 + '8%2!89!2% ; ! 1 %&#!&#+584, !+7+84+C4#F!82!+! 1 %&#! 9'86\* '6&#5!-%& 1 + 'F!+25!+C4#!'!C#!#4#\* '8%28\*+44, !#J\* (+2N#5!' (&%6N (%6'!) (#! (#+4' (!+25! (#+4' (\* +&#!\*%2'8266 1 /! : 9!+!8#964'F!' (#!82-%& 1 + '8%2!\*+2!C#!C#'#&!69#5!-%&! `6+48', ! 8 1 \$8%7# 1 #2'F!\$6C48\*! (#+4' (F!+25!&#9#+&\* (F!+25!\*+2!98N28-8\*+2'4, !\*%2'88C6'#!'! 8 1 \$8%7# 1 #2'9!82! (#+4' (!+25! (#+4' (!\* +&#!-%&!82587856+49!+25!\$%\$6+'8%29/! : 9!' (#! '&+29-%& 1 + '8%2!'!%!3L@!+25!+!S 3LS!%\* \*6&9F!' (#&#!89!+2!%C48N+'8%2!'!+996&#!+\$\$8%\$88+'#! 5+'+!9'# ; +&59(8\$!%7#&! (#!69#9!%-!82587856+49a! (#+4' (!5+'+! /!

! B (#!O--8\*#!%~!' (#!S+'8%2+4!A%&%582+'%&!-%&!3#+4' (!L2-%& 1 + '8%2!B#\* (2%4%N, !XOSAY!+9=#5! ' (#!S+'8%2+4!A% 1 1 8''###!%2!T'8'+4!+25!3#+4' (!) '+ '89'8\*9!X SAT 3 ) Y!'!%5#7#4%\$! &#\*% 1 1 #25+'8%29!-%&!+!\*%2\*#\$'6+4!+25!\$%48\* , !-8+ 1 # ; %&=#!'!C+4+2\*#!' (#!C#2#-8'9F! 9#298'878'8#9F!%C48N+'8%29F!+25!\$8%#\* '8%29!%-!69#9!%-! (#+4' (!5+'+F!82\*46582N!-%&!69#9!%-! (#+4' (!5+'+!-%&! `6+48', ! 1 #+96&# 1 #2'F!&#%&'82NF!+25!8 1 \$8%7# 1 #2' /! /!

! L2!5#7#4%\$82N!&#\*% 1 1 #25+'8%29!'!%!' (#!) #\* &#'+&, !%-!3#+4' (!+25!36 1 +2!) #878\*#9!X33 ) YF! SAT 3 ) !+5%\$'#5!N68582N!\$882\*8\$4#9!' (+ \_! 1 +82'+82!%&!9'8#2N' (#2!82587856+4a9! (#+4' (! 82-%& 1 + '8%2!\$887+\* , d!#2+C4#!8 1 \$8%7# 1 #2'9!82! (#+4' (!+25! (#+4' (!\* +&#d!-+\*848'+#! +\$\$8%\$88+'#!69#9!%-!##\* '8%28\*! (#+4' (!82-%& 1 + '8%2!d!82\*8#+9#!' (#!\*4+88', !+25!625#89'+2582N! %~!4+ ; 9!+25!&#N6+'8%29!\$88'+8282N!'!82-%& 1 + '8%2!\$887+\* , !+25!9#\*688', d!C6845!6\$%2! #J89'82N!4#N894+'8%2!+25!&#N6+'8%2! ; (#2#7#&!+\$\$8%\$88+'#d!+25!2%!'!&#964'!82!6256#! +5 1 8289'&+'87#!C6&5#2! /!

! B (#!SAT 3 ) !8#\*% 1 1 #25+'8%29F!' (#&#-%&#F!+&#!82'#25#5!'!\$8%785#!+!56&+C4#!5+'+! 9'# ; +&59(8\$!-&+ 1 # ; %&=#!-%&!+44!69#9!%-! (#+4' (!5+'+!+!C, !+44!69#89F!88&#9\$#\* '87#!%-!3LM : : ! \*%7#&#5!#2'8', !9'+ '69!B (89!-&+ 1 # ; %&=#!+25!%!' (#&! 1 #+96&#9!+44% ; !-%&!+!&+298'8%2!'!%\* \*6&! '%! (#+4' (!82-%& 1 + '8%2!#J\* (+2N#!X 3L@YF!+!S 3LSF!+25!C# , %25! /!

### Terminology

#### “Secondary Uses” of Health Data

! : 9!+2!828'8+4!9'#\$!82!5#7#4%\$82N!8'9!&#\*% 1 1 #25+'8%29F!SAT 3 ) !#4#\*#5!'!%5#9\*88C#!#+\* (! 69#9!%-! (#+4' (!5+'+!829'#+5!%-!6982N!' (#!'#& 1 !secondary uses, !+9! (+9!', \$8\*+44, !C##2!69#5! '%! \*%44#\* '87#4, !5#9\*88C#!+! ; 85#!7+88#', !%-!69#9!%-! (#+4' (!5+'+!) #\*%25+&, !69#9!%-! (#+4' (! 5+'+! (+9!2%!9'+25+&5!&#-#&#2\*# /!) % 1 #!'!%2985#&!\$88 1 +&, !69#9!%-! (#+4' (!5+'+!+9!' (%9#! &#4+'82N!'!%588#\* '!\* +&#!%24, F!+25!+44!%!' (#&!69#9!9#\*%25+&, /!O' (#&9!'!%2985#&!\$88 1 +&, !69#9! 82\*46987#!%-!\$+, 1 #2'!+25! (#+4' (\* +&#!%\$88+'8%29!+9!5#-82#5!625#&! ' (#!3LM : : !M887+\* , ! " 64#!L2!+558'8%2F!N&%6\$82N!7+88%69!69#9!%-! (#+4' (!5+'+!625#&! ' (#!&6C88\*!%-!9#\*%25+&, ! 69#9! 1 +, !&#964'!82!'&#+82N!+44!69#9! ; 8' (82!' (+!'!4+99!' (#!9+ 1 #! /!O--8&#2'!+\$\$8%+\* (#9! 1 +, !

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(\$!<&+ 1 # ; %&=-!-%&!>) #\*%25+&,!. 9#9?!%~!@4#\*'&%28\*+44,!A%44#\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+' +  
!  
C#!2##5#5!'%!+--%&5!\$&%'#\*'8%29!-%&!58--#&#2!' , \$#9!%-!69#9/!<82+44, F!' (#!'#& 1 !9#\*%25+&, !  
69#!\* +&&8#9!' (#!'\*%22%'+'8%2!' ('+'! (#9#!69#9!%~! (#+4' (!5+'+!+&#!4#99!8 1 \$%&'+2!' ('+2!' (#&!  
69#9/! : 9!+!&#964'F!SAT3 )!6&N#9!' ('+'! (#!'#& 1 !>9#\*%25+&, !69#?!C#!+C+25%2#5!82!-+7%&!%~!  
#J\$48\*8'!5#9\*88\$'8%2!%~!#+\* (!69#!%~! (#+4' (!5+'+F!96\* (!+9!>&#%&'! \*% 1 1 628\*+C4#1589#+9#!'%!  
\$6C48\*! (#+4' (F?!>69#! (#+4' (!5+'+!-%&!` 6+48', !8 1 \$&%7# 1 #2'?!%&!>=#\$! (#+4' (!82-%& 1 +'8%2!82!  
1 ,!\$#&9%2+4! (#+4' (!&#\*%&5/?!!

*Terms Describing Health Data*

!  
B (#&#!+&#!-%6&!=# ,!'#& 1 9!5#9\*88C82N! (#+4' (!5+'+f82-%& 1 +'8%2<sup>G</sup>' ('+!+&#!8 1 \$%&'+2'!82!' (#!  
\*%2'J'!'%~! (89!&#%&'!+25!' (# ,!+&#!5#9\*88C#5!C#4% ; /!!  
!  
! *Individually identifiable health information* 89!5#-82#5!82!3LM : : !+9!>+!96C9#!'%~!  
(#+4' (!82-%& 1 +'8%2F!82\*46582N!5# 1 %N&+\$ ( 8\*!82-%& 1 +'8%2!\*%44#\*'#5!-8% 1 !+2!  
82587856+4!+25\_XDY!89!\*&#+'#5!%&!&#\*#87#5!C ,!+! (#+4' (\*+&#!\$&%785#&F! (#+4' (!\$4+2F!

# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

## Enhanced Protections for Uses of Health Data: !

:!)'# ; +859(\$!<8+ 1 # ; %&=-!%&!>) #\*%25+&, !. 9#9?!%!@##\*%&28\*+4, !A%4##\*#5!+25!B&+29 18''#5!3#++! (!0+ +!  
!'  
' (&%6N (%6'!) (89!&#%\$%'F!82!'#9'8 1 %2, !+25!&#4+'#5!5%\*6 1 #2'9F!+25!625#&9\*%&#9!' (#!  
C&%+5#&!2##5!-%&!9'+25+&58P+'8%2!%-'!#& 1 9!/<%&!#J+ 1 \$4#F!' (#!'#& 1 9!de-identification!  
anonymization!+25!pseudonymization!+&#!+4!+99%\*8+'#5! ; 8' (!\$&% '#\*'82N!85#2'8', F!C6'!  
1 +, !C#!+\$\$48#5!7+&&+C4, !82!58--#&#2!'\*%2'#J'9F!9% 1 #!%-'! ; (8\* (!587#&N#!-% 1'!) (#!3LM : :!  
5#-828'8%2!%-!5#]85#2'8-8\*+'8%2!%&!48 1 8'#5!5+'+!9#!'XgDZK/WDKX+YF!XCYF!X\*YF!+25!X#YF! (#&#82!  
&#-#&&#5!'!+9!HIPAA de-identification/!

### Organization of Report

B (89!&#%\$%'!82\*465#9\_!

D/! **Background!**c!5#9\*88C82N!' (#!\$&%\*#99!SAT 3 )!625#&'%%=!'! (#+&!#9'8 1 %2, !+25!  
%C'+82!82\$6'!%2!' (#!\*6&#2'!9'+#!+25!8996#9!&#4+'#5!'!69#9!%-'! (#+4' (!5+'+'! (+!  
-%& 1'!) (#!C+989!-%&!') (#!&#\*% 1 1 #25+'8%29/!

G/! **Testimony and Considerations!**c!96 1 1 +&8P82N!' (#!'#9'8 1 %2, !\*%2\*#&282N!' (#!  
\*6&#2'!9'+#!%-'! (#+4' (!5+'+!69#9!+25!85#2'8-, 82N!98N28-8\*+2'!N+\$9!82!\$&% '#\*'8%29!-%&!  
' (#9#!69#9! ; (8\* (! 1 +, !C#!+ 1 \$48-8#5!+9! (#+4' (!82-%& 1 + '8%2!'#\* (2%4%N, !X3LBY!+25!  
3L@!C#\*% 1 #! 1 %&#!\$&#7+4#2'!/!

Q/! **Guiding Principles!**c!85#2'8-, 82N!' (#!98!N68582N!\$882\*8\$4#9!' (+'!) (#4\$#5!58&#\*!'! (#!  
&#\*% 1 1 #25+'8%29/!

K/! **Observations and recommendations!**c!\$&%78582N!%C9#&7+'8%29!+25!  
&#\*% 1 1 #25+'8%29!5#9\*88C#5! ; 8' (82!+!-&+ 1 # ; %&=-!%-!5+'+!9' # ; +859 (\$\$!!

+/! L28'8+4!-%\*69!89!%2!\$&+\*8\*+4!9%46'8%29!' (+!'\*+2!C#!8 1 \$4# 1 #2'#5!'!%5+, !'!  
+55&#99!%7#&+4!N+\$9!82!+\*%62'+C848', F!'&+29\$+&#2\* , F!82587856+4!\$+&'8\*8\$+'8%2F!  
5#]85#2'8-8\*+'8%2F!9#\*688', !9+-#N6+859F!+25!5+'+'! 6+48', !+25!82'#N88', /!!

C/! ) \$#\*8-8\*!'+'#2'8%2!89!+49%!\$+85!'!%&#\*% 1 1 #25+'8%29!-%&!69#9!%-'! (#+4' (!5+'+'!  
' (+!'&#! 1 %9'!8 1 1 #58+'#4, !#2 (+2\*#5!'! (&%6N (!3LB!+25!3L@!c!` 6+48', !  
1 #+96&# 1 #2'F!&#%&'82NF!+25!8 1 \$&%7# 1 #2'!+25!&#9#+&\* (/!

\*/! B (#&#!+&#!&#\*% 1 1 #25+'8%29!-%&!#7+46+'8%2!%-'!+\$&%+\* (#9!968'+C4#!%\$&% '#\*!'!  
' (#&!+25!\$%'#2'8+44, !62+2'8\*8\$+'#5!69#9!+9!'&+298'8%2!89! 1 +5#!'!+!S3LS/!!

5/! " #\*% 1 1 #25+'8%29!' (+'! 1 +, !'+=#!4%2N#&!%!8 1 \$4# 1 #2'!+&#! 1 +5#!-%&!  
+558'8%2+4!\$887+\*, !\$&% '#\*'8%29F!+2'8]589\*88 1 82+'8%2F!+25!9+'#14+ ; ! 1 +\$\$82N/!

## Report Background

### NCVHS Coverage of Topic

SAT3 )! (+9!+!4%2N! (89'%&, !%-'!#2N+N82N!\$6C48\*!'\*% 1 1 #2'F!+2+4, P82N!8996#9F!+25! 1 +=82N!  
&#\*% 1 1 #25+'8%29!'! (#!) #\*#&#+&, !%-!3 3 )!%2!69#9!%-'! (#+4' (!5+'+!-% 1 ! 1 64'8\$4#!  
\$#&9\$#\*'87#9/!!

# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

## Enhanced Protections for Uses of Health Data: !

:!)'# ; +&59(8\$!<&+ 1 # ; %&=-!-%&!>) #\*%25+&!, !. 9#9?!%~!@##'&%28\*+4, !A%4##\*#5!+25!B&+29 1 8''#5!3#++! (!0+ + !  
!

L2!DEEZFI!M6C48\*!i + ; !DHKJDEDF! (#!3#++! (!L296&+2\*#!M%&'+C848', !+25! : \*\*%62'+C848', !: \*'!  
X3LM : : Y!%-!DEEZFI!58&#\*'#5!' (#!SAT3)! '%!C#!&#9\$%298C4#!N#2#&+44, !-%&!+578982N!' (#!  
) #\* &#'+&, !%-!333)!+25!' (#!A%2N&#99!%2!' (#!9'+ '69!%-!' (#!8 1 \$4# 1 #2'+ '8%2!%-!' (#!3LM : : !  
: 5 1 8289'&+'87#!) 8 1 \$48-8\*+'8%2!\$8%7898%29/!) 6C9#` 6#2'4, F!SAT3)! (+9!8996#5!+226+4!  
&#%\$&'9!%2!7+&8%69!3LM : : !\*% 1 \$48+2\*#!8996#9/!M6C48\*!i + ; !DHKJDED!+49%!58&#\*'#5!' (#!  
SAT3)! '%!j9'65, !' (#!8996#9!&#4+'#5!'%!' (#!+5\$%8%2!%-!1628-%& 1 !5+'+'9'+25+&59!-%&!\$+'8#2'  
1 #58\* +4!&#\*%&5!82-%& 1 +'8%2!+25!' (#!#4#\*'8%28\*!#J\* (+2N#!%-!96\* (!82-%& 1 +'8%2F?! ; (8\* (!  
N#2#&+'#5!9#7#&+4!9# '9!%-!&#\*% 1 1 #25+'8%29/!!!

SAT3)! (+9!C#2!+'!' (#!-%&#-8%2'!%-!\$8% 1 %'82N!3LB!+25!3L@/!L2!GHHDF!SAT3)!  
N#2#&+'#5!+1&#%&'!%2!*Information for Health: A Strategy for Building the National Health  
Information Infrastructure*!9\$#\*8-8\*+44, !+55&#9982N!' (#!2##5!-%&!+!\$8&7+'#F!9#\*6&#F!+25!  
#--#\*'87#!S3LS/!!*Recommendations on the Initial Functional Requirements for a NHIN!*  
; +9!5#487#&#5!'%!' (#!) #\* &#'+&, !%2!O\* '%C#!QHF!GHHZ/!M8&7+\* , !8996#9! ; 8' (82!+!S3LS! ; #&#!  
+55&#99#5!82!' (#!SAT3)!b62#!GGF!GHHZ!4#''#&!&#%&'!F!*Recommendations Regarding  
Privacy and Confidentiality in the Nationwide Health Information Network!*! : 2!6\$5+ #'!%!  
' (#!M8&7+\* , !i #''#&! ; 8' (!&#9\$#\*!'!%!\*%7#&+N#!%-! (#+4' (\*+&#!+25!'% (#&!%&N+28P+'8%29! ; +9!  
5#487#&#5!'%!' (#!) #\* &#'+&, !%2!b62#!GDF!GHHI/!B (#!SAT3)!*Report and  
Recommendations on Personal Health Records and Personal Health Record Systems!*  
-8% 1 !<#C&6+&, !GHHZ!+25!'8'9!*Letter Report to the Secretary on Personal Health Record  
(PHR) Systems!*-8% 1!) # \$' # 1 C#&!EF!GHHWF!5#9\*8&C#!' (#!9'+ '#!%-!+---8&9! ; 8' (!&#9\$#\*!'!%!  
96\* (! (#+4' (!5+'+'\*%44#\*'8%2/!

SAT3)! (+9!+49%!5#487#&#5!26 1 #&%69!&#%\$&'9!5#9\*8&C82N!69#9!%-! (#+4' (!5+'+'!-%&!  
\$%\$64+'8%2!9'658#9!+25!-%&!69#!82!' 6+48', !8 1 \$8%7# 1 #2'/!L'9!*Recommendations on  
Populations Based Data Collection*!5#487#&#5!'%!' (#!) #\* &#'+&, !%-!333)!%2! : 6N69!GQF!  
GHHK!+25!'8'9!*Report on Measuring Health Care Quality* 82!U+ , !GHHK!+&#!9# 1 82+4! ; %&=9!  
%2!=#, !8996#9!-%&!6982N! (#+4' (!5+'+'/!B (#!*Recommendation Letter on Data Linkages to  
Improve Health Outcomes!*%2!b62#!GDF!GHHI!+49%!+55&#99#5!' (#!9\$#\*8+4!8996#!%-!  
1 #&N82N!5+'+'!-%& 1 !589\$+&+'#!9%6&\*#9/!!

B (#!SAT3)! e #C!98'#!X ('\$ ff2\*7(9/((9/N%7Y!\$8%785#9!+\*#99!'%!+44!SAT3)!5%\*6 1 #2'9!  
&#-#&#2\*#5F!+9! ; #44!+9!'% (#&9/!

### NCVHS Process

B%#!#2+C4#!SAT3)! '%! 1 +=#!\$8+\*'8\* +4!&#\*% 1 1 #25+'8%29!'%!+\*848'+ '#!69#9!+25!#J\* (+2N#!  
%-! (#+4' (!5+'+'F!) (#!A% 1 1 8''##a9!+5! (%\*! ; %&=N&%6\$!X**Appendix AY!**&#\*#87#5!\$6C48\*!  
\*% 1 1 #2'F!C%' (!82!-%& 1 +4!'#9'8 1 %2, !+25!82!%\$#2!\$6C48\*!9#998%29/!!

### Testimony and Comment

SAT3)!\*%27#2#5!' (#! ; %&=N&%6\$!+'!8'9! 1 ##'82N!%2!b62#!GDF!GHHI d!' (#2! (#45!' (&##!9# '9!  
%-!\$6C48\*! 1 ##'82N9!82!' (#! e +9(82N'%2F!0A!+&#+'!%2!b64, !DIJDEF! : 6N69'!D]QF!+25! : 6N69'!



# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

## Enhanced Protections for Uses of Health Data :

:!)'# ; +859(\$!<8+ 1 # ; %&=!-%&!>) #\*%25+&, !. 9#9!%#!@4#\*'&%28\*+4, !A%4#\*'#5!+25!B&+29 18''#5!3#+4' (!0+'+ !

GQJGKFIGHHI!'!&#\*#87#17#&C+4!+25! ; &8''#2!'#9#1%2, /!L!\$6C489 (#5!+!5&+-'!5%\*6 1 #2'!%2!8'9! ; #C!98'#!%2!O\*'C#&!DEF!GHHI F!+25! (#45!+2!%\$#2!\*+4!-%&!\$6C48\*!'\*% 1 1 #2'!%2!O\*'C#&!QDF! GHHI /!XB#9'8-8#&9!+25!\*% 1 1 #2'##&9!+&#!489'5!82!Appendix B/Y!SAT 3 )!+49%!!&#\*#87#5!+!

98N28-8\*+2'!26 1 C#&!%#!#] 1 +84!\*% 1 1 628\*+'8%29!-8% 1 !\$&87+'#!\*8'8P#29!\*%2\*#&282N! 82587856+4a9!'\*%29#2'!-%&!69#9!%#! (#+4' (!5+'+!L2!' (#15#7#4%\$ 1 #2'!%#! (89!&#%\$&'F!SAT 3 )! \$&#9#2'#5!82'##8 1 !-82582N9!'%!' (#! : 1 #88\*+2!3#+4' (!L2-%& 1 +'8%2!A% 1 1 628' , !X : 3LAY! A%296 1 #&!@ 1 \$% ; #& 1 #2'! e %&=! \ &%6\$F!) # \$ # 1 C#&!DGd! ^6+48' , ! e %&=! \ &%6\$F!O\*'C#&!Q! +25!0#\*# 1 C#&!DKd!+25!-64! : 3LA!\$6C48\*! 1 ##'82N!82!A (8\*+N%!!2!S%7# 1 C#&!DQF!GHHI /! !

A% 1 1 #2'9! ; #&#!&#\*#87#5!-% 1 !\$&%785#&!%&N+28P+'8%29F!\$&%-#998%2+4!+99%\*8+'8%29F! +\*\*&#58'82N!%&N+28P+'8%29F!\*%296 1 #&!&#&#9#2'+87#9F! (#+4' (!\$4+29F! `6+48' , !8 1 \$&%7# 1 #2'! %&N+28P+'8%29F! (#+4' (!82-%& 1 +'8%2!#J\* (+2N#9F!5+'+!+NN&#N+'%&9F!&#9#+&\* (!+25!\$6C48\*! (#+4' (!\*% 1 1 628'8#9F!+25!82587856+4a9!'\*%29#2'!%&!69#9!%#! (#SAT 3 )!+49%!!&#\*#87#5!+! 2232 . 79283 ' (#!\*%2-##2\*#!%2! Toward a National Framework for the Secondary Use of Health Data! 9\$%29%&#5!C, !' (#! : 1 #88\*+2!U#58\*+4!L2-%& 1 +'8\*9! : 99%\*8+'8%2!X : UL : YF!b62#!DKJDF!GHHI /! !

: 4' (%6N (!'8 1 #!-%&!82\$6'! ; +9!7#& , !9 (%&'F!SAT 3 )!89!+\$\$&#\*8+'87#!%#!' (#!#--%&!9%! 1 +2 , !\$6'! 82'!%\*%2'88C6'82N!\*% 1 1 #2'9/!

## Major Themes from Testimony about Uses of Health Data

CATG) %88487481/ : H48/ : 2\*45!88%14\*!88%28!8!888481% / / # : ! / (15+! : !89!L!5%2'8%7#898+4!

O' (#&!\*' 1 1 #2' #&9!5#9' &8C#5! (#!8 1 \$%& +2 #!%!-8+ +!9 # , +859 (\$!<8+ 1 # ; %&=!-%&!>) #\*%25+&, !. 9#9!%#!@4#\*'&%28\*+4, !A%4#\*'#5!+25!B&+29 18''#5!3#+4' (!0+'+ !

(#+4' (!5+'+!c!

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(8\$!<8+ 1 # ; %&=-!-%&!>) #\*%25+& ,! . 9#9?!% -!@4#\*'%&28\*+4 ,!A%44#\*'#5!+25!B&+29 18''#5!3#++' (!0+' +  
!  
!

*At the point of care!* 3LB!#2 (+2\*#9!+\*\*#99!'!%82-%& 1 +'8%2F!+--%&59!\$+'82'!9+-#', !+4#&'9!  
+25! (#+4' (! 1 +82'#2+2\*#!&# 1 825#&9F!+25!96\$%&'9! \*+&#! 1 +2+N# 1 #2'!/L2!+2!# 1 #&N#2\* ,F!  
3LB!#2+C4#9!9\$##58#&!+\*\*#99!'!%\* &&'8\* +!82-%& 1 +'8%2/!<%&!#J+ 1 \$4#F!56&82N!' (#! ( 6&&8\* +2#!  
589+9' #&9!%-!GHHWF!' (#!+7+84+C848' ,!%-! 1 %&#!#4#\* '%&28\*! (#+4' (!&#\*%&59! ; %645! (+7#!  
8 1 \$&%7#5! (#+4' (!%6'\*% 1 #9!+25!48=#4 ,! ; %645! (+7#!9+7#5!487#9/! : \*%&99!' (#!\*%2'8266 1 !%-!  
\*+&#F!3L@!#2+C4#9! 1 %&#!\*% 1 \$4#'#!82-%& 1 +'8%2!+25!\*%&582+'8%2!%-!\*+&#!+ 1 %2N!#&-#&&82N!  
\$&%785#&9!+25!-%&!&+29-#&!%-\*+&#F!96\* (!+9!-& 1 !+! (%9\$8'+4!'!+!4%2N!'#& 1 !\*+&#!+\*848' ,/!!  
!

*For quality measurement, reporting, and improvement!* +6'% 1 +'#5!5+'+!\*%44#\* '%2!  
\$&%\*#99#9!-%&!%C'+8282N!\*4828\*+4!5+'+!XC# ,%25! ; (+!89!+7+84+C4#!82!\*4+8 1 9!5+'+Y!\$&%785#!  
&&\* (#&!5+'+!82!+2!+\*\*#998C4#!-%& 1 !' (+!-+\*848'+!#9!C#2\* ( 1 +&=82N!+25!85#2'8-8\*+'8%2!%-!  
'6+48' ,!8 1 \$&%7# 1 #2'!%\$%&'628'8#9!82!\*+&#!5#487#& ,/!3LB!#2+C4#9!78&'6+4!+NN&#N+'8%2!%-!  
5+'+!+25!5+'+!482=N#F!96\* (!+9!82587856+4!\$#&9%2! 1 +'\* ( 82N!+4N%&&' ( 1 9!/B ( 89!96\$%&'9!  
4%2N8'6582+4!5+'+!\*%44#\* '%2!%#!J\$+25!625#&9'+2582N!%-!' (#!C#2#-8'9!%-!7+&&69!' (#&+\$8#9!  
%&!82'8&7#2'8%29!/B#9'8-8#&9!+49%!5#9\*88C#5!8 1 \$&%7#5!+25!5#7#4%\$82N!'#\* ( 28`6#9!+7+84+C4#!  
'%!9#\*6&#!5+'+!+25!'!+''+\* (!+6' (%&&P+'8%2!-%&!69#!%-!5+'+!'!%!' (#!5+'+!8'9#4-/!!  
!

*Clinical and population research* \*+2!C#!9'&#2N' (#2#5/!<%&!#J+ 1 \$4#F!9'65 ,82N!+!  
\$%\$64+'8%2!%-!\* (845#&2! ; 8' (!+6'89 1 ! 1 8N ( '!+44% ; !625#&9'+2582N!%-!' (#!#278&%2 1 #2'+4!%&!  
C8%4%N8\* +4!\*+69#9!%-!82\* &#+9#5!82\*85#2\*#!+25!\$%#2'8+44 ,!\$#& 1 8'!#+&48#&!5#'#\* '%2/! : 49%F!  
85#2'8-8\*+'8%2!+25!\$+'8\*8\$+'8%2!%-!\*+2585+'#9!-%&!4828\*+4!'&&+49!+\*%&99!+! ; 85#&!N#%N&+\$ (8\*!  
+&#!+!#2+C4#9!4+&N#&!\*% (%&'9!-%&!#9'82N! ( , \$%' (#9#9/!3#+4' (!9#&78\*#9!+25!'!% ( #&!  
\$%\$64+'8%2]C+9#5!&#9#+&\* (! 1 + , !C#!+85#5!' ( &%6N (!N&#+#&!+7+84+C848' ,!'!5+'+!/!!  
!

*Disease surveillance* 113.9569

# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

## Enhanced Protections for Uses of Health Data: !

:!)'# ; +859(8\$!<8+ 1 # ; %&=-!-%&!>) #\*%25+& ,! . 9#9? !%-!@##'&%28\*+4 ,!A%4##\*'#5!+25!B&+29 18''#5!3#++' (!0+ '+!  
!  
'%!(+7#!+!(8N(!5#N&###!%-'!&69'!82!' (#8&!\$&%785#89!/!B (#&#!+49%!+\$&#&9!'!C#!+!(8N(!5#N&###!  
%-!'&69'!82!\$6C48\*! (#+4' (!-&% 1 !' (#!\$&9\$#\* '87#!%-\$&% #'\* '82N!+N+829'!589#+9#%1%6'C&#+=9d!  
+25!82! (#+4' (!&#9#+&\* (! ; (#2!+\*%\* 1 \$+28#5!C ,!82-%& 1 #5!\*%29#2'!/!B&69'! 1 + ,!#&%5#!+25!  
\$&87+\* ,!\*%2\*#&29! 1 + ,!82\*#&+9#F! (% ; #7#&F! ; (#2!69#9!%-! (#+4' (!5+ '+!+&#! 1 +5#!-%&!%') (#&!  
4#99! ; 85#4 ,!&#\*%N28P#5!\$6&\$%9#9!/!L2!+558'8%2F! ; (#2! (#+4' (!5+ '+!+&#!9%45!c!#7#2! ; (#2!  
69#5!'!#296&#!' (#!969'+82+C848' ,!%-! (#!C6982#99! 1 %5#4!-%&!#J\$+25#5!69#9!%-!3LB!+25!  
3L@!%&! ; (#2! (#!5+ '+!+&#!5#]85#2'8-8#5!c!' (#&#!+&#! (#8N ('#2#5!\*%2\*#&29!/  
!

*Compromises to health care!* 1 + ,!&#964'! ; (#2!82587856+49!-+84!'!9##=!'&#+ ' 1 #2'!%&!  
\* (%%9#!%!' ; 8' ( (%45!82-%& 1 + '8%2!' (+!'\*%645!8 1 \$+\*'!5#\*898%29!+C%6'!' (#8&!'&#+ ' 1 #2'!  
C#\*+69#!' (# ,!5%12%!625#&9'+25! (% ; !' (#8&!5+ '+! 1 + ,!C#!69#5!%&! (# ,! 1 + ,!2%!'!&69'!' (+!  
' (#8&!85#2'8' ,! ; 844!C#!\$&% #'\* '5F!\$+&'8\*64+84 ,!8-! (# ,!\*%2985#&!' (#8&!82-%& 1 + '8%2'!'!C#!  
#9\$#\*8+44 ,!9#298'87#!3LB!\*+2!+--%&5!N&#+ '#&!\$&% #'\* '8%29F!C6'!' (#9#! 1 69'!C#!5848N#2'4 ,!  
+\$&48#5!+25! 1 +5#!=2% ; 2!'!82587856+49!//!  
!

*Risk of discrimination and personal embarrassment!* 1 + ,!C#!+ 1 \$48-8#5!+9!#4#\*'&%28\*!  
(#&4' (!5+ '+!C#\*% 1 #! 1 %&#! ; 85#4 ,!+7+84+C#!' (&%6N (!N&#+ '#&!+C848' ,!'!+6% 1 + '#! (#+4' (!  
5+ '+!'\*%44#\*'8%2F!\*% 1 \$84#14%2N8'6582+4!5+ '+F!#]85#2'8- ,!5+ '+!' (+! (+7#!C##2!5#]85#2'8-8#5F!  
+25!9 (+&#!5+ '+!' (&%6N (!3L@!/!B (#&#! (+7#!4%2N!C##2!\*%2\*#&29!' (+!\$#&9%2+4! (#+4' (!  
82-%& 1 + '8%2!89!C#2N!69#5!'! 1 +=#!5#\*898%29!' (+!+57#89#4 ,!+-#\*!'!+2!82587856+4F!96\* (!+9!  
82!# 1 \$4% , 1 #2'F!C#2#-8'9!'\*%7#&+N#F!%&!+\* # \$+2\*#'-%&!4%+29!%&! 1 %&'N+N#9!/  
!

*Potential for group-based harm!* 1 + ,!+&89#! ; (#2!5+ '+!+&#!+NN&#N+'#5!+25!&#964'9!  
\$%#2'8+44 ,! 1 8969#5!/<%&!#J+ 1 \$4#F!' (#&#!89!' (#!\$%'#2'8+4!' (+!'\*4+998- ,82N!589#+9#!+9! 1 %&#!  
\$&#7+4#2'!82!\*#&'+82!# (28\*!%&!&+\*8+4!N&%6\$9!%-!\$#%\$4#!%&!82!\*#&'+82!\*% 1 1 628'8#9! 1 8N ('!  
\*+69#! 1 # 1 C#&9!%-! (+!N&%6\$!%&!\*% 1 1 628' ,!'!C#!96C!#\*!'!%1589\*88 1 82+'8%2!%&!9'8N 1 +F!  
#7#2!+9!+8582N! (8N (!889=1N&%6\$9!C ,!96\$%&'82N!2# ; ! (#+4' (!9#&78\*#9!+25!'&#+ ' 1 #2'9!/  
!

## HIPAA Privacy and Security Rules

! e (84#!9#7#8+4!'#9'8-8#&9!%C9#&7#5!' (+!' (#!3LM : :!M887+\* ,!+25!) #\*688' ,!" 64#9!\$&%785#!+!  
-%625+'8%2!-%&!5+ '+!9# ; +859(8\$!'#9'8 1 %2 ,!+49%85#2'8-8#5!' (+!' (#&#!9'844!89!'\*%2-698%2!  
+ 1 %2N!\*%7#&#5!#2'8'8#9!%2! (% ; !'!'\*+&& ,!%6'!9% 1 #!%-! (#!&#` 688# 1 #2'9!%-!3LM : :!c!82!  
C%' (!\*688#2'!69#9!%-!\$&% #'\* '5! (#+4' (!82-%& 1 + '8%2!+25!82!48N ('!%-!2# ; !69#9!%-! (#+4' (!5+ '+!  
#2+C#5!C ,!3LB!+25!3L@/!

## Variation in State Laws

! 3LM : :!&#N6+'8%29!\*+22%'!96\$#&\*#5#!+!\*%2'&+& ,!\$&%7898%2!%-!) '+ '#!4+ ; !8-! (#!) '+ '#!4+ ; !  
8 1 \$%9#9! 1 %&#!9'882N#2'!8#` 688# 1 #2'9!B (#!&#964'+2'!7+88+'8%2!

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**  
**Enhanced Protections for Uses**

# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

## Enhanced Protections for Uses of Health Data: !

:!)'# ; +&59(8\$!<&+ 1 # ; %&=!-%&!>) #\*%25+&,!. 9#9?!%!@4#\*'&%28\*+4, !A%44#\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+'+  
!  
9\$%29%&#5!C, !+!\*%7#&#5!#2'8', !%&!C6982#99!+99%\*8+'#F!' (#!\$#&9%2+4! (#+4' (!82-%& 1 +'8%2!89!  
2%!'\$&% '#\*'#5!625#&!3LM : :/!!  
!  
B#9'8-8#&9!%C9#&7#5!' (+!' (#&#! ; 844!C#!82\*#&+982N!\* (+44#2N#9! ; 8' (!&#9\$#\*#!'!%3LM : :!+25!  
\* (+82!%-!'&69!' ; 8' (! (, C&85!M3 " 9F!82! ; (8\* (!C%' (!\*%7#&#5!#2'8', ]96\$\$48#5!+25!82587856+4]  
96\$\$48#5! (#+4' (!5+'+!+&#!\*%44#\*'#5/!

### Importance of Data Stewardship

!  
: 9!\*%2\*#&29!82\*#&+9#!+C%6!' (#! ; 85#282N!&+2N#!%-!69#9!%-! (#+4' (!5+'+F!' (#&#!89!+2!  
82\*#&+982N!2##5!-%&!+\$&%\$&8+'#15+'+9'# ; +&59(8\$!C, !+44!%&N+28P+'8%29!+25!82587856+49!  
' (+!' (+7#!+\*'#99!'! (#+4' (!5+'+F!825#\$#25#2'!%-!3LM : :!\*%7#&#5!#2'8', !9+'69! e (#2!+2!  
82587856+4!\$&%785#9!\$#&9%2+4! (#+4' (!82-%& 1 +'8%2F! ; (#' (#&'!%+!\$&%785#&F!\$+, #&F!%2482#! ; #C!  
98'#F!%&!+2, %2#!#49#F!' (#!82-%& 1 +'8%2!89!\$&%785#5!82!\*%2-85#2\*#!+25! ; 8' (!' (#!\$

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(8\$!<&+ 1 # ; %&=!-%&!>) #\*%25+&,!. 9#9?!%~!@4#\*'&%28\*+44,!A%44#\*'#5!+25!B&+29 1 8''#5!3#+4'(!0+'+  
!  
\$&2\*8\$4#9!-%&!69#9!%~!(#+4'(!5+'+!/: 9!2# ; !69#9!%~!(#+4'(!5+'+!+&#! 1 +5#!82!+!2# ; ! ; %&45!  
%-!3LB!+25!3L@F!'(#!-&+ 1 # ; %&=!%~!5+'+!9'# ; +&59(8\$!82(##2'!82!3LM: : !2##59!  
&#+48N2 1 #2'!'%!+5+\$!'%'! (89!\* (+2N82N!4+259\*+\$#/: \$\$&%\$&+#!5+'+!9'# ; +&59(8\$!89!  
8 1 \$%&' +2'!-%&!C684582N!'&+29\$+&#2\* ,!+25!'&69'!' (&%6N(%6'!+44!%&N+28P+'8%29!'(+! 1 + ,!69#!  
(#+4'(!5+'+!-%&!+2, !\$6&\$%9#d!+25!82!\$+&'8\*64+&'!%#!#296&#!'(+!82587856+49!+&#!82-%& 1 #5!  
+C%6'!69#9!%~!'(#8&! (#+4'(!5+'+! ; (8\*(! ( # ,! 1 + ,!2%'!+2'8\*\$+'#!!  
!  
L'!89!8 1 \$%&' +2'!-%&!+4!9'+=#(%45#&9!'%'! (%&%6N(4, !625#&9'+25!

# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

## Enhanced Protections for Uses of Health Data !

:!)'# ; +&59(8\$!<&+ 1 # ; %&=&-!-%&!>) #\*%25&&,! . 9#9?%!-!@#\*'%&2#\*+4, !A%4#\*%#5!+25!B&+29 1 8''#5!3#++' (!0+#+

C#'; ##2!\$&%785#&9!&#4+'82N!%'!+2!82587856+4d!%&!' (#!&#-#&&+4!%-!+2!82587856+4!-%&!  
(#+4' (!\*+&#!-% 1 !%2#!\$&%785#&!%'!+2%' (#&!)

o! *Payment!*&#-#&9!%'! (#!+\*'878'8#9!625#&'+=#2!C, !+! (#+4' (!\$+2!'%15#'#& 1 82#!  
\*%7#&+N#!+25!\$&%7898%2!%-!C#2#-8'9!625#&! (#!\$+2!+25!'!%C'+82!%&!\$&%785#!  
&#8 1 C6&9# 1 #2'!-%&!' (#!\$&%7898%2!%-! (#+4' (!\*+&#!)

o! *Healthcare operations!*#2\*% 1 \$+99!`6+48', !+99#99 1 #2'F!\*% 1 \$#'#2\*, !&#78#; F!  
(#+4' (!C#2#-8'9!\$&%\*%99#9F!\*% 1 \$+8+2\*#!+\*'878'8#9!F!C6982#99!\$+2282NF!+25!N#2#&+4!  
+5 1 8289'+87#!+'878'8#9!XKW!A< " !gDZK/WHDY/!

:!\*% 1 1 %2!' (# 1 #!' (!SAT3) ! (#+&5!82!'#9'8 1 %2, !&#4+'#5!'%! (#!C&%+5!9\*%\$#!%-!9% 1 #!  
+9\$#\*%9!%-' (#!3LM: :!M&87+\*, !+25!)#\*6&8', !" 6!49!/B#9'8-8#89!%C9#87#5!' (!+!3LM: :! 1 +, !  
9#&7#!; #4!#2%6N (!82!\$&%78582N!5+'!9'#!; +&59(8\$!N685+2\*#!-%&!' (#!>&#++' 1 #2'!+25!  
\$+, 1 #2'?\$&%\*%99#9!%-!\*+&#!5#487#&, F!C6'! (#!+&#!+!%-!> (#+4' (\*+&#!%\$#&+8%29?; +9!  
%C9#87#5!'!C#!C&%+5!82!9\*%\$#!+25!%-!#2!2%'!; #4!625#&9%'%5!/L!; +9!2%'#5!' (!+!&69!  
1 +, !+\*'%'! 1 %&# (!#+784, !' (+2!4+; 9!+25!&#N6+8%29!; 8' (!&#9\$#\*%'!%182587856+49!+25!' (#8&!  
\$&87+\*, !\*%2\*#&29!/B (#!-6&' (#&!+!69#!%-! (#+4' (!5+'!+89!-% 1 !' (#!\$%82!%!'\*+&#F!' (#!4#99!  
'&+29\$+&#2\* ,!' (#&#! 1 +, !C#!+25!' (#!4#99!82587856+49! 1 +, !'869!' (#!+C848', !%-! (#8&! (#+4' (!  
5+'+!%!C#!\$&%\*%#5!!

### Uses of Health Data for Quality Measurement, Reporting, and Improvement

B (#!5#-828'8%2!%-!`6+48', !+99#99 1 #2'!+25!8 1 \$&%7# 1 #2'!+\*'878'8#9F!82\*465#5!82!' (#!3LM: :!  
M&87+\*, !" 6!4!625#&! (#+4' (\*+&#!%\$#&+8%29F!82\*465#9!>%6\*% 1 #9!#7+46+'8%2!+25!  
5#7#4%\$ 1 #2'!%-!\*4828\*+4!N685#482#9F!\$&%785#5!' (!'! (%!%C'+8282N!%-!N#2#&+48P+C4#!  
=2%; 4#5N#!89!2%'! (#!\$&8 1 +&, !\$6&\$%9#!%-!+2, !9'658#9!&#964'82N!-% 1 !96\* (!+\*'878'8#9d!  
\$%\$64+'8%2]C+9#5!+\*'878'8#9!&#4+'82N!'8 1 \$&%782N! (#+4' (!%&!&#56\*82N! (#+4' (!\*+&#!\*%9'9F!  
\$&%'%\*%4!5#7#4%\$ 1 #2'F!\*+9#! 1 +2+N# 1 #2'!+25!\*+&#!\*%&582+'8%2F!\*%2+'82N!%-! (#+4' (!  
\*+&#!\$&%785#&9!+25!\$+'82'9!; 8' (!82-% 1 +8%2!+C%6'!&#+' 1 #2'!+4#&2+'87#9d!+25!&#4+'#5!  
-62\*'8%29!' (!+!5%12%'!82\*465#!&#+' 1 #2'?!XKW!A< " !gDZK/WHDY/!!

*Benefits* %-!`6+48', ! 1 #+96&# 1 #2'!+25!&#%&82N!82\*465#! (#!\*+\$+\*8', !%'+99#99!\$&%N&#99!  
'%; +&5!+\* (8#782N! (8N (!\$#&-%& 1 +2\*#!82!' (#!98J!58 1 #298%29!%-!\*+&#!85#2'8-8#5!82!' (#!  
L29'8'6'#!%-!U#58\*82#! *Quality Chasm!*&#%\$F!82\*46582N!>C#'#&!9+-' , F!#--\*#87#2#99F!  
\$+'8#2]\*#2'#&#52#99F!'8 1 #482#99F!#--8\*82\*, F!+25!#`68', ?!B (#9#!+8 1 9!&#`68&#! 1 %&#!  
\*4828\*+44, !88\* (!82-% 1 +8%2!'+2!; (+!89!+7+84+C4#!9%4#4, !-8% 1 !\*4+8 1 9!5+'!L2587856+49!\*+2!  
1 +=#! 1 %&#!82-% 1 #5!5#\*898%29!+C%6'! (#8&!\*+&#!; (#2!`6+48', !89!+\*'6&+4, !&#%\$&'#5!/  
M&%785#&9!\*+2!8 1 \$&%7#!' (#!`6+48', !%-!\*+&#!5#487#&#5!; (#2!' (#, !625#&9'+25!' (#!6&8#2!  
9'+69!%-! (#!\*+&#!C#82N!\$&%785#5!+25! (+7#!+\*'899!'!#785#2\*#]C+9#5!\$&%\*%49/!M+, #89!  
\*+2!+996&#!N&#+#8!7+46#! (%6N (!\$+, !-%&!\$#&-%& 1 +2\*#F!\$+, !-%&!`6+48', F!+25!%' (#&!  
1 #\* (+289 1 9!/M6&\* (+9#&9!%-!\*+&#!\*+2!#296&#!' (#, !+&#!&#\*#8782N!7+46#!; (#2!' (#, !+7#!

!!

!L29'8'6'#!%-!U#58\*82#F!*Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century!*  
e +9(82N'%2!0A\_S+'8%2+4! : \*+5# 1 8#9!M&#99F!GHDF!\$!KQ

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'#; +859(\$!<8+ 1 #; %&=-%&!>) #\*%25+&,!. 9#9?!%~!@#\*'&%28\*+4, !A%4#\*' #5!+25!B&+29 1 8'' #5!3#+4' (!0+' +  
!  
+\*\*#99!'%!+\*\*6&+'#!`6+48', !&#\$%&'82N!/B (#9#!C#2#-8'9!+&#!; #4!625#&9'%%5F!C, !\$%785#&9F!  
\$6&\* (+9#&9F!+25!\$, #&9F!C6!'\$%&4, 1625#&9'%%5!%&!+\$&#\*8+'#5!C, !82587856+49/! \&#+ '#&!  
#56\*+'8%2!%-!' (#!\$6C48\*!89!2##5#5!82!' (89!+&#+/!  
!

*Challenges!*82!69#9!%-! (#+4' (!5+'+!-%&!`6+48', ! 1 #+96&# 1 #2'F!&#\$%&'82NF!+25!8 1 \$&%7# 1 #2'!  
82\*465#!C+4+2\*82N!' (#!2##5!-%&!+\*\*6&+'#!+25!\*% 1 \$4#'#!5+'+'!#296&#! 1 #+282N-6!  
%6'\*% 1 #9!; (84#!\$&%#' #'82N!82587856+49a!\$&87+\*, /!. 9#9!%-!85#2'8-8+C4#! (#+4' (!5+'+!-%&!`  
`6+48', !8 1 \$&%7# 1 #2'!+&#!\$& 1 8''#5!625#&!3LM: : /!3%; #7#&F!%&N+28P+'8%29!+&#!  
82\*8#+982N4, !\* (+44#2N#5!'!\$&%#' #'!96\* (!5+'+!+25!'!82\*8#+9#!+; +&#2#99!82!82587856+49!%-!  
' (#!7+46#!%-!6982N! (#+4' (!5+'+!-%&!`6+48', !8 1 \$&%7# 1 #2'!/!3LB!+25!3L@!#2+C4#9! 1 %&#!  
\*% 1 \$4#'#!+25!+\*\*6&+'#!5+'+'! (&%6N (!482=82N! (#+4' (!5+'+!+C%6'!82587856+49!4%2N8'6582+44, F!  
+\*&%99! 1 64'8\$4#!9#'82N9F!+25!-% 1 ! 1 64'8\$4#!9%6&\*#9/!<%&!#J+ 1 \$4#F!5+'+!482=+N#!#2+C4#9!  
85#2'8-8\*+'8%2!%-!-+\*'%&9!96\* (!+9! (%9\$8'+4!&#]+5 1 8998%2!&+'#9! ('+! 1 +, !98N28-, !`6+48', !  
8996#9!/B (#&#!



**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'#; +&59(\$!<&+ 1 # ; %&=-%&!> ) #\*%25+&,!. 9#9?!%-!@4#\*'&%2!+4, !A%4#\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+'+  
!  
!  
B (#!&#964'!

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +859(\$!<8+ 1 # ; %&=-%&!>) #\*%25+&,!. 9#9?!%-!@4#\*'8%28\*+44,!A%44#\*'#5!+25!B&+29 1 8''#5!3#+4'(!0+'+  
!  
M6C48\*!(#+4'(!5+'+!\*%44#\*'#5!588#\*'4,!C,!'(#!A#2'#89!-%&!089#+9#!A%2'8%4!+25!M&#7#2'8%2!  
XA0AY!+&#!%C'+82#5!6982N!+!7+&8#',!%-!1 #\*(+289 1 9!/L2\*465#5!+&#!(#+4'(!9+'89'8\*+4!5+'+!  
%C'+82#5!-% 1 !96&7#,9F! ; (8\* (!1 +,!C#!\*%256\*'#5!625#&!+2!L " R!\$8%\*#99!%&! ; 8'(!'(!  
82-%& 1 #5!\*%29#2'!%-!'(!82587856+4!&#9\$%2582N!'! '(#!96&7#,/!B(#9#!5+'+! 1 +,!C#!  
&#4#+9#5!'!%' (#&9!%24,!' (&%6N(!9'88\*'!5+'+!&#4#+9#!+N&## 1 #2'9!%&!+9!9+'89'8\*+44,!5#]  
85#2'8-8#5!5+'+9#'9!/A0A!89!9'+&'82N!2+'8%2 ; 85#!5+'+!\*%44#\*'8%2!#--%&'9F!96\* (!+9!'(!  
R8%)#29#!\$8%!\#\*'F'(+!827%47#!\*%2'&+\*6+4!+N&## 1 #2'9!98 1 84+&'!%!3LM : :!C6982#99!  
+99%\*8+'#!\*%2'&+\*'9!)6\* (!#--%&'9!6'848P#!2# ; !5+'+!9%6&\*#9!+25!+&#!#2+C4#5!C,!  
+6%' 1 +'#5!5+'+!\*%44#\*'8%2!\$8%\*#99#9!+25!5+'+!482=+N#!\*+\$+C848'8#9!/3%/

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(\$!<&+ 1 # ; %&=-%&!>) #\*%25+&,!. 9#9?!%-!@4#\*'&%28\*+44,!A%44#\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+' +  
!  
@3 " !9, 9'# 1 ! 1 +, !\*%2'&+\* '! ; 8' (!+!\$&%785#&! '%!9#4!5#]85#2'8-8#5! (#+4' (!5+' +!-&% 1 !' (#!  
\$&%785#&a9!@3 " !'!'%' (#&! \*% 1 \$+28#9!82!&# '6&2!-%&!96\$\$4, 82N!' (#!\$&%785#&! ; 8' (!+!\$%&'8%2!%-!  
' (#!\$&%\*##59!-&% 1 !' (#!9+4#!%-'! (#!5+' +!/B (#!@3 " !96\$\$48#&! 1 +, ! 1 #&N#!' (89!5+' +! ; 8' (!  
%' (#&!5+' +C+9#9F!\$%' #2'8+44, !\*+6982N!8!'!'%!C#!&#]85#2'8-8+C4#!/L2587856+49!#J\$&#99#5!  
\*%2\*#&2!+C%6!96\* (!62+2'8\*8\$+'#5!69#9!%-!' (#8&! (#+4' (!82-%& 1 +'8%2F!' (#!-82+2\*8+4!N+82!  
-&% 1 !96\* (!&+29+\*'8%29F!+25!' (#!\$%' #2'8+4!-%&!&#]85#2'8-8\*+'8%2!%-!' (#!5+' +/!  
!  
*Use*

# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

## Enhanced Protections for Uses of Health Data: !

:!)'# ; +859(\$!<8+ 1 # ; %&=-!-%&!>) #\*%25+&, !. 9#9?!% !@4#\*'&%28\*+4, !A%4#\*' #5!+25!B&+29 18'' #5!3#++' (!0+' + !

## Guiding Principles for Making Recommendations on Enhanced Protections for Uses of Health Data

! : 9!SAT3 )!\*%2985#&#5!' (#!'#9'8 1 %2 , !+25!8'9!' +9=!%!5#7#4%\$!&#\*% 1 1 #25+'8%29!-%&! #2 (+2\*#5!\$&% '#\*'8%29!-%&!69#9!%-(#+' (!5+' +!82!48N ('!%-!2# ; !'#\* (2%4%N8#9!+25! (#+' (! 82-%& 1 +'8%2!#J\* (+2N#F!8'!&#\*%N28P#9!' (#&#!+&#!587#89#!78# ; \$%82'9!c!C%' (!82!' (!#\$6C48\*! +25! ; 8' (82!8'9! 1 # 1 C#&9 (\$!/SAT3 )!+5%\$'#5!' (#!-%44% ; 82N!N68582N!\$882\*8\$4#9<sup>DH</sup>!'! (#4\$! 5#7#4%\$!&#\*% 1 1 #25+'8%29!' (+!9'88=#!+!C+4+2\*#!C#'; ##2!+996882N!C#2#-8'9!-8% 1 !%\$'8 1 +4! 69#9!%-(#+' (!5+' +!C6'!2%'!+'!') (#!\*%9'!%-!&#+9%2+C4#!\$887+\* , /!M&% '#\*'8%29!9 (%645! /! /! /! /!

D/! 1 +82'+82!%&!9'&#2N' (#2!82587856+4a9! (#+' (!82-%& 1 +'8%2!\$887+\* , !

G/! #2+C4#!8 1 \$&%7# 1 #2'9!82!' (#! (#+' (!%-! : 1 #88\*+29!+25!' (#! (#+' (\*+&#!5#487#&, ! 9, 9' # 1 !%-!' (#!S+'8%2!

Q/! -+\*848+'#!+\$&%\$&%\$&+#!69#9!%#!4#\*'8%28\*! (#+' (!82-%& 1 +'8%2!

K/! 82\* &#+9#!' (#!\*4+88' , !+25!625#89'+2582N!%-!4+ ; 9!+25!&#N64+'8%29!\$#&'+8282N!%'! \$887+\* , !+25!9#\*688' , !%-!' (#!+' (!82-%& 1 +'8%2!

W/! C6845!6\$%2!#J89'82N!4#N894+'8%2!+25!&#N64+'8%29! ; (#2#7#&!+\$&%\$&+#!

Z/! 2%'!&#964'!82!6256#!+5 1 8289'&+'87#!C6&5#2!!

## Observations and Recommendations

*Today, the health industry relies upon the HIPAA construct of covered entities and business associates to protect health data. The following recommendations call for a transformation to enhanced protections for all uses of health data by all users, independent of HIPAA covered entity status. NCVHS believes that all organizations and individuals with access to personal health data should follow attributes of appropriate stewardship, inc*

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(8\$!<+ 1 # ; %&=!-%&!>) #\*%25+&,!. 9#9?!%~!@4#\*'&%28\*+4, !A%44#\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+'+  
!  
!-&+ 1 # ; %&=!%-!5+'+!9'# ; +&59(8\$!-%&! (#+4' (!5+'+!69#9! 1 +, !+85!\$%'#2'8+4!69#&9!  
\*%2'# 1 \$4+'82N!+!9\$#\*8-8\*!69#!%~! (#+4' (!5+'+!'%!+2+4, P#!' (#!69#!+25!\*%2985#&!+\$&%\$&&+'#!  
; +, 9!'%!+55&#99!5+'+!9'# ; +&59(8\$!/L2!N#2#&+4F!+!-&+ 1 # ; %&=!89!+!'\*%2\*#\$'6+4!9'&6\*'6&#!  
69#5!'%!' (82=!+C%6'!+!'\*% 1 \$4#J!8996#!+25!%6'482#!\$%998C4#!\*%6&9#9!%-!+ \*'8%2/! : \* (8#782N!  
' (#!C#2#-8'9!%~! (#+4' (!5+'+!69#9! ; (84#!&#56\*82N!' (#!\$%'#2'8+4!-%&! (+& 1 9!\$&#9#2'9!+!  
\*% 1 \$4#J!8996#!+ 1 %2N!+! 1 , &&+5!%-!69#9!+25!69#&9!%~! (#+4' (!5+'+!/S%!982N4#!&#\$%&'! \*+2!  
85#2'8-, !+4!69#9!+25!69#&9F!

# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

## Enhanced Protections for Uses of Health Data: !

:!)'# ; +859(8\$!<8+ 1 # ; %8=-!-%&!>) #\*%25+8, ! . 9#9?!%~!@##\*%&28\*+4, !A%4##\*#5!+25!B&+29 18''#5!3#++' (!0+' +  
!  
C8259!' (!C6982#99!+99%\*8+'#!'%' (!#5+'+'9# ; +859(8\$!\$882\*8\$4#9!82(##&#2'!82!' (!#3LM : : !  
M887+\* , !+25!) #\*688' , !" 64#9!/B(#!\*%7#8#5!#2'8' , !1 + , !\$#& 1 8'!' (!#C6982#99!+99%\*8+'#!'%'!  
69#!+25!589\*4%9#!\$8%'#\*#5! (#+' (!82-%& 1 +'8%2!-%&! ('!\$8%\$#8! 1 +2+N# 1 #2!'!+25!  
+5 1 8289'8+'8%2!%~!' (!#C6982#99!+99%\*8+'#!+25!'!\$8%785#15+'+'+NN&#N+'8%2!9#878\*#9!  
&#4+'82N!'%' (!#+' (!\*+8#!%\$#8+'8%29!%~!' (!#\*%7#8#5!#2'8' , !/B(#!\$8%7898%29!82!' (!#3LM : : !  
M887+\* , !+25!) #\*688' , !" 64#9!5#9\*88C#! ('+' (!#\*%2'8+\*!' 1 69'!C#!+C4#!'!C#!'#8 1 82+'#5!C , !  
' (!#\*%7#8#5!#2'8' , !8-' (!88#!89!+ 1 +'##8+4!C&#+' (!+'!'+22%'!C#!8#+9%2+C4 , !\*68#5!%&!#25!  
' (!#78%4+'8%2F!+9!+\$8\*+C4#F!+25!8-!96\* (!9'#9!'%'68#! ; ###!6296\*\*#99-64!/XKW!A< " !  
gDZK/WHKX#Y!+25!gDZK/QDKX+YY!  
!  
L2!\$8+\*'8\*#F!SAT 3) !(#+85!' ('+'+2!#J\$8\*8'!#26 1 #8+'8%2!%~! ; ('+'5+'+' (!#C6982#99!  
+99%\*8+'#! ; 844!69#!%&! ( % ; !8'!82'#259!'!69#!' (!#5+'+'89!%-#2!2%'!82\*465#5!82!C6982#99!  
+99%\*8+'#!\*%2'8+\*9!/U+2 , !C6982#99!+99%\*8+'#!\*%2'8+\*9!+8#!7+N6#!%2! ; ('+' (!#  
C6982#99!+99%\*8+'#!\*+2!5%! ; 8' (!\$8%'#\*#5! (#+' (!82-%& 1 +'8%2!/  
!  
<68' (#8 1 %&#F!982\*#!3LM : : !5#]85#2'8-8#5!5+'+'+8#!2%'!\$8%'#\*#5! (#+' (!82-%& 1 +'8%2!625#8!  
3LM : : !F!C6982#99!+99%\*8+'#9!%&! ('##8!+N#2'9! 1 + , !69#!5#]85#2'8-8#5!5+'+'+-%&!\$68\$%9#9!2%'!  
&#`688#5!'!C#!5#9\*88C#5!82!' (!#C6982#99!+99%\*8+'#!\*%2'8+\*9!/B(###!+8#!+49%!2%!  
+9968+2\*#9!' ('+' (!#5#]85#2'8-8\*+'8%2!\$8%'#99!69#5!C , !' (!#C6982#99!+99%\*8+'#! ; 844!C#!  
\*%2989'#2!' ; 8' (!+'!&#`688#5!C , !3LM : : !/!SAT 3) !(#+85!'#9'8 1 %2 , !\*%2\*#8282N!7+8 , 82N!  
; + , 9!\$8%'#\*#5! (#+' (!82-%& 1 +'8%2! 1 + , !C#!5#]85#2'8-8#5!/  
!  
e 8' (%6'+9968+2\*#9!%~!\$8%\$88!5#]85#2'8-8\*+'8%2! 1 #' (%59!C#82N!# 1 \$4% , #5!+25! ; 8' (%6'+2!  
+ ; +8#2#99!%-!' (!#69#9! 1 +5#!%-!5#]85#2'8-8#5!5+'+'+F!\*%7#8#5!#2'8'8#9!+8#!62+C4#!'%'!  
5#9\*88C#! ; ('+'!69#9! 1 + , !C#! 1 +5#!%-!82587856+49a!5+'+'+25!+8#!2%'!+C4#!'%'\*%2-88 1 !  
; (#' (#8!\$8%\$#8!+25!#88+C4#! 1 #' (%59!%-!5#]85#2'8-8\*+'8%2!+8#!C#82N!69#5!/B(#!889=!%-!  
82-%& 1 +'8%2!C#82N!&#]85#2'8-8#5!\*%2'826#9!'!82\*8#+9#!+9! 1 %&#!\$6C48\*!5+'+'+C+9#9!C#\*% 1 #!  
+7+84+C4#!+25!#\* (28`6#9!-%&!&#]85#2'8-8\*+'8%2!C#\*% 1 #! 1 %&#!9%\$ (89'8\*+'#5!/  
!  
" #]85#2'8-8\*+'8%2!%-!82-%& 1 +'8%2!' ('+' ; +9!\$8#78%694 , !C#48#7#5!'!C#!5#]85#2'8-8#5!  
\*%29'8'6'#9!+!69#!%~!\$8%'#\*#5! (#+' (!82-%& 1 +'8%2!2%'!5#9\*88C#5!82F!+25!82!78%4+'8%2!%~!+!  
C6982#99!+99%\*8+'#!\*%2'8+\*9!/L-!&#]85#2'8-8\*+'8%2!%~\*689!-68' (#8!5% ; 2!' (!#\* (+82!%-!'!869'F!8'  
89! 1 %&#!58--8\*64!-%&! ('!#C6982#99!+99%\*8+'#!'!85#2'8- , !96\* (!+!78%4+'8%2!+25!&#8%\$'!8'!'%' (!#  
\*%7#8#5!#2'8' , !/A%29#`6#2'4 , F!' (#9#!8996#9!%\$2!6\$!+2!82587856+4a9!5+'+'!69#9!' ('+' (!#  
82587856+4!5%#9!

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'#; +&59(\$!<&+ 1 # ; %&=-!-%&!>) #\*%25+& . 1 9#92!%-1@4#\*'&%2!+44,!A%44#\*'#5!+25!B&+29 1 8''#5!3#+4'(!0+'+  
!

*business associate* [REDACTED] *site for public reporting of provider-specific  
chronic disease bene*

! R69&2#99!+99%\*8+'#9!+&#!+49%\$#& 1 8''#5!'!6'848P#!+N#2'9!&2!96\$\$%&'!%-!' (#8&! ; %&=! ; 8' (!  
\*%7#&#5!#2'8'8#9!/R69&2#99!+99%\*8+'#9! 1 69'!#296&#!' (+!+2, !+N#2'9F!82\*465&2N!+!  
96C\*%2'&+\*'%'&F!'%! ; (% 1 !8'!\$&%7&5#9!\$&%'#\*'#5! (#+4' (!82-%& 1 +'8%2!/!/!/!+N&##9!'%!' (#!9+ 1 #!  
&#9'&8\*'8%29!+25!\*%25&8'8%29!' (+!+\$4,!'%!' (#!C69&2#99!+99%\*8+'#?!XgDZK/WHKX#YXGYX88YXOYYF!  
%&!82!' (#!\*+9#!%-!' (#!) #\*6&8',!" 64#!>#296&#!' (+!+2, !+N#2'F!82\*465&2N!+!96C\*%2'&+\*'%'&F!'%!  
; (% 1 !

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +859(\$!<&+ 1 # ; %&=-!-%&!>) #\*%25+&!, . 9#9?!-!@##\*%&28\*+4, !A%4##\*#5!+25!B&+29 1 8''#5!3#++' (!0+' +  
!  
82587856+4!-8% 1 !%2#17#&98%2!%-!' (#!S+'8%2+4!A%62\*84!-%&!M&#9\*88\$'8%2!0&6N!M&%N&+ 1 9!  
XSAM0MY!9'+25+&5!'%!+2%' (#&F!%&!-8% 1 !' (#!##\*%&28\*!&+29+\*'8%2!'%!+!-+J ; (#&#!+2!  
82587856+429!\$&#-##&#5!\$( +& 1 + \* , !\*+22%'!+\* \*\$#!+!'&+29+\*'8%2!/R+2=9!+&#!82\*8#+982N4, !  
N+8282N!+\* \*#99!'%!#J\$+2+'8%29!%-!C#2#-8'9!+55&#99#5!'%!82587856+49!+9!' (#, !\$&%\*#99!  
#4#\*'%&28\*!-6259!'&+29-#&9/!) % 1 #!%-!' (#9#!%&N+28P+'8%29!&#\*%N28P#!' (# 1 9#47#9!+9!  
C6982#99!+99%\*8+'#9!%&!+&#!&#` 688#5!C, !' (#!\*%7#&#5!#2'8', !; 8' (! ; (% 1 !' (#, !5%!C6982#99!  
'%! (+7#!C6982#99!+99%\*8+'#!\*%2'&+\*'9/!L2!' (#&!+9#9F! (% ; #7#&F!' (#!%&N+28P+'8%2! 1 +, !  
&88N82+4, !2%'! (+7#!C##2!+!C6982#99!+99%\*8+'#F!C6'!%7#&!8 1 #!' (#!4#7#4!%-!+\* \*#99! 1 +, !  
82\*8#+9#/!!

*For example, an e-prescribing gateway that only initially transmitted data between providers and pharmacies as a conduit may become a business associate when it is asked to follow a provider's specific routing instructions based on drug type for prescription refill requests.*

**D/D! Recommendation on business associate contract provisions !33 )!9(%645!  
6\$5+#!+\$48\*+C4#!N685+2\*#15%\*6 1 #2'9F!82\*46582N!8'9!C6982#99!+99%\*8+'#!\*%2'&+\*!  
1 %5#4!-%& 1 F!+25!'+=#!' (#&!+\$48\*+C4#! 1 #+29!'#!#296&#!' (+!\*%7#&#5!#2'8'8#9!  
specify the limits of health data use in their business associate contracts!  
) 6\* (!N685+2\*#+25! 1 %5#49!9 (%645!\*%2'826#!%!C#!+7+8+C4#!-%&!69#!%2!+!7%462'+&, !  
C+989/!!L2!+558'8%2F!33 )!9(%645!+\$4, !' (#9#! 1 #+29!'!48 1 8'!69#9!%!(#+4' (!5+'+!82!  
' (#88!% ; 2!+N&## 1 #2'9!/A%7#&#5!#2'8'8#9!9 (%645!9\$#\*8-, !82!' (#88!C6982#99!+99%\*8+'#!  
\*%2'&+\*'9\_!**

**D/D/D! terms that explicitly describe what identifiable health data may be used and for what purposes, by both the business associate and by any agents with whom the business associate may contract.  
) \$#\*8-8\*8', !82!' (#!\*%2'&+\*'!+44% ; 9!' (#!\*%7#&#5!#2'8', !%!5#9\*88C#!96\* (!69#9!  
'%!82587856+49!+25!5#'#& 1 82#!+2, !\$%'#2'8+4!\* (+2N#9!%7#&!8 1 #/!!The  
contract must not permit the business associate to use or disclose identifiable health data in ways that the covered entity is not permitted to use or disclose. !**

**D/D/G! terms that explicitly describe what HIPAA-de-identified data may be used and to whom HIPAA de-identified data are supplied.!B (89!+44% ; 9!  
' (#!\*%7#&#5!#2'8', !%!5#9\*88C#!96\* (!69#9!'%!82587856+49!+25!5#'#& 1 82#!+2, !  
\$%'#2'8+4!\* (+2N#9!%7#&!8 1 #/!!**

**D/D/Q! that there must exist a contract, with protections equivalent to the business associate contract as described above, between the business associate and all of its agents!82\*46582N!+N#2'9!%-!+N#2'9/!!  
B (89!+996&#9!+!\* (+82!%-!'&69'!-8% 1 !' (#!\*%7#&#5!#2'8', !' (&%6N (!+44!  
&%N+28P+'8%29!' (+! 1 +, ! (+7#!+\* \*#99!'%!85#2'8-8+C4#!%&!3LM : : !5#]85#2'8-8#5!  
(#+4' (!5+'+!/L'!+49%#2+C4#9!' (#!\*%7#&#5!#2'8', !%!C#!+C4#!%!5#9\*88C#!69#9!**



# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

## Enhanced Protections for Uses of Health Data: !

! :) '# ; +&59(\$!<&+ 1 # ; %&=-!-%&!>) #\*%25+&, ! . 9#9?!%~!@##\*!&%2!&\*+4, !A%4##\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+ +  
!

%~! (#+4' (!5+'+! 1 +5#!C, !+N#2'9!'!%!&25!&7!&56+49!+25!5#!& 1 &2#!+2, !\$%'#2'&+4!  
\* (+2N#9!%7#&!& 1 #/!

! D/D/K! **that any organization that supplies de-identified health data for a specified purpose will ensure that the de-identification process follows the HIPAA requirements for de-identification/!X) ##!+49%!  
" #\*% 1 1 #25+'!&2!K/D/!/!!!**

! D/G! **Recommendation on confirmation of business associate contract compliance\_! 3 3 ) !9 ( %6!5!' +=#!+\$\$48\* +C4#! 1 #+29!'!%#296&#!' (+!' \*%7#&#5!#2'8'8#9!  
\*+2!' \*%2-8& 1 !\*% 1 \$48+2\*#!C, !C69&2#99!+99%\*8+'#9! ; 8' (!' (!' #& 1 9!'~!' (!'C69&2#99!  
+99%\*8+'#!\*%2'&+\*!'!%2!+!&#N64+&!C+9!9/! : !&#N64+&!\*%2-8& 1 +!8%2!%~!' \*% 1 \$48+2\*#! ; 8' (!  
' (!'C69&2#99!+99%\*8+'#!\*%2'&+\*!' ; %6!5!#296&#!' (+'\_!!**

X+Y!! C69&2#99!+99%\*8+'#9a!+\*!8%29!&# 1 +&2!\*%29&9'#2'! ; 8' (!' (!' \$!& 1 8''#5!69#9F!!  
XCY!! +4!+N#2'9! (+7#!C##2!\$&\$#&4, !#2N+N#5!C, !' (!'C69&2#99!+99%\*8+'#9F!+25!|  
X\*Y!! ' (!'C69&2#99!+99%\*8+'#!+25!8'9!+N#2'9!+&#!&2!\*% 1 \$48+2\*#! ; 8' (!+44!%' (#&!  
+\$\$48\* +C4#!\$&%7!89&29!%~!' (!'C69&2#99!+99%\*8+'#!\*%2'&+\*!' /!!

! L2!' (!#7#2'!%~!+2, !\* (+2N#9!&2!69#9!%&!+N#2'9F!' (!'C69&2#99!+99%\*8+'#!\*%2'&+\*!'!  
1 69'!C#!+ 1 #25#5!B (89!&#\*% 1 1 #25+'!&2! 1 +, !C#!+\*% 1 \$489 (#5!C, !3 3 )\_!

!! D/G/D! 8996&2N!N685+2\*#!+C%6!'!\$&+\*!8\*+4!9\*#2+&8%9! ; (#&#!+!\*%7#&#5!#2'8', !-+849!'!  
+\$\$&%\$&8+'#4, !+55&#99!+!\*%2'&+\*!'6+4!7!8%4+'!8%2!C, !+!C69&2#99!+99%\*8+'#!' (+!  
\*%645!&#964'!&2!7!8%4+'!8%29!%~!' (!'3!M : : !M&87+\* , !" 64#!~%&!+!\*%7#&#5!#2'8', !

! D/G/G! 6\$5+'!2N!' (!'C69&2#99!+99%\*8+'#!\*%2'&+\*!' 1 %5#4!~%& 1 !

! D/G/Q! 82\*%&\$&+!&2N!96\* (!\*%2-8& 1 +'!8%2!%~!' \*% 1 \$48+2\*#!&2!3 3 )!% ; 2!C69&2#99!  
+99%\*8+'#!+N&## 1 #2'9/!!

! D/Q! **Recommendation on organizations providing data transmission functions\_!**

3 3 ) !9 ( %6!5!\$&%7!85#!N685+2\*#!' (+!' \*4+&8-8#9!' (+!' +2, !%&N+2!P+'!8%2!\$&%7!85!&2N!5+'+!  
'&+29 1 899&2!%~!-\$&% #'#5! (#+4' (!&2-~%& 1 +'!8%2!&2!%&5#&!%'! \*%256\*!' (!'&+29 1 899&2!&9!+!  
C+9!9!'! (!' \$&% #'#5! (#+4' (!&2-~%& 1 +'!8%2!&2!%&5#&!%'! \*%256\*!' (!'&+29 1 899&2!&9!+!  
C69&2#99!+99%\*8+'#!+25! 1 69'!C#!C%625!C, !' (!'&#` 6&# 1 #2'9!~%&!C69&2#99!  
+99%\*8+'#9!B (89!5%#9!2%'!+\$4, !'!%&!&6'!&2N!&29'&6\*!8%29!#J'#&2+4!'! (!' \$&% #'#5!  
(#+4' (!&2-~%& 1 +'!8%2!\*%2'!%~!' (!'&+29 1 899&2!2%&!%'!%24, !&2\*85#2'+4!\*%2-8& 1 +'!8A 1 2Tm (\*%2-8& 1 404

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data :**

:!)'# ; +859(\$!<8+ 1 # ; %&=!-%&!>) #\*%25+&,!. 9#9?!%~!@4#\*'8%28\*+4, !A%44#\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+' +  
!

--+8' (!#--%&'!%!( +7#!' (#!82587856+4!+ \* =2% ; 4#5N#!&#\* #8\$'!%-!' (#!SMM/! : 9!+!&#964'F!' (#!SMM!  
89!%- '#2!&#-#&#2\*'#5!+9!+!>3LM : :!\*%29#2'F?! ; (#2!8'!89!%24, !+2!82-%& 1 +'8%2+4!5%\*6 1 #2'!  
+578982N!82587856+49!+C%6'!' (#!\*%7#&#5!#2'8' , a9!82-%& 1 +'8%2!\$%48\*8#9!+25!\$&%\* #56&#9/!L2!  
+558'8%2F!' (#!SMM!89!-8#` 6#2'4, !4%2NF!58-8\*64'!'!&#+5F!+25!89!%24, !&#` 68&#5!'!%\$&%785#!  
#J+ 1 \$4#9!%-!69#9!+25!589\*4%96&#9/! : !SMM!89!2%'!&#` 68&#5!'!5#9\*8C#!\$%'#2'8+4!69#9!%-!  
5#]85#2'8-8#5!5+'+/  
!

R#\* +69#!%-!' (#!48 1 8'+ '8%29!82 (##2'!82!' (#!SMM!+25!8'9!69#F!+25!' (#!#J'#2987#!2#'; %&=!%-!  
C6982#99!+99%\*8+'#9!+25!' (#8&!+N#2'9!' (+! 1 +2, !\*%7#&#5!#2'8'8#9!69#F!' (#!SMM!89!2%'!  
9#&782N! ; #4!82!+4#&'82N!82587856+49!'!+4!\$%'#2'8+4!69#9!%-!' (#8&! (#+4' (!5+'+!%&!\*4+88', !  
96&&%62582N! (% ; !' (#, ! 1 +, !#J#&\*89#!\*%2'8%4!%7#&!69#9!%-!' (#8&! (#+4' (!5+'+!/SAT3) !  
(#+&5!'#9'8 1 %2, !+C%6'!9#7#&+4!\$&%\#\* '9!-%\*6982N!%2!' (#!22 5Tj 1 2 09\$-892\*. 8482!540 . 240 1 Tm(!) Tj 1 2  
\*% 1 1 628\*+'8%2!+C%6'!\$&9%2+4!82-%& 1 +'8%2/!<82582N9!-8% 1 !' (#9#!\$&%\#\* '9!&#7#+4#

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

# ; +859 ( - 1 # ; %&=-!-%&!> ) #\*%25+&, ! . 9#9?!%~!@#\*%&28\*+4, !A%44#\*#5!+25!B&+29 1 8''#5!3#+4' (!0+'+

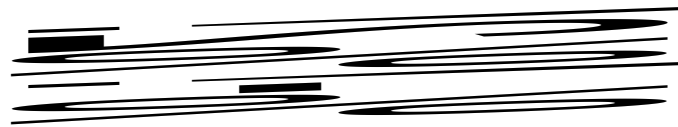
1887+\* #!permits!+!\*%7#&#5!#2'8', !'!%C'+82!+!consent -%&!69#9!+25!589\*4%96&#9!  
#+ ' 1 +, 1 #2'F!+25! (#+4' ( \*+&#!%\$#&+ '8%29!C, !\*%7#&#5!#2'8'8#9!XgDZK/WHZX+YY!  
ent! #' (!\*+&#! 1 %&#!\*% 1 1 %24, !&#-&#9!'!%!' (#!\$#& 1 8998%2!N87#2!C, !+2!82587856+4!  
&!\$%78582N! (#+4' ( \*+&#!9#&78\*#9!X ; (8\* (! 1 +, !82\*465#!82'#&78# ; 82NF!  
\$#\*8 1 #2!\*%44#\*#8%2F!+25!'&#+ ' 1 #2'!%-! (#!82587856+4F!+9! ; #4!+9!69#!%-!  
8%2Y!L2!96 1 1 +&, F! (#!69#!%-! (#!'#& 1 9!authorization!+25!consent,!+25!  
&#` 68&#5!%&!\$#& 1 8''#5F!\*+69#9!\*%2-698%2/!!

!%\*29#2!XKW!A< " !gDZK/WHZX+YY!82!' (#!%&8N82+4!3LM : : !M887+\* , ! " 64#! ; +9!  
HG!-&% 1 !&#` 68&82N!'!%\$#& 1 8''82N!\*%29#2'!-%&!69#9!%&!589\*4%96&#9!%-!+2!  
8 #\*#'#5! (#+4' ( !82-%& 1 + '8%2!-%&!+! \*%7#&#5!#2'8', a9!69#9!82!'&#+ ' 1 #2'F!  
\$ #+4' ( \*+&#!%\$#&+ '8%29!/B (89!9'84!+44% ; 9!\*%7#&#5!#2'8'8#9!'!%C'+82!\*%29#2'!+9!  
5 %!-%44% ; ! 1 %&#!9'&82N#2'!9'+ '#!4+ ; 9!\*%2'+8282N!>\*%29#2'!&#` 68&# 1 #2'9?!-%&!  
6 4%96&#9!%-!\$%#\*#'#5! (#+4' ( !82-%& 1 + '8%2!-%&!&#+ ' 1 #2'F!\$+ , 1 #2'F!+25!  
( #&+ '8%29/! ) % 1 #!\$6C48\*!%\* 1 1 #2'!6&N#5!+!&#`6&2!'!%!' (#!&#` 68&# 1 #2'!%-!  
\* 4!69#9!+25!589\*4%96&#9!%-!\$%#\*#'#5! (#+4' ( !82-%& 1 + '8%2/!!  
S 12%!96\$%&'! \* (+2N82N! (89!&#` 68&# 1 #2'!'+!' (89!'8 1 #F!C6'!'!%C6845!6\$%2!' (#!  
3 , ! " 64#!%!'#2 (+2\*#!\$887+\* , !\$%#\*#'#8%29!+25!'!%#7+46+'#! ; +, 9!'! 1 +2+N#!  
82 6' ( %&8P+ '8%29!82!+!S3LS!X9##! " #\*% 1 1 #25+'8%2! [/D/GY/!!

B ( 8996#! ; 8' (!&#9\$#\*#!'!' (#!+6' ( %&8P+'8%2!&#` 68&# 1 #2'!82!' (#!3LM : : !M887+\* , !  
" 6 #\*#'#5! (#+4' ( !82-%& 1 + '8%2!-%&!+! \*%7#&#5!#2'8', a9!69#9!82!'&#+ ' 1 #2'F!  
+6 2!X+!gDZK/WH[X\*YY!/B ( #9#!#4# 1 #2'9!+&#!82'#25#5!'!+--%&5!'&+29\$+&#2\* , F!C6'!  
8-!2 182!\$4+82!4+2N6+N#F! 1 +, !C#!\*%2-6982N!+25!#7#2!82'8 1 85+'82N!SAT3 ) !  
&#\* 1 1 #2'9!' (+!'4+88- , 82N! (#!69#9!+25!\*%2'#2'!%-!+6' ( %&8P+'8%2!-%& 1 9! ; %645!C#!  
(#4\$ T3 ) !+49!'!%C9#&7#5!' (+!' ( #&#!+&#!+!26 1 C#&!%-!%!' (#!&#` 68&# 1 #2'9!-%&!  
+51 87#!5%\*6 1 #2'+ '8%2!' (+!' ; %645!48=#4, !C#2#-8!-% 1 ! \*+&#-64!&#78# ; /!

G/D! Recommendation on Transparency\_133 ) 9 ( %645!8996#!N685+2\*#!%!'#296&#!' (+!  
7856+49! (+7#!' (#!%\$%&'628', ! 6&N#5!\*%888N82+4! G/D!

QQ!



**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +859(8\$!<8+ 1 # ; %8=-!-%&!>) #\*%25+& ,! . 9#9?!% !@##\*%&2\*#+4 ,!A%4##\*#5!+25!B&+29 1 8''#5!3#+4' (!0+ + !

+6' (%&8P+'8%29!82!\$4+82!4+2N6+N#/#B (89!N685+2\*#19 (%645!#J'#25!'!%' (#&! +5 1 8289' &+'87#!5%\*6 1 #2'+ '8%2!&#` 68&#5!-%&!#785#2\*#!%-% 1 \$48+2\*#! ; 8' (!' (#! 3LM : : !M&87+\* ,!+25!) #\*688' ,! " 64#9/!!

!!

G/D/Q! **making information available about the specific uses and users!of protected health information when requested\_!33 ) !9 (%645!8996#! N685+2\*#!%!\*%7#&#5!#2'8'8#9!'!%82\*%&\$%&+'#!&#-#&#2\*#!82!' (#!SMM!' (+! +558'8%2+4!82-%& 1 +'8%2!+C%6'! (% ; !\$&%#\*#5! (#+4' (!82-%& 1 +'8%2!89!69#5!C ,! C6982#99!+99%\*8+'#9!+25!' (#8&!+N#2'9!9 (+4!C#! 1 +5#!+7+84+C4#!6\$%2! &#` 6#9'! : !&#N64+&!%\*2-8& 1 +'8%2!% !C6982#99!+99%\*8+'#9!+25!' (#8&!+N#2'9! 96\* (!+9!5#9\*8&C#5!82! " #\*% 1 1 #25+'8%2!D/G ; %645!\$#& 1 8!' (#!%7#&#5!#2'8' ,! '%!=##\$!96\* (!82-%& 1 +'8%2!\*6&&#2'!+25!+C4#!'!%196\$4 ,! (#!82-%& 1 +'8%2! ; (#2! 82587856+49!#J\$#99!\*%2\*#&2!+C%6'!69#9!%-!' (#8&! (#+4' (!5+'+!!**

!

G/D/K! **making information available about the specific nature of protected health information disclosed to other organizations, such as public health\_!33 ) !9 (%645!8996#N685+2\*#!%!\*%7#&#5!#2'8'8#9!'!%82\*%&\$%&+'#! &#-#&#2\*#9!82!' (#!SMM!+C%6'! ; (+!' , \$9!%-!\$&%#\*#5! (#+4' (!82-%& 1 +'8%2! +&#!589\*4%9#5!'!%' (#&!%&N+28P+'8%29F!96\* (!+9! ; (#2!4#N+44 ,!&#` 68&#5!%&! \$#& 1 8''#5!-%&!\$6C48\*! (#+4' (!\$6&\$%9#9F!+25! 1 +=#!' (89!82-%& 1 +'8%2!+7+84+C4#! '%!82587856+49!6\$%2!&#` 6#9'!**

!

G/G! **Recommendation for education on uses of and protections for health data\_! 33 ) !9 (%645!5#7#4%\$!+25! 1 +82'+82!+! 1 64'8]-+\*#5!2+'8%2+4!#56\*+'8%2!828'8+'87#!' (+!' ; %645!#2 (+2\*#!' &+29\$+&#2\* , !&#N+&582N!69#9!%-( (#+4' (!5+'+F!82\*46582N!-%&!` 6+48' ,! 1 #+96&# 1 #2'F!&#%\$&'82NF!+25!8 1 \$&%7# 1 #2'!+25!-%&!&#9#+&\* (F!82!+2!625#89'+25+C4#! +25!\*64'6&+44 ,!9#298'87#! 1 +22#&!/B (#!828'8+'87#19 (%645!827%47#!+44!&#4#7+2'!33 ) ! +N#2\*8#9!/@56\*+'8%2+4!+'878'8#9!9 (%645!C#!+\$&%\$&8+'#4 ,!82'#N&+'#5!82'!<#5#&+4! +N#2\*8#9!&#9\$#\* '87#!\$&%N&+ 1 9F!\$%48\*8#9!+25!\$&+\* '8\*#9F!+9! ; #4!+9!588#\* '4 ,!'+&N#'#5! '%!\$6C48\*!+25!\$&%-#998%2+4!+658#2\*#9!/T+88%69!#56\*+'8%2+4! 1 %5+48'8#9!9 (%645!C#! 82\*465#5!82!S3 S! &8+4!8 1 \$4# 1 #2'+ '8%29!+25!%' (#&!-#5#&+44 ,!9\$%29%&#5! 5# 1 %29!&+'8%29/!**

**3. Observations and Recommendations for Data Stewardship on Individual Participation and Control over Personal Health Data Held by Organizations Not Covered by HIPAA Privacy and Security Rules**

!

M&%#\* '8%29!+--%&5#5!C ,!3LM : : !%24 ,!#J'#25!'!%!\*%7#&#5!#2'8'8#9!+25!' (&%6N (!\*%2' &+\* '6+4! +&&+2N# 1 #2'9!'!%' (#8&!C6982#99!+99%\*8+'#9!+25!' (#!+N#2'9!%-!' (#!C6982#99!+99%\*8+'#9! B (89!4#+7#9! 1 +2 ,!%&N+28P+'8%29!%6'985#!%-' (#!\$&%#\* '8%29!+--%&5#5!C ,!3LM : : !

!

- o! *Providers who do not accept insurance or who do not file claims electronically!* +&#!2%'!%7#&#5!#2'8'8#9!/SAT3 )!%C9#87#9!' (+!9#7#&+4!' , \$9 %-!\$&%785#&9!+&#!2%'! %7#&#5!C ,!3LM : : /!B (#9#!\$&%785#&9! 1 + , !C#!7#& ,!9 1 +4!+25!#J# 1 \$!-8% 1 !-8482N! #4#\* '%&28\*! \*4+8 1 9! ; 8' (!U#58\* +&#F!5%!2%'!-84#! \*4+8 1 9! ; 8' (!U#58\* +&#!+25!+&#!

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

Enhanced Protections for Uses of Health Data: !

:!)'# ; +&59(\$!<+ 1 # ; %&=-%&!>) #\*%25+&, !. 9#9?!%!@4#\*'&%28\*+44, !A%44#\*'#5!+25!B&+29% (!#)5T3#2'(04'2487 . 50627 17

!

%' (#& ; 89#!2%'!&#` 68&#5!'%!-84#!\*4+8 1 9!#4#\*'&%28\*+44, F!%&! (' #8&!\$+'8#2'9!9#4-]\$, /!B( #, !  
1 +, !+49%!C#!\$&%785#&9!' (+!'\*#+'#!&#\*%&59!\*%7#&#5!C,!' (#!<+ 1 84, !@56\*+'8%2+4!  
" 8N('9!+25!M&87+\*, !: \*'!X<@ " M: Y! ; (8\* (!+&#!#J\$48\*8'4, !#J\*465#5!-8% 1!' (#!5#-828'8%2!  
%-!\$&%#'#\*'#5! (#+4' (!82-%& 1 +'8%2/DK!!

!

- o! *Personal health record services* ' (+!'&#!2%'!%--#&#5!C, !\*%7#&#5!#2'8'8#9!+&#!  
82\* &#+982N!82!26 1 C#&! e ( 84#!+!26 1 C#&!%-\$#&9%2+4! (#+4' (!&#\*%&59!+&#!96\$%&'#5!  
C, !\$&%785#&9!%&! (#+4' (!\$4+29F!%' (#&9!+&#!825#\$#25#2!'\*% 1 1 #&\*8+4!\$&%56\*'9F!  
-&#` 6#2'4, !%--#&#5!78+! ; #C!98'9!#B (#!A%2N&#99! (+9!2%'!#2+\*'#5!+2, !4+ ; !&#` 68882N!  
\$&87+\*, !\$%48\*8#9!%2! ; #C!98'9d! (% ; #7#&F!' (#!<#5#&+4!B&+5#!A% 1 1 8998%2!X<BAY!  
(+9!C&%+5!+6' (%88', !625#&! ('#!<#5#&+4 B&+5#!A% 1C9898!%2!

\$%248', B2&+\*'8%/!'

+49%!

#-%&\*# 15#2'!

&N+28P++'8%9, !

\$%48, /(!) Tj 1200 12 1 86636954357 . 4404TmL2, !

&, !

\$+\*+'\*8#9!

# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

## Enhanced Protections for Uses of Health Data: !

:!)'# ; +859(\$!<8+ 1 # ; %&=-%&!>) #\*%25+&,!. 9#9?!%!@##\*'%28\*+4, !A%4##\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+' + !

82\*465#5/!33 )!9(%645!' (#2!\*%4+C%&+'#! ; 8' (!' (#!<BA!'!\$&% 1 %'#! (+& 1 %28P+'8%2!%-! &#N6+'8%29!\*%7#&82N!' (#9#!%&N+28P+'8%29!'!#296&#!'\*%2989'#2'!\$&87+\* , !\$&% '#\*'8%2/!

! Q/G! **Recommendation on obtaining authorization!for use of personal health information not covered by HIPAA protections!**!33 )!9(%645!' +=#!+\$\$48\*+C4#! 1 #+29!'!#296&#!' (+!'+2!+6' (%&8P+'8%2!-% 1 !' (#!82587856+4!89!%C'+82#5!-%&! \*%44#\*'8%2F!69#F!+25!589\*4%96&#!%-\$#&9%2+4! (#+4' ( 182-%& 1 +'8%2! (#45!C, !+2, ! %&N+28P+'8%2!*not covered!*C, !3LM : :/!) ##!+49%! " #\*% 1 1 #25+'8%2!E/D!

### 4. Observations and Recommendations for Data Stewardship on De-Identification

! B (#!3LM : : !M&87+\* , ! " 64#!+\$\$48#9!%24, !'!\$&% '#\*'#5! (#+4' (!82-%& 1 +'8%2/!B (#&#-%&#F!' (#! M&87+\* , ! " 64#!\$#& 1 8'9!69#!%-!5#]85#2'8-8#5!5+'+! ; 8' (%6'!82587856+4!+6' (%&8P+'8%2/!B (#! M&87+\* , ! " 64#!&# `68&#9!#8' (#&!+!9+#! (+&C%&!%&!9'+89'8\*+4!+\$\$&%+\* (!%!5#]85#2'8-8\*+'8%2/! 0#]85#2'8-8\*+'8%2!&# 1 %7#9!' (#!5+'+!-% 1 !' (#!\$&% '#\*'8%2!%-!3LM : : !&# `68&# 1 #2'9/!!

! L2!+558'8%2F!+\$\$48\*+'8%29!%-!3LM : : a9!9+#! (+&C%&!5#-828'8%2!%-!5#]85#2'8-8\*+'8%2!%-!#2! &# 1 %7#!%24, !' (#!D! !5+'+!#4# 1 #2'9!82!' (#!5#-828'8%2!+25!8N2%&#!' (#!&# `68&# 1 #2!'!%! &# 1 %7#!>+2, !%' (#&!628 `6#!85#2'8-, 82N!26 1 C#&F!\* (+&+\* '#889'8\*F!%&!\*%5#F!#J\*#\$'!+9! \$&# 1 8''#5?!XgDZK/WDKXCXGXYX8YX " YY!<6&' (#& 1 %&#F!%2#!'9'8-8#&!8258\*+'#5!' (+!'&# 1 %7+4!%-' (#! D! !5+'+!#4# 1 #2'9!9\$#\*8-8#5!82!3LM : : ! 1 +, !&#964'!82!+!9 1 +4!+C848' , !'!&#]85#2'8-, !+2! 82587856+4

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(8\$!<8+ 1 # ; %&=-!-%&!>) #\*%25+&, ! . 9#9?!!-!@4#\*'8%28\*+4, !A%4#\*'5!+25!B&+29 1 8' '#5!3#+' (!0+' +!

*Example 2: There is potential for risk to accrue not only to individuals but providers as well. The Prescription Project raised concerns about potential conflicts of interest in the medical profession created by pharmaceutical marketing conducted through linking physician prescribing records with physician demographic data.<sup>17</sup>*

*Example 3: Data mining is another technology increasingly being applied to health data. Electronic health records may be mined to generate on-screen ads. While meant to afford the opportunity for physicians to acquire electronic health record systems at no cost, there are also concerns that such a business model may violate individual-physician trust.<sup>18</sup>*

**K/D! Recommendation on de-identification\_!3 3 ) !9 (%645!8996#!N685+2\*#!'!'\*%7#&#5!  
#2'8'8#9!XD/Y!#J\$4+8282N!' (#!\$&+\*'8\*+4!98'6+'8%29!+25!\$&%C4# 1 +'8\*!8996#9!96&&%62582N!  
69#9!+25!589\*4%96&#9!%-!3LM : : !5#]85#2'8-8#5!5+'!+25!XG/Y!\*4+&- , 82N!' (+!' (#!  
3LM : : !5#-82'8%2!%-!5#]85#2'8-8\*+'8%2!XC, !' (#!9+'89'8\*+4! 1 #' (%5!%&!\*% 1 \$4#'#!9+-#!  
(+&C%&!5#-82'8%2Y!89!' (#!%24, !\$## 1 8''#5! 1 #+29!'!5#]85#2'8-, !\$&%#\*'#5! (#+4' (!  
82-%& 1 +'8%2/!!**

**K/G! Recommendation on uses of de-identified data\_!SAT 3 )!(#+&5!' (+!' (#&#!+&#!  
98N28-8\*+2!'\*%2\*#&29!96&&%62582N!69#9!%-!5#]85#2'8-8#5!5+'!+25!' (+!' (#9#! ; +&&+2!'!  
1 %&#!' (%8%6N (!+2+4, 989!/!SAT 3 ) ! ; 844!\*%256\*!' (#+&&2N9!'!5#'#& 1 82#! (% ; !'!  
9'&6\*'6&#!N685+2\*#!-%&!C#9'!5+'!+9# ; +&59(8\$!\$&+\*'8\*#9!/B#\$8\*9! ; (8\* (!9 (%645!C#!  
+55&#99#5! 1 + , !82\*465#F!C6'!2%!'C#!48 1 8'#5!'!%F!69#!%-!' (#!9+'89'8\*+4!5#]  
85#2'8-8\*+'8%2!\$&%\*#99!'! 1 ##'+!\*#&'+82!' (&#9 (%45!-%&!\$&%C+C848' , !%-!&#]  
85#2'8-8\*+'8%2F!69#9!827%4782N!9+4#!%-!5#]85#2'8-8#5!5+'!F!#J\$%96&#!-%& 1 !&#]  
85#2'8-8\*+'8%2F!\$%#2'8+4!-%&!N&%6\$]C+9#5! (+& 1 9F!+25!+44% ; +C4#!69#9!%-!5#]  
85#2'8-8#5!5+'!+!!**

**5. Observations and Recommendations for Data Stewardship on Security Safeguards and Controls**

B (#!3LM : : !M&87+\* , ! " 64#!5#9\*88C#9!8 1 \$4# 1 #2+'8%2!9\$#\*8-8\*+'8%29!-%&! 1 828 1 6 1 !  
2#\*#99+&, !69#9!%-!\$&%#\*'#5! (#+4' (!82-%& 1 +'8%2F!82\*46582N!' (#!85#2'8-8\*+'8%2!%-!\$#&9%29!%&!  
\*4+99#9!%-!\$#&9%29!82!8'9! ; %&=-%&\*#! ; (%!2##5!+\*\*#99!'!\$&%#\*'#5! (#+4' (!82-%& 1 +'8%2!'!  
\*+&&, !%6'!' (#88!56'8#9F!+25!-%&!#\*+\* (!\$#&9%2!%&!\*4+99!%-!\$#&9%29!' (#!\*+'#N%&, !%&!  
\*+'#N%&8#9!%-!\$&%#\*'#5! (#+4' (!82-%& 1 +'8%2!'! ; (8\* (!+\*\*#99!89!2##5#5F!+25!+2, !  
\*%258'8%29!+\$&%\$88+'#!'!96\* (!+\*\*#99!XgDZK/WDKX5YX9YX : Y!+25!XRYY/!L'!+49%182\*465#9!+!  
> 1 828]9#\*6&8' , !&64#?'+!gDZK/WQHX\*Y! ; (#&#!' (#!\*%7#&#5!#2'8' , ! 1 69'! (+7#!82!\$4+\*#!  
+\$&%\$88+'#!+5 1 8289'&+'87#F!'#\* (28\*+4F!+25!\$ ( , 98\*+4!9+-#N6+&59!'!\$&%#\*#!' (#!\$887+\* , !%-!  
\$&%#\*'#5! (#+4' (!82-%& 1 +'8%2/!

!!  
D! ) #+2!<4, 22F!M&#9\*88\$'8%2!M&%!#\*#F! : 6N69!GQF!GHH!/  
D! !0%+2F!M/i/F!><###!@4#\*'8%28\*!U#58\*+4! " #\*%&5! ) , 9' # 1 !A% 1 #9! ; 8' (!) '882N9! : ''+\* (#5F?!AMNews!U+ , !IF!  
GHHI/!

# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

## Enhanced Protections for Uses of Health Data: !

:!)'# ; +&59(\$!<&+ 1 # ; %&=-!-%&!>) #\*%25+&, ! . 9#9?!%~!@##\*%&28\*+4, !A%4##\*#5!+25!B&+29 1 8''#5!3#+4' (!0+!' !

B (#!3LM : :!)#\*6&8', !" 64#!+--%&59!' (#!+5 1 8289'&+'87#!+25!'#\* (28\*+4!9+--#N6+&59!'!%96\$\$%&! 1 828 1 6 1 !2#\*#99+&, !69#9!+25!589\*4%96&#9/! : 5 1 8289'&+'87#!9+--#N6+&59!82\*465#!+\*#99! +6' (%&8P+'8%2!82! ; (8\* (!%48\*8#9!+25!\$%&\*#56&#9! 1 69'!59\*8&C#! (% ; !+\*#99!'!#4##\*%&28\*! \$%&'#\*#5! (#+4' (!82-%& 1 +'8%2! 1 +, !C#!N&+2'#5F!-%&!#J+ 1 \$4#F!'!+! ; %&=9+'8%2F!'&+29+\*'8%2F! \$%&N&+ 1 F!\$%&\*#99F!'&!% ' (#&! 1 #\* (+289 1 !XgDZK/QH[X+YXKYX88YXRYY!/B#\* (28\*+4!9+--#N6+&59! &#` 6&8#!8 1 \$4# 1 #2+'8%2!-%!'#\* (28\*+4!%48\*8#9!+25!\$%&\*#56&#9!-%&!#4##\*%&28\*!82-%& 1 +'8%2! 9, 9'# 1 9!' (+! 1 +82+82!#4##\*%&28\*!\$%&'#\*#5! (#+4' (!82-%& 1 +'8%2!'!+4% ; !+\*#99!%24, !%!' (%9#!\$#89%29!'&!9%-'; +&#!\$%&N&+ 1 9!' (+! (+7#!C##2!N&+2'#5!+\*#99!88N ('9!+9!9\$#\*8-8#5! 82!gDZK/QH[X+YXKY!/B (89!&#` 6&8# 1 #2!'-%&!+\*#99!\*%2'8%49!82\*465#9!+!&#` 6&8# 1 #2!'-%&! # 1 #&N#2\*, !+\*#99!\$%&\*#56&#9F!'\*% 1 1 %24, !&#-#&#5!'!%82!' (#!82569'&, !+9!>C&#+=]' (#] N4+99?!' (+!#2+C4#9!2#\*#99+&, !+\*#99!82!+2!# 1 #&N#2\*, !/!2!\$#+\*'8\*#F!' (#9#! 1 #\* (+289 1 9! +&#!%-#2!+\*#99! 1 \$+28#5!C, !' (#! 1 #+29!'!` 68\*=4, !+22%'+'#!+!&+'8%2+4#!-%&! (#!+\*#99!+25! N#2#&+'8%2!-%!+!9\$#\*8+4!+658!'&+84/!!

! B#9'8-8#&9!'!SAT3 )!&#\$%&'#5!' (+!96\* (!#\* (2%4%N, !+25!' (#&9!' (+!+&#!2%'!2#\*#99+&84, ! &#` 6&8#5!C, !3LM : : !C6'!+--%&5!9'&%2N#&19#\*6&8', F!96\* (!+9!58N8'+4!98N2+'6&#!6982N!q/WHE! \*#&'8-8\*+'#!+25!2%2]&#\$658+'8%2!-%&!\$#89%2!'&!#2'8', !+6' (#2'8\*+'8%2F!+&#!#\* (2%4%N8#9! +7+84+C4#!+25!C#82N!69#5!96\*#99-64, !82!9% 1 #!8 1 \$4# 1 #2+'8%29/DE!!<%&!#J+ 1 \$4#F!9#7#&+4! (%9\$8'+49!&#\*#2'4, !+5%\$#5!+!>P#&#%]'%4#&+2\*#!\$%48\*, ?!%2!\*%2-85#2'8+48', F!82\*46582N!69#!%-! \*% 1 \$6'#&!\$%&N&+ 1 9!'!85#2'8-, !\$%#2'8+4!\*+9#9!%-!82+\$%&\$&8+'#!+\*#99F!+25!-%625! 98N28-8\*+2'!#56\*'8%2!82!# 1 \$4%, ##9!589\*8\$482#5!-%&!\$887+\*, !78%4+'8%29/GH!L! ; +9!+49%! %C9#&7#5F! (% ; #7#&F!' (+!2%'!+44!\*%7#&#5!#2'8'8#9!2##5!'!5#\$4%, !9'8%2N#&!#\* (2%4%N, F! +25!' (+!#\* (2%4%N, !\*%2'826#9!'!% (+2N#!/B (#!3LM : :!)#\*6&8', !" 64#!89!&89=]C+9#5!+25! 1 69'!&# 1 +82!-4#J8C4#!+25!9\*+4+C4#!%!' +\*#99! 1 1 %5+'#!' (#!2##59!%-!+! ; 85#!7+&8#', !%-' \*%7#&#5!#2'8'8#9/!

! W/D! **Recommendation!on technical data security management approaches!** 3 3 )!9 (%645!8996#!N685+2\*#!%!\*%7#&#5!#2'8'8#9!'!\$%& 1 %#!169#9!%-!#\* (28\*+4! 9#\*6&8', ! 1 #+96&#9!'!&#56\*#!62+6' (%&8P#5!+\*#99F!+25!'!#296&#!' (+!' (#8! C6982#99!+99\*8+'#9!+25!+N#2'9!+&#!-644, !\*% 1 \$48+2'! ; 8' (!' (#!3LM : :!)#\*6&8', !" 64#! &#` 6&8# 1 #2'9F!82\*46582N!+6' (%&8P+'8%2F!+\*#99F!+6' (#2'8\*+'8%2F!+25!+658!'!%2'&%4/! B (89!N685+2\*#!-%&!9#\*6&8', ! 1 +2+N# 1 #2'!9 (%645!+49%!C#!588#\*#5!'!%&N+28P+'8%29! ' (+!'&#!2%'!\*%7#&#5!#2'8'8#9!' (+! 1 +82+82!+25f%&!&+29 1 8'!\$#89%2+4! (#+4' (! 82-%& 1 +'8%2F!+9! ; #44!+9!'!7#25%&9!%-! (#+4' (!82-%& 1 +'8%2!'#\* (2%4%N, /!

### 6. Observations and Recommendations for Data Stewardship on Data Quality and Integrity

3LB!+25!3L@!\*+2!+85!82!\*% 1 \$&# (#2987#!5+'!+\*%44#\*%8%2!+25!9 (+&82NF!C6'!5+'+!82'#N88', F! 628-%& 1 8', !%-!5#-828'8%2F!+25!7+4858', ! 1 69'!C#!+996&#5/!b69'!C#\*+69#!5+'+!+&#!+7+84+C4#! #4#\*%&28\*+44, F!5%#9!2%'! 1 #+2!' (+!'! (#!5+'+!+&#!+\*#6&+!



**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(\$!<@+ 1# ; %&=-!-%&!

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(\$!<&+ 1 # ; %&=!-%&!>) #\*%25+&,!. 9#9?!%~!@4#\*'&%2!+44,!A%44#\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+'+  
!  
+\$\$4,/!^6+48',!+99#99 1 #2'!+\*'878'8#9!+&#!5#-82#5! ; 8' (82!3LM: : !+25!\*8'#5!+9!\$#& 1 8998C4#!  
69#9!%~!\$&% '#\* '#5! (#+4' (!82-%& 1 +'8%2!625#&! (#+4' ( \*+&#!%\$#&+'8%29/! " #9#+&\* (!89!+49%!  
5#-82#5! ; 8' (82!3LM: : F!6982N!' (#!5#-828'8%2!-&% 1 !B(#!A

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(\$!<&+ 1 # ; %&=-%&!>) #\*%25+&, !. 9#9?!%~!@4#\*'&%28\*+44, !A%44#\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+' +  
!  
) #7#&+4!&#\*#2'!+&'8\*4#9!+49%!5#9\*88C#!' (#!9'+ '#!%-!+--+8&9!82!`6+48', !8 1 \$&%7# 1 #2'!/!  
Oam+2#<sup>GD</sup>!%C9#&7#9!' (+!> 1 %9'! 1 +2+N# 1 #2'!9'&6\*'6&#9!5%!2%'!96\$%\$%&!82'#N&+'#5!`6+48', !  
1+2+N# 1 #2'?!' (+! ; %645!#2 (+2\*#!+\*\*%62'+C848', !-%&!`6+48', F!+25!5#9\*88C#9!' (#!2##5!-%&!  
+!`6+48', !%7#&98N ('!\$%\*#99!C, !+!&#9\$%298C4#!9'&6\*'6&#!+\*\*%62'+C4#!'!9#28%&!  
1+2+N# 1 #2'+25!' (#!N%7#&2+2\*#!%~!' (#!829'8'6'8%2!-%&!+44!`6+48', !8 1 \$&%7# 1 #2'+\*'878'8#9!!  
!  
B#9'8 1 %2, ! ; +9!+49%! (#+&5!' (+!'96NN#9'#5!' (#!5#98&#!-%&!+! ; 85#&!&%4#!-%&!82587856+49!82!  
5#\*8582N! ; (#' (#&!%'!\$#& 1 8'!' (#8&! (#+4' (!5+'+'!'!C#!69#5!-%&!`6+48', !+99#99 1 #2'+\*'878'8#9!/  
L2!+!9'65, !%2!+6' (%&&P+'8%2!C8+9!-%&!+!5+'+!C+9#5!&#9#+&\* (!9'65, !&#\$%&'#5!C, !3+&&89F!Q/G!  
\$#&\*#2'!%-!82587856+49!+'87#4, !5#\*482#5!\$+&'8\*8\$+'8%2F! ; (84#!+2%' (#&!D I /W!\$#&\*#2'!585!2%'!  
&#9\$%25

# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

## Enhanced Protections for Uses of Health Data: !

:!)'# ; +859(8\$!<8+ 1 # ; %8=-!-%&!>) #\*%25+8, ! . 9#9?!% !@4#\*'8%28\*+4, !A%44#\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+' + !

!

I/D/Q !!would benefit from a voluntary, proactive oversight process!

+\*%62'+C4#!'!9#28%&! 1 +2+N# 1 #2'!+25!' (!N%7#&2+2\*#!%-!' (!829'8'6'8%2!  
'#!#296&#!' (#&#!89!\*% 1 \$48+2\*#! ; 8' (!3LM : : !82!69#9!%-! (#+4' (!5+'+!-%&!  
' 6+48', ! 1 #+96&# 1 #2'F!&#\$%&'82NF!+25!8 1 \$8%7# 1 #2'!) 6\* (!N685+2\*#! 1 +, !  
5&+ ; !-% 1 !' (!!\$&+\* '8\*#9!' (+!'+&#!\*6&&#2'4, !82!\$4+\*#!%5+, !' (+!6'848P#! 1 %5#4!  
N%7#&2+2\*#!9'&6\*#6&#9F!\$8%\*#99#9F!\* (#\*=489'9F!+25!+N&## 1 #2'9/! e (#&#!8'!  
89!5#'#& 1 82#5!' (&%6N (!+!889=fC#2#-8'!+2+4, 989!' (+!' (#&#!89! (#8N ('#2#5!&89=  
'!82587856+49!-8% 1 !' (!!' 6+48', !&#\$%&'82N!\$8%\*#99F!' (!%7#&98N ('!\$8%\*#99!  
9(%645!&#\*% 1 1 #25!#J'&+!\$8#\*+6'8%2+&, ! 1 #+96&#9!'!\$8%\*#\*!' (!'  
82587856+49/!

!

### Uses of Health Data for Research

!

B (#!A% 1 1 %2! " 64#!X\*%58-8#5!-%&!33 ) !+'!KW!A< " !KZF!96C\$+&'! : Y!5#-82#9!&#9#+&\* (!+9!>+!  
9, 9'# 1 +'8\*!827#9'8N+'8%2F!82\*46582N!&#9#+&\* (!5#7#4%\$ 1 #2'F!'#9'82N!+25!#7+46+'8%2F!  
5#98N2#5!'!5#7#4%\$!%&!\*%2'&8C6'#!'!N#2#&+48P+C4#!=2% ; 4#5N#/?!B (89!89!+49%!' (!'  
5#-828'8%2!%-!&#9#+&\* (!625#&!' (!M&87+\* , ! " 64#!XgDZK/WHDY/!B (#&#!+&#!9#7#&+4!8 1 \$%&' +2'!  
8996#9F! (% ; #7#&F!82!69#9!%-! (#+4' (!5+'+!-%&!&#9#+&\* (\_!

!

! Variations in Interpretation of Research Regulations\_!<#5#&+44, ]&#N64+'#5!  
&#9#+&\* (!9'658#9!827%4782N! (6 1 +2!96C\#\*#9!N#2#&+44, !&#` 688#!+\$8%7+4!C, !+2!  
829'8'6'8%2+4!&#78# ; !C%+&5!XL " RY!+25!+2!82-%& 1 #5!\*%29#2'!'!>%\$!82?!'!%!  
\$+&'8\*8\$+'82N!82!' (!!&#9#+&\* (!!\$8%/\#\*'/!SAT3) ! (#+&5!'#9'8 1 %2, !' (+!' (!&#!89!  
7+&8+'8%2!82!82' #&\$&#+'8%29!%-!&#N64+'8%29!+55&#9982N! (6 1 +2!&#9#+&\* (!!\$8%\*#\*#8%29!  
+\*%&99!' (!!3LM : : !M&87+\* , ! " 64#F!' (!!A% 1 1 %2! " 64#F!'

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

Enhanced Protections for Uses of Health Data: !

:!)'# ; +859(8\$!<8+ 1 # ; %&=-%&!>) #\*%25+&,!. 9#9?!%~!@#\*%&28\*+4, !A%4#\*%5!+25!B&+29 1 8''#5!3#++' (!0+' + !

! Distinguishing Quality Activities from Research\_!SAT3 )!(#+&5!-8% 1 !9#7#&+4! '9'8-8#&9!82!&#78# ; 82N!7+88%69!&#%\$&'9GK!' (+!'` 6+48' , !+\* '878'8#9!+&#19% 1 #'8 1 #9! 58--8\*64!'!%1589'82N689 (!-8% 1 !&#9#+&\* (F!+25!' (+!'9% 1 #!'` 6+48' , !+\* '878'8#9! 1 + , !#7%47#! 82'%'!&#9#+&\* (!9'658#9!/L'! ; +9!%C9#&7#5!' (+!' (#!>482#C# ; ##2!'` 6+48' , !8 1 \$&%7# 1 #2'! +25!\*4828\* +4!&#9#+&\* (!89!&#4+'87#4, !\$#& 1 #+C4#F!+25!8'!89!9% 1 #'8 1 #9!58--8\*64!'!%! 5#'#& 1 82#! ; 8' (!\$&#\*898%2! ; (#' (#&!+\$!\$&%!#\*!'9(%645!C#!\*%2985#&#5!'` 6+48' , ! 8 1 \$&%7# 1 #2'!'%&!&#9#+&\* (F!#9\$#\*8+44, ! ; (#2!+!'` 6+48' , !9'65, !1 + , !6'848P#!#\* (28` 6#9! %-!&+25% 1 8P+'8%2!+25!\$&%9\$#\*'87#!82'##7#2'8%2! ; 8' (!' (#!96\$%\$&'!%-!#4#\*'8%28\*! 5+'+C+9#9/?GWI B#9'8 1 %2, !'!SAT3 )!5#9\*8&C#5!+!-64!9\$#\*'86 1 !%-!( ; ! %&N+28P+'8%29!+55&#99#5!'` 6+48' , f&#9#+&\* (!%7#&4+\$9F!-8% 1 !&#` 6#9'82N!+226+4! " R! &#78# ; !%-!` 6+48' , !9'658#9!X#/N/F!' (#!S%&' (#&2!S# ; !@2N4+25!A+&58%7+9\*64+&! 089#+9#!)'65, ! \ &%6\$YF!6982N!+!5#\*898%2!'###!-8+ 1 # ; %&=!'!N685#182'##2+4! +\*'878'8#9!82!5#'#& 1 8282N! ; (#2!+2!+\*'878' , !89!2%'!&#9#+&\* (!X#/N/F!' (#!A#2'##!-%&! 3#+4' (!)'658#9!+'! \ &%6\$!3#+4' (!A%#\$#&+'87#YF!'!%\*2985#882N!+2, !9'65, ! ; 8' (!82'##2' !%!\$6C489 (!&#9#+&\* (!X#/N/F!U+ , %!A4828\*Y/!!

\ %%5!'` 6+48' , !8 1 \$&%7# 1 #2'!+\*'878'8#9!9 (+&#!8 1 \$%&' +2'!\* (+&+\*'##889'8\*9! ; 8' (!&#9#+&\* (F! #9\$#\*8+44, ! ; 8' (!&#9\$#\*!'!%'! (#8&!#' (8\* +4!625##&\$82282N9/! i 6 1 \$=82!%C9#&7#9!' (+!C+98\*! \$&82\*8\$4#9!%-!C8% 1 #58\* +4!# (8\*9F!82\*46582N!&#9\$#\*!'!-%&!+6'%2% 1 , F!C#2#-8\*#2\*#F!2%2] 1 +4#-8\*#2\*#F!+25!69'8\*#!&#4+'#!%'!+44!+9\$#\*9!%-!3LM : : !BMOF!+25!#` 6+44, !82!'` 6+48' , F! \$6C48\*! (#+4' (F!+25!&#9#+&\* (!69#9!%-! (#+4' (!5+'+/GZ!!!

: 9!' (#!S+'8%2!9##=9!7+46#]5&87#2! (#+4' (!\* +&#F!\*4+88- , 82N!&#9#+&\* (!&#N6+'8%29!+25! 589'82\*'8%29!C# ; ##2!'` 6+48' , !+\* '878'8#9!+25!&#9#+&\* (!89!\*88'8\*+4/!

I/G!! Recommendation on harmonizing research regulations !33 )!9(%645!\$&% 1 % #!

(+& 1 %28P+'8%2!%-!&#9#+&\* (!&#N6+'8%29! ; 8' (82!33 )!+25! ; 8' (!%' (#&!0#\$+&' 1 #2'9!

' (+!'!%7#&9###!&#N64+'8%29!%2! (6 1 +2!&#9#+&\* (!\$&%#\*%'8%29!'!#296&#!5 1 . 45W5 1 . 45W5 1 . 45W5620

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +859(8\$!<8+ 1 # ; %&=-%&!>) #\*%25+&, ! . 9#9?!% !@4#\*'&%28\*+4, !A%44#\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+'+  
!

I/K! **Recommendation for wide dissemination of quality/research overlap guidance:!**33 )!9 (%645!#2\*%6&+N#!' (#!O--8\*#!%-!36 1 +2! " #9#+&\* (!M&% '#\*'8%29!  
XO3 " MY!82!\*% 1 \$8482N!8'9!\*4+&8-, 82N! ; %&=!%2!' (#!5#-828'8%2!%-!&#9#+&\* (!%!' ; 85#4, !  
5899# 1 82+'#!' (#!&#964'9!/! i 8 1 8'82N!96\* (!5899# 1 82+'8%2!%24, !%!' (#!&#9#+&\* (!  
\*% 1 1 628', !\*+2!48 1 8'!8'9!69#-642#99!-%&!\$&%785#&9F!\$+, #&9F!+25!%' (#&9! ; (%! 1 +, !2%!  
\*%2985#&!' (# 1 9#47#9!&#9#+&\* (#&9F!C6'! ; (%! 1 +, !C#\*% 1 #!#2N+N#5!82!`6+48', ! ; %&=!  
' (+!64'8 1 +'#4, !-+449! ; 8' (82!' (#!9\*%\$#!%-!&#9#+&\* (!%2!(6 1 +2!96C!#\*'9/!

! I/W! **Recommendation for means to!transition quality activities into research when appropriate\_!**33 )!9 (%645!-%9'#!' (#!%44+C%&+'87#!#--%&'9!C#'; ##2!O3 " M!  
+25!OA " !%!'85#2'8-, !+\$&%+\* (#9!'#!#296&#!' (+!' ; (#2!+!`6+48', !9'65, !C#\*% 1 #9!  
N#2#&+48P+C4#!+25!#7%47#9!82'!%&#9#+&\* (F!' (+!3LM : : !M&87+\*, !+25!L " R!  
&#`68&# 1 #2'9!+&#!&#9\$#\*'#5/!

!! I/Z!! **Recommendation on further investigation into uses of health data for research: SAT 3 )!**85#2'8-8#5!\*#&+82!+&#+9!' (+!&#`68&#!-6&' (#&!827#9'8N+'8%2F!96\* (!  
+9!&#9#+&\* (!C+9#5!9%4#4, !%2!5+'+!-% 1 !#4#\*'&%28\*! (#+4' (!&#\*%&59F!+25!5#\*#5#2'!  
&#9#+&\* (!/!L!+49%!(#+&5!' (#!\$%'#2'8+4!7+46#!-%&!+!\*% 1 1 %2!%7#&98N ('!%-!`6+48', !+25!  
&#9#+&\* (! ; 8' (82!+2!%&N+28P+'8%2!/SAT 3 )! ; 844!'+=#!' (#!4#+5!

# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

## Enhanced Protections for Uses of Health Data: !

:!)'# ; +859(8\$!<8+ 1 # ; %&=-!-%&!>) #\*%25+&,!. 9#9?!%~!@#\*%&28\*+4,!A%4#\*%#5!+25!B&+29 1 8''#5!3#++' (!0+' +  
!<br>82-%& 1 +'8%2!/B (#9#!82\*465#! (#+' (!&#\*%&5!C+2=82N! 1 %5#49F!\*%29#2'! 1 #'+5+'+F!+25!  
-#5#&+'#5!\*%29#2'!&#N89'88#9!/ e (84#!' (#9#!' #\* (2%4%N8#9!+&#!2# ; !+25!&#` 688#!'#9'82NF!' (#, !  
1 +, !&#%785#!+!968'+C4#! ; +, !-%&!+2!+6' (%&8P+'8%2!'!-%44% ; !5+'+!!!  
!

### [/D!! Recommendation on adoption of data stewardship within a NHIN\_!33 )!

9 (%645!\*%2'826#!%!\$6&96#!-6&' (#&!5#-828'8%2!%-!+!S 3LS!+25!8'9!69#9F!+25!  
\*%2\* 6&&#2'4, !9'65, !(% ; !%!C+4+2\*#!' (#!C#2#-8'9!%-! (#+' (!5+'+!69#9!+9!  
5#7#4%\$ 1 #2'!%-!+!S 3LS!\$&#N&#99#9! ; 8' (!' (#!\*%2\*#&29!#J\$&#99#5!+C%6'!\$%'#2'8+4!  
-%&! (+& 1 9!B&+4!8 1 \$4# 1 #2'+!8%29!+25!%' (#&!-#5#&+4, ]9\$%29%&#5!5# 1 %29'&+'8%29!  
9 (%645!82\*465#\_!

### [/D/D! evaluation of the impact of applying enhanced data stewardship,

82\*46582N! (% ; !' (#!N4%99+&, !%~!#& 1 9! 1 +, !(+7#! (#4\$#5!82-%& 1 !' (#!  
+\$\$48\*+'8%2!%-!+\$\$&%\$&8+'#!5+'+!9'# ; +859(8\$!-%&!7+88%69!69#9!%-! (#+' (!  
5+'+F!#9\$#\*8+4, !+9! 1 %&#!\*% 1 \$&# (#2987#!5+'+C+9#9! 1 +, !C#!\*% 1 \$84#5!C, !  
%&N+28P+'8%29!' (+!+&#!2%'!3LM : : !\*%7#&#5!#2'8'8#9!' (+!+&#!9\$+ ; 2#5!C, !+!  
S 3LS/!

### [/D/G!! evaluation of ways to manage individuals' authorizations\_!33 )!

9 (%645!82\*465#!82!8'9!S 3LS!'&+4!8 1 \$4# 1 #2'+!8%29!+25!%' (#&!-#5#&+4, ]  
9\$%29%&#5!5# 1 %29'&+'8%29!' (#!#7+46+'8%2!%-! (% ; !2# ; !' #\* (2%4%N8#9!' (+!  
(+7#!+!'+\* =!&#\*%&5!%-!96\* \*#99!82!%' (#&!9#''82N9! 1 +, !+-%&5!' (#!+C848, !-%&!  
82587856+9!'!\$&%785#!+6' (%&8P+'8%2!-%&!69#9!%-!' (#&!\$&% #' #5! (#+' (!  
82-%& 1 +'8%2!/B (#!#7+46+'8%2!%-!96\* (!' #\* (28` 6#9!9 (%645!82\*465#!  
5#'#& 1 8282N!'! ; (+!5+'+!9 (+&82N!9\*#2+88%9!+2!+6' (%&8P+'8%2! ; %645!  
\$&%785#!%\$'8 1 +4!\$&% #' #\* %2! ; (84#!+996&82N!' (#!C#2#-8'9!%-! (#+' (!5+'+!69#9/!

### [/D/Q! evaluation of new methods or techniques to de-identify health data!

'%!5#'#& 1 82#!' (#&#!#--#\*'87#2#99!'!\$&% #'#!85#2'8', !+25!2%'!#2+C4#!&#]  
85#2'8-8\*+'8%2! ; (#2!2%'!82'#25#5/!

### [/D/K! evaluation of and continued maturity of chain of trust mechanisms

'%!5#'#& 1 82#!' (#!8 1 \$+\*'!%2!C6982#99!+99%\*8+'#!&#4+'8%29(8\$9!+25!#296&#!  
'&+29\$+&#2\* , !C# ; ##2!\*%7#&#5!#2'8'8#9!+25!C6982#99!+99%\*8+'#9!+25!' (#&!  
+N#2'9/!

### [/D/W! evaluation of educational modalities '%!5#'#& 1 82#!' (#! 1 %9!'!#--#\*'87#!

1 #99+N#9!+25! 1 #58+!-%&!7+88%69!' +&N#'+!658#2\*#9/!

### [/D/Z! evaluation of appropriate safeguards needed to ensure that there is no unintended harm to individuals as de-identified data may be sold to support ' (#!\$%998C4#!C6982#99! 1 %5#49!%-!+!S 3LS/!

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

Enhanced Protections for Uses of Health Data: !

:!)'# ; +&59(8\$!<8+ # ; %&=-%&!>) #\*%25&!, . 9#9?%!@##\*%&28\*+4, !A%4##\*#5!+25!B&+29 18''#5!3#++' (!0+' + !

9. Observations and Recommendations on Additional Privacy Protections

B#9'8 1 %2, !8258\*+'#9!' (+!' (#&#!89!+!\*%2'8266 1 !%-!69#&9!%-! (#+4' (!5+'+!c!-&% 1 !' (%9#! ; 8' (!+! \*4%9#!2#J69! ; 8' (!' (#!5#487#&, !%-!\*+&#!-%&! (#!82587856+4!X8/#/F!82587856+4!\*+&#!&#\*8\$8#2'9F! \$&%785#&9F!+25!\$+, #&8Y!'!%' (%9#!' (+!'&#!7#&, !-+&!&# 1 %7#5!-&% 1 !' (#!82587856+4]\$&%785#&] \$+, #&!&#4+'8%29 (8\$!X#/N/F!5+'+! 1 8282N!%&N+28P+'8%29!' (+!'&+\*=(#+' (]8#4+'#5! ; #C!98'#9Y/! B#9'8 1 %2, !+49%!85#2'8-8#5!' (+'F! ; (84#!' (#!3LM : : !M&87+\*, !+25!) #\*6&8', !8#N6+'8%29! +55&#99!\$&% #'8%29!+9! (#+4' (!5+'+!+&#!69#5!\*4%9#!'!%' (#!2#J69!%-!\*+&#!5#487#&, F!' (#! -+&' (#&!&# 1 %7#5!-&% 1 !\*+&#!5#487#&, F!' (#!4#99!\$&% #'8%2F!8-!+2, F!89!+--%&5#5!/B (#!4+\*=%!%-! +5#` 6+'#!\$&% #'8%29!+\*8%99!+4!69#9!%-! (#+4' (!5+'+!\*+2!&#964'!82!9#&8%69! (+& 1 9!'%! 82587856+49!+25!64'8 1 +'#4, !' (#!` 6+48', !%-! (#+4' (!+25! (#+4' (!\*+&#!82!' (#!S+'8%2/!!

SAT3)!(+9!\$&#78%694, !1 +5#!9#7#&+4!9#9!%-!&#\*% 1 1 #25+'8%29!9#''82N!' (#!C&%+5! \*%2'J!'!-%&!\$&87+\*, !8 1 \$&%7# 1 #2'F!82\*46582N!' (+!'\$&87+\*, !864#9!9 (%645!+\$&\$4, !'!+4! 82587856+49!+25!%&N+28P+'8%29!' (+!'\*#+'#F!\*% 1 \$84#F!9'%&#F!&+29 1 8'F!%&!69#!\$&#9%2+4! (#+4' (!82-%& 1 +'8%2/!) '+#9!+&#!+4&#+5, !C#N82282N!'!#2+\*!4+ ; 9!82'#25#5!'!C&%+5#2! \$&% #'8%29/!!

*For example, California AB 1298, which goes into effect January 1, 2008, adds to the class of covered entities under California's Confidentiality of Medical Information Act "any business organized for the purpose of maintaining medical information in order to make the information available to an individual or a provider for purposes of allowing the individual to manage his or her health information, or for the diagnosis or treatment of the individual." This would include businesses that maintain PHRs. It also amends the State's consumer notification law requiring the owner or licensee of computerized personal information to provide notice of a breach of security of the data to any California resident whose unencrypted personal information was, or is reasonably believed to have been, acquired by an unauthorized person.!*

<82+44, F!' (#&#!89!' (#!2#5!'!+55&#99!7+88+'8%29!82!9'+#14+ ; 9! ; 8' (!&#9\$#\*!'!'\$&87+\*, /! e (84#!8'!89!8 1 \$%&&'+2!'!%85#2'8-, !C#9!\$&+\*8\*#9!+25!9'+#9! 1 +, !C#!82!' (#!C#9!\$%98'8%2!'!%' #9!'!7+&8%69!\$&+\*8\*#9F!589\$+&+'#!4+ ; 9!+\*8%99!9'+#9! 1 +=#!8'!\*%9'4, !+25!58-8\*64!'!-%&! \*%7#&#5!#2'8'8#9!'!%' 1 \$4, ! ; 8' (!+44!26+2\*#9!%-! (#!4+ ; 9! ; (#2!5+'+!+&#!#J\* (+2N#5! +\*8%99!9'+#!C%625+&8#9!/b69!'!+9!'#\* (28\*+4!82'#8%\$#&+C848', !89!2#\*#99+&, !82!+!S3LSF! \$&87+\*, !4+ ; !82'#&%\$#&+C848', !89!2##5#5!+9! ; #44/!

E/D!! Recommendation on additional federal privacy legislation\_!33) !9 (%645! ; %&=! ; 8' (!%' (#&!-#5#&+4!+N#2\*8#9!+25!' (#!A%2N&#99!)

E/D/D for more inclusive, federal privacy legislation!9%' (+!'!+44!82587856+49!+25! %&N+28P+'8%29!' (+!'69#!+25!589\*4%9#!82587856+4, !85#2'8-8+C4#! (#+4' (! 82-%& 1 +'8%2!+&#!\*%7#&#5!C, !' (#!5+'+!9# ; +&59(8\$!\$&82\*8\$4#9!82 (#&#2'!82!96\* (! 4#N894+'8%2F!82\*46582N!+!&+2N#1!-%&N+28P+'8%29!2%!\*6&&#2'4, !\*%7#&#5!C, ! 3LM : : /! "#-#&#2\*#!SAT3)!Recommendations Regarding Privacy and



**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(8\$!<8+ 1 # ; %&=-!-%&!>) #\*%25+&,!. 9#9?!%~!@4#\*'%&28\*+4, !A%44#\*'#5!+25!B&+29 18''#5!3#++' (!0+' +  
!

*Confidentiality in the Nationwide Health Information Network!9#2'!'%!' (#!  
) #\* &#'+&, !%-!33 ) !%2!b62#!GGF!GHHZ/!!*

!

E/D/G **on expanding the definition of covered entity under HIPAA!***In the  
absence of comprehensive privacy legislation, 33 ) !9 (%645!+55&#99!' (#!  
2##5!-%&! 1 %&#!48 1 8' #5!4#N894+'8%2!' (+!'#J\$+259!' (#!5#-828'8%2!%-!\*%7#&#5!  
#2'8' ,!625##&!3LM: : !-&% 1 !8'9!-%\*69!%2!-82+2\*8+4!+25!+5 1 8289'&+'87#!  
'&+29+\*'8%29!'!%\*%7#&!%' (#&!%&N+28P+'8%29!' (+!' 1 +2+N#F!\*%44#\*#F!78# ; F!9'%&#F!  
9 (+&#F!589\*4%9#F!%&!%' (#& ; 89#! 1 +=#!69#!%-!\$#&9%2+4! (#+4' (!82-%& 1 +'8%2/! : '!+!  
1 828 1 6 1 F!96\* (!%&N+28P+'8%29!9 (%645!82\*465#!96\$\$48#&9!%-\$#&9%2+4! (#+4' (!  
&#\*%&5!9, 9' # 1 9!' (+!'&#!2%'!%\*%7#&#5!#2'8'8#9!/O' (#&!#J+ 1 \$4#9! 1 +, !82\*465#!  
(#+4' (!889=!+99#99 1 #2'!96\$\$48#&9!+25!\$#&9%2+4! (#+4' (!'&+82#&9/!) 6\* (!  
4#N894+'8%2!9 (%645!2%'!82+57#&'#2'4, ! ; #+=#2!#J89'82N!\$887+\*, !\$&%'#\*8%29!  
<%&!#J+ 1 \$4#F!9% 1 #!\*% 1 1 #2' #&9!#J\$&#99#5!\*%2\*#&2!' (+!'%&N+28P+'8%29!!  
'%5+, !' (+!'\$88 1 +884, !%C'+82!+NN&#N+'#5!5+'+F!96\* (!+9!# 1 \$4%, #&!9\$%29%&9!%-!  
(#+4' (!\$4+29F!2%'!C#!82\*465#5!82!' (#!5#-828'8%2!%-!\*%7#&#5!#2'8' ,F! (69!  
\$%'#2'8+44, !#2+C482N!' (# 1 !'%! (+7#!+*

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'#; +&59(\$!<4+ 1#; %Health

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS  
Enhanced Protections for Uses of Health Data: !**

:!)'#; +&59(\$!

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +859(\$!<8+ 1 # ; %&=-!-%&!>) #\*%25+&,!. 9#9?!%!@4#\*'&%28\*+4, !A%44#\*'#5!+25!B&+29 1 8''#5!3#++' (!0+' +  
!

**Staff of the Centers for Disease Control and Prevention, National Center for Health Statistics**

! 0#CC8#!b+\*=9%2!  
m+' (#882#!b%2#9!  
U+88#'+'!) `688#!  
A,2' (8+!) ,52#,!

**NCVHS Ad Hoc Work Group on Secondary Uses of Health Data**

! ) 8 1 %2!M!/A% (2F!U/O/F!U/M/3/F!A (+88!  
b69'82#!U!/A+8&F!U/O/F!A%]T8\*#!A (+88!  
3+8&,!" #,2%459F!A%]T8\*#!A (+88!  
b!/U+8\*!O7#& (+N#F!U/O/F!M(/O/!  
U+8=!: /! " %' (9'#82F!b/O/!  
e 848+ 1 !b!) \*+24%2F!M(/O/!  
M+6!B+2NF!U/O/!  
m#782!A!/T8N84+2'#F!U/O/F!U/M/3/!

**Work Group Staff**

m#4, !A&%282F!33 ) F!O--8\*#!%-' (#!S+'8%2+4!A%%&582+'%&!-%&!3#+4' (!L2-%& 1 +'8%2!B#\* (2%4%N, !  
U+&, !b%!0##882NF!M(/O/F!33 ) !S+'8%2+4!L29'8'6'#9!%-'!3#+4' (F!S+'8%2+4!A+2\*#&!L29'8'6'#!  
b!/U8\* (+#!<8'P 1 +688\*#!F!M(/O/F! : N#2\* , !-%&!3#+4' (\*+&#! " #9#+&\* (!+25!^6+48' ,!  
U%8889! : /! i +25+6F!b/O/F!U/3/ : /F! i /i /U/F!33 ) F!O--8\*#!%-' (#!S+'8%2+4!A%%&582+'%&!-%&!  
3#+4' (!L2-%& 1 +'8%2!B#\* (2%4%N, ! B#\* (2%4%N, !  
b% (2! i %%29=F!U/O/F!O--8\*#!%-' (#!S+'8%2+4!A%%&#! " #9#+&\*5TE

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +859(8\$!<8+ 1 # ; %&=-%&!>) #\*%25+&,!. 9#9?!%~!@4#\*'&%28\*+4, !A%44#\*'#5!+25!B&+29 1 8''#5!3#++' (!0+'+  
!

**Appendix B: Testifiers and Commenters on Uses of Health Data**

!  
m+&#2! : 5+ 1 9F!M (/O/F!S+'8%2+4! ^6+48', !<%&6 1!  
!  
@489+C#' (!R#4 1 %2'F!@9` /F!U+82#3#++' (!  
!  
) 6#! : /!R4#7829F!L29'8'6'#!-%&!3#++' (!&##5% 1!  
!  
U#&, 4!R4%% 1 &%9#2F!U/R/ : /F! " 3L : F! : 1 #&8\*+2!U#58\*+4!L2-%& 1 +'8\*9! : 99%\*8+'8%2!  
!  
A+& 1 #44+!R%\* (82%F! : 1 #&8\*+a9!3#++' (!L296&+2\*#!M4+29!  
!  
A825, !R&+\* (F! : N#2\* , !-%&!3#++' (\*+&#! " #9#+&\* (!+25!^6+48', F!33 )!  
!  
e 8448+ 1 !R&+8' ( ; +8' #F!U/O/F!M (/O/F!3#++' (!L2-%& 1 +'8%2!M%48\* , !A%2964'82N!  
!  
0+785!A+&4894#F!U/O/F!A+48-%&28+!O--8\*#!%-!) '+'# ; 85#!3#++' (!M4+2282N!+25!0#7#4%\$ 1 #2'!  
!  
b#+2!A (#2% ; #' (F!B (% 1 9%2!3#++' (\*+&#!  
!  
0#289#!A (845&#99F!S+'8%2+4!R6982#99! \ &%6\$!%2!3#++' (!  
!  
0#C%&+ (!A%44 , +&F! \ &%6\$!3#++' (!A%%\$#&+'87#!  
!  
b%58! \ /!0+28#4F!b/O/F!U/M/3/F!O--8\*#!%-!' (#!S+'8%2+4!A%%&582+'%&!-%&!3#++' (!L2-%& 1 +'8%2!  
B#\* (2%4%N, F!33 )!  
!  
A+&%4!08+ 1 %25F!U/O/F!U/M/3/F!U+&=4#!<%625+'8%2!  
!  
" 8\* (+&5!) /!08\* =F!M (/O/F!k%6!B+=#!A%2'&%4!  
!  
3% ; +&5!08\* =4#&F!U/O/F! : 99%\*8+'8%2!%-! : 1 #&8\*+2!U#58\*+4!A%44#N#9!  
!  
i 825+! i /!08 1 8'&%\$%64%9F!M (/O/F! " BL!L2' #&2+'8%2+4!  
!  
U+&\* (#44#!0!%&5!#78\*F! : 1 #&8\*+2!A%44#N#!%-!) 6&N#%29!  
!  
<4% , 5!@89#2C#&NF!U/O/F!U/M/3/F!) 8# 1 #29!U#58\*+4!) %46'8%29!3#++' (!) #&78\*#9!  
!  
i , 22!@' (#&#5N#F! \ #%&N#! e +9(82N'%2! . 287#&89' , !  
!  
m&89'82!<8'PN#&+45F!A%2-85#2'8+48', !A%+48'8%2!

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(8\$!<8+ 1 # ; %&=!-%&!>) #\*%25+&,! . 9#9?!%~!@4#\*'&%28\*+4, !A%44#\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+' +  
!  
!)# +2!<4, 22F! i #N+4!A%2964'+2!'%'! (#!M&#9\* &8\$'8%2!M&%!#\*'  
!  
b%(2!M/! \ 4+9#&F!M (/O/F! : 3LA!M#&9%2+48P#5!3#+4' (!A+&#! e %&=! \ &%6\$!  
!  
b%2+' (+2! \ %45F!U/O/F!U 3 : F!U ) AF!U \*m#99%2!M&%785#&!B#\* (2%4%N8#9!  
!  
i #%2! \ %45 1 +2F!U/O/F!R#' (!L9&+#!0#+ \*%2#99!U#58\* +4!A#2' #&!  
!  
b%#4! e /! \ %45 ; #82F!U/O/F!@4#=' +F!L2\* /!  
!  
B82+!O49%2! \ &+25#F!3#+4' (\* +&#! i #+5#89 (8\$!A%62\* 84!  
!  
U+&N+&#!' \ 62' #&F!M (/O/F! " SF!3 UO! " #9#+&\* (!S#' ; %&=!+25! i %7#4+ \*#!A4828\*!  
<%625+'8%2fSU! " 3LO!  
!  
b%(2!3+4+ 1 =+F!U/O/F!A+&# \ &%6\$!3#+4' (!) , 9'# 1 !+25!3+&7+&5!U#58\*+4!) \* (%%4d!3#+4' (!  
L2-%& 1 + '8%2!B#\* (2%4%N, !)' +25+&59!M+2#4!  
!  
: 99+~!3+4#7 , F!5CU%'8%2F!L2\* /!  
!  
0%6N!3#24# , F! : 3LA!M#&9%2+48P#5!3#+4' (!A+&#! e %&=N&%6\$!  
!  
U+&\* #4482#! " /!3+&889F!M (/O/F! " SF!U+ , %!A4828\*!  
!  
T8\* =8!3% (2#&F!U/R/ : /F!<%J!) , 9'# 1 9F!L2\* /!  
!  
\ +84!3%&48\* =F!U/ ) / e /F!b/O/F!O~8\*#!%~!) \*8#2'8~8\*! " #N64+'%&, ! ) #&78\*#9F!A#2' #&9!-%&!089#+9#!  
A%2' &%4!+25!M&#7#2'8%2!  
!  
U%28\* +!b%2#9F!B (#!L2-%& 1 +'8%2!A#2' #&!-%&!3#+4' (!+25!) %\*8+4!A+&#F! . m!  
!  
b648#!m+2#9 (8&%F!O~8\*#!-%&!36 1 +2! " #9#+&\* (!M&% '#\* '8%2F!3 3 )!  
!  
) 69+2!m4#8 1 +22F!M (/O/F!m4#8 1 +22!A%2964'82N! \ &%6\$!  
!  
) '#7#2!@/! i +C=%~F!U/O/F!< : AMF!M~8P#&!3#+4' (\* +&#!L2-%& 1 +'8\*9!  
!  
) (8&4# , !)/! i +5 , F!R46#!A&%99!R46#!) (8#45! : 99%\*8+'8%2!  
!  
i #948#! i #2#&'F!U/O/F!A#2' #&9!-%&!089#+9#!A%2' &%4!+25!M&#7#2'8%2!  
!  
U+&84 , 2!v8N 1 625! i 6=#F! : 1 #88\* +a9!3#+4' (!L296&+2\*#!M4+29!  
!  
b%(2! " /! i 6 1 \$=82F!U/O/F!UM3F! " %C#&'! e %%5!b% (29%2!<

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**  
**Enhanced Protections for**

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'#; +&59(\$!<&+ 1#; %&=-!-%&!>)#\*%25+&,!.9#9?!%~!@4#\*'&%2!+44,!A%4#\*'#5!+25!B&+291!#5!3#+4'(!0+'+!  
!  
!b#2!-#&! ) 1 \$9%2F! : 1 #&8\*+2! : 99%\*8+'8%2!%-!M#%\$4#! ; 8' (!0!9+C848!8#9!  
!  
b%#4!) 4+\*= 1 +2F!R46#!A&%99!R46#! ) (8#45! : 99%\*8+'8%2!  
!  
) (+&%2! i!/!) \$&#2N#&F! " 3L : F!AM3 ^F!UM : F!B (#!b%82!'!A% 1 1 8998%2!  
!  
i+'+2, +!) ; ##2#, F!M (/0/F!A+&2#N8#]U#44%2! . 2!7#&98' ,!  
!  
) (+&%2!</!B#&&, F!U/ : /F! \ #2#'0\*! : 448+2\*#!  
!  
b#+2#'#!B (%&2'%2F! : 1 #&8\*+a9!3#+4' (!L296&+2\*#!M4+29!  
!  
U8\*=, !B&&\$+' (8F!M (/0/F!UMMF!U+99+\* (69#'!9!#3#+4' (!A%44+C%&+'87#!  
!  
@ 1 84, !e #4#C%CF! "/S/F!U/) /F!L25!+2+!3#+4' (!L2-%& 1 +'8%2!@J\* (+2N#F!L2\*!/  
!  
M!/b%2! e (8' #F!U/0/F! : N#2\* , !-%&!3#+4' (\*+&#! " #9#+&\* (!+25!^6+48' ,!  
!  
) '#7#2! e %/!\*8=F!S+'8%2+4!R69!2#99! \ &%6\$!%2!3#+4' (!  
!  
e 8448+ 1! : /!k+92%--F!U/0/F!M (/0/F!3#+4' (! " #\*%&5!R+2=82N! : 448+2\*#!  
!  
) \*%'!k%62NF!U/0/F!m+89#&!M#& 1 +2#2'#!  
!  
!  
!  
!  
!  
!  
!  
!  
!  
!  
!  
!



NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

Enhanced Protections for Uses of Health Data: !

:!)'# ; +859(8\$!<8+ 1 # ; %8=-!-%&!>) #\*%25+8,!. 9#9?!%~!@4#\*'8%28\*+4, !A%44#\*'#5!+25!B8+29 1 8''#5!3#++' (!0+ '+ !

Appendix C: Glossary of Terms

! B(89!N4%99+&, !%-!'#& 1 9!85#2'8-8#9!+25!5#-82#9!#& 1 9!69#5!C, !' #9'8-8#&9!X+25!82!\*%44+'#&+4! 5%\*6 1 #2'9Y!82!589\*6998%2!%-169#9!%-! (#+4' (!5+'+!L'9!\$6&\$%9#!89!'!%\$8%785#!N685+2\*#!'%'! '(#!&#'+5#&!%-'! (89!&#%&'!+9! ; #44!+9!'!%82-%& 1 '! (#!5#7#4%\$ 1 #2'!%-!8'9!8\*% 1 1 #25+'8%29! B(#!9'86\*#6&#!%-!' (#! \ 4%99+&, !%-!B#& 1 9!89!N#2#&+4, !\*%2989'#2'! ; 8' (!' (#!>) #\*%25+8, !. 9#9! +25! " #]69#9!%-!3#++' (\*+&#!0+'+\_!B+J%2% 1, !-!%&!M%48\*, !<%& 1 64+'8%2!+25!M4+2282N?! X+/=+/F! : UL : !B+J%2% 1, Y!5#7#4%\$#5!C, !' (#! : 1 #88\*+2!U#58\*+4!L2-%& 1 +'8\*9! : 99%\*8+'8%2! X : UL : Y!13% ; #7#&F' (8&#!+&#!C%' (198 1 84+&8'8#9!+25!58--#8#2\*#9!C# ; ##2!' (#!' ; %! 5%\*6 1 #2'9!' (+!'&#!8 1 \$%&'+2!'!%2%'#\_!

!! B(#!SAT3)! \ 4%99+&, !%-!B#& 1 9!89!82'#25#5!'!%82-%& 1 '! (#!&#\*% 1 1 #25+'8%29! 82\*465#5! (8&#82!+25!'! (84\$!\$8%785#!N685+2\*#82!5#'#& 1 8282N!968'+C4#!5+'+! 9'# ; +859(8\$!+\$8%&+\* (#9!-%&!7+88%69!69#9!%-! (#+4' (!5+'+!C, !' (#!%&N+28P+'8%2! (+782N!V6&8958\*'8%2!%7#&! (#!69#/#!

!! : UL : !9+'#9!' (+!'8'9!B+J%2% 1, !89!82'#25#5!'!C#!69#5!+9!+!>#9%6&\*#!82! 5#7#4%\$82N!\$4+29!+25!\$%48\*8#9!&#4+'#5!'!9#\*%25+8, !69#9!%-! (#+4' (\*+&#!5+'+/?!B(#! : UL : !B+J%2% 1, !\$8%785#9!+!\*+'#N%88P+'8%2!%-! (#+4' (!5+'+!69#9!' (+!'\*%645!C#! 5#9\*88C#5!C, !7+88%69!+'88C6'#9!+25!' (8&#-%&#!&#4+'#!\$%48\*, !9+'# 1 #2'9!'! (#! \$+&'8\*6+&!69#/#!

!! B(#!SAT3)! \ 4%99+&, !%-!B#& 1 9!82\*465#9!+22%'+'#5!5#-828'8%29!'!N685#! (#!&#'+5#&! %-'! (#!&#%&'!+9! ; #44!+9!'!%\$8% 1 %#!+5%\$'8%2!%-!9'+25+&5!#& 1 82%4%N, !+99%\*8+'#5! ; 8' (!69#9!%-! (#+4' (!5+'+!#!!

Terms

B#& 1 9! . 9#5!'!0#9\*88C#!) '+69!%-!L2-%& 1 +'8%2!

**Health information**F!+9!5#-82#5!C, !3LM : : !M&87+\*, f) #\*688', f@2-%&\*# 1 #2'!&#N64+'8%29\_! >+2, !82-%& 1 +'8%2F! ; (#' (8&!%&+4!%&!8#\*%&5#5!82!+2, !-%& 1 !%&! 1 #586 1 F!' (+\_!XDY!89!\*&#+'#5!'%&! &#\*#87#5!C, !+! (#+4' (\*+&#!\$8%785#&F! (#+4' (!\$4+2F!\$6C48\*! (#+4' (!+6' (%88', F!# 1 \$4%, #8F!48-#! 8296&#&F!9\* (%%4!%&!6287#&98', F!%&! (#+4' (\*+&#!\*4#+&82N (%69#d!+25!XGY!&#4+'#9!'! (#!\$+9'F! \$8#9#2'F!%&!-6'6&#!\$ (, 98\*+4!%&! 1 #2'+4! (#+4' (!%&!\*%258'8%2!%-!+2!82587856+4d!' (#!\$8%7898%2!%-! (#+4' (!\*+&#!%&!+2!82587856+4d!%&! (#!\$+9'F!\$8#9#2'F!%&!-6'6&#!\$, 1 #2'!-%&! (#!\$8%7898%2!%-! (#+4' (!\*+&#!%&!+2!82587856+4/?!XKW!A< " !gdZH/DHQY!

**Individually identifiable health information**!XLL 3LYF!+9!5#-82#5!C, !3LM : : ! M&87+\*, f) #\*688', f@2-%&\*# 1 #2'!&#N64+'8%29\_!>+!96C9#!'!%-! (#+4' (!82-%& 1 +'8%2F!82\*46582N! 5# 1 %N&+\$ (8\*!82-%& 1 +'8%2!\*%44#\*'#5!-%& 1 !+2!82587856+4!+25!XDY!89!\*&#+'#5!'!&#\*#87#5!C, ! +! (#+4' (\*+&#!\$8%785#&F! (#+4' (!\$4+2F!# 1 \$4%, #8!%&! (#+4' (\*+&#!\*4#+&82N (%69#d!+25!XGY! &#4+'#9!'! (#!!1/!1/! (#+4' (!%-!+2!82587856+4F!\$8%7898%2!%-! (#+4' (!\*+&#!%&!+2!82587856+4F!%&!/!1/! \$+, 1 #2'!-%&! (#!\$8%7898%2!%-! (#+4' (!\*+&#!%&! (#!82587856+4d!+25!XQY!' (+!'85#2'8-8#9!' (#!

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +859(8\$!<8+ 1 # ; %&=-!-%&!>) #\*%25+&,!. 9#9?!%!@4#\*'&%28\*+44,!A%44#\*'#5!+25!B&+29 1 8''#5!3#+4'(!0+'+  
!  
82587856+4d!%&!XKY! ; 8' (!&#9\$#\*'!'%! ; (8\* (!' (#&#!89!+!&#+9%2+C4#!C+989!'!C#48#7#!' (#!  
82-%& 1 +'8%2!\* +2!C#!69#5!'!85#2'8-,!' (#!82587856+4?!XKW!A< " !gDZH/DHQY!  
!

**Protected health information!XM3LYF!+9!5#-82#5!C,!3LM : :!**

M887+\*,f) #\*6&8',f@2-%&\*# 1 #2'!&#N64+'8%29\_!>82587856+44,!85#2'8-8+C4#!(#+4'(!82-%& 1 +'8%2! h!  
'(+!89!'&+29 1 8''#5!C,!#4#\*'&%28\*! 1 #58+d! 1 +82'+82#5!82!#4#\*'&%28\*! 1 #58+d!%&!&+29 1 8''#5!%&!  
1 +82'+82#5!82!+2,!%' (#&!-%& 1 !%&! 1 #586 1 ?!C,!+2!#2'8',!\*%7#&#5!625#&!3LM : :!X8/#/F! (#+4' (!  
\$4+29F!\*4#+&82N(%69#9F!+25!\$&%785#&9!' (+!'&+29 1 8''!+2,! (#+4' (!82-%& 1 +'8%2!82!#4#\*'&%28\*!  
-%& 1 !82!\*%22#\*'!

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +859(8\$!<8+ 1 # ; %&=-%&!>) #\*%25+&,!. 9#9?!%~!@4#\*'8%28\*+44,!A%44#\*'#5!+25!B&+29 1 8''#5!3#+4'(!0+!'+  
!  
\$6C48\*!+9!\$+&'8\*8\$+'82N!82!+!V%82'!+&&+2N# 1 #2'd!+25!X88Y!\$+&'8\*8\$+'#!82!V%82'!+\*'878'8#9!'(+!  
82\*465#! 4#+9'!%2#!%-!'(#!-%44% ; 82N\_X : Y!6'848P+'8%2!&#78# ; !/!/!/F!XRY!` 6+48' ,!+99#99 1 #2'  
+25!8 1 \$&%7# 1 #2'!+\*'878'8#9!/!/!/F!%&!XAY!\$+ , 1 #2'!+\*'878'8#9F!8-!'(#!-82+2\*8+4!&89=-%&!  
5#487#&82N! (#+4' (!\*+&#!89!9 (+&#5!/!/!/d!XQY!+!N&%6\$! (#+4' (!\$+2!+25!+! (#+4' (!8296&+2\*#!  
8996#&!%&!3 UO!/!/!/d!XKY!+!N&%6\$! (#+4' (!\$+2!+25 % #!%&! 1 %&#!% + 2Tj 1200

!Tj 1200 1 22! (3) 76!65265402362 1(20)5265200Tm22#438797252654408T\*%7#+&#5!

(#+4'(!

1 ! \$ 2 !% + N +Tj 1200 151 3465

'(#!

WI!

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

Enhanced Protections for Uses of Health Data: !

:!)'# ; +859(\$!<8+ 1 # ; %&=-!%&!>) #\*%25+&, ! . 9#9?!%~!@4#\*%&28\*+4, !A%4#\*%#5!+25!B&+29 1 8''#5!3#++' (!0++' !

**Privacy board**!+9!5#-82#5!C, !3LM : : !M&87+\* , ! " 64#\_!+!N&%6\$! ; (%9#! 1 # 1 C#&9! (+7#! >7+&, 82N!C+\* =N&%6259!+25!+\$&%\$&8+\*#!\$&%-#99%2+4!\*% 1 \$# '#2\* , !+9!2#\*#99+&, !'!&#78# ; ! '(#!#--\*%'!-!r+s!&#9#+&\* (!&%%'%\*%4!%2!r+2s!82587856+4a9!\$&87+\* , !&8N('9!+25!&#4+'#5!82'##&#9'9d! 82\*465r82Ns!+'!4#+9'!%2#! 1 # 1 C#&! ; (%!89!2%'!+--848+'#5! ; 8' (!' (!' \*%7#&#5!#2'8' , !2%'!+--848+'#5! ; 8' (!+2, !#2'8' , !\*%256\*'82N!%&!9\$%29%&&2N!' (!#&#9#+&\* (F!+25!2%'!&#4+'#5!'!+2, !\$#&9%2! ; (%!89!+--848+'#5! ; 8' (!+2, !%-!96\* (!#2'8'89d!+25!5%#9!2%'! (+7#!+2, ! 1 # 1 C#&!\$+&8'8\$+'82N! 82!+!&#78# ; !%-!+2, !\$&%\#\*%'!82! ; (8\* (!' (!' 1 # 1 C#&! (+9!+!\*%2-48\*'!%-!82'##&#9!'! : !\*%7#&#5! #2'8' , ! 1 + , !69#!%&!589\*4%9#!\$&%\*%'#5! (#+4' (!82-%& 1 +'8%2!-%&!&#9#+&\* (F!&#N+854#99!%-!' (! 9%6&\*%'!%-!-625!82N!%-!' (!#&#9#+&\* (!&%785#5!' (+!'/!'/!'/ (!' \*%7#&#5!#2'8' , !%C'+829! 5%\*6 1 #2'+8%2!' (+!+2!+4'#&+'8%2!'!%&! ; +87#&F!82! ; (%4#!%&!82!\$+&'F!%-!' (!#82587856+4! +6' (%&8P+'8%2!'/!'/!'/ (+9!C##2!+\$&%7#5!C, !#8' (#&!+2!L29'8'6'8%2+4! " #78# ; !R%+&5!'/!'/!d!%&!+! \$&87+\* , !C%+&5!'/!'/!/?!XKW!A< " !gDZK/WDX8YY!

**Data use agreement**!+9!5#-82#5!C, !3LM : : !M&87+\* , ! " 64#\_!+2!+N&## 1 #2!'C# ; ##2!+! \*%7#&#5!#2'8' , !+25!' (!#&#\*8\$82'!%-!+148 1 8'5!5+'+9#!' (+!#9'+C489 (#9!' (!#&#8 1 8''#5!69#9! +25!589\*4%96&#9!%-!' (!#48 1 8'5!5+'+9#!'/!XKW!A< " !gDZK/WDX#YY!!

**Data stewardship**!+9!5#-82#5!C, !' (!' : 1 #&8\*+2!U#58\*+4!L2-%& 1 +'8\*9! : 99%\*8+'8%2! >#2\*% 1 \$+99#9!' (!#&#9\$%298C848'8#9!+25!+\*%62'+C848'8#9!+99%\*8+'#5! ; 8' (! 1 +2+N82NF! \*%44#\*'82NF!78# ; 82NF!9'%&&2NF!9 (+&82NF!589\*4%982NF!%&!% (#& ; 89#! 1 +=82N!69#!%-!\$#&9%2+4! (#+4' (!82-%& 1 +'8%2/?!<6&' (#&F! : UL : !2%'#9!' (+!>\$&82\*8\$4#9!%-!5+'+19'# ; +859 (\$!+\$&\$4, !'!+44! '(#!\$#&9%22#4F!9, 9'# 1 9F!+25!\$&%\*#99#9!#2N+N82N!82! (#+4' (!82-%& 1 +'8%2!9'%&+N#!+25! #J\* (+2N#! ; 8' (82!+25!+\*%99!%&N+28P+'8%29/?!

**Organization**!+9!69#5!82!' (89!&#\$%&'!+25!+9!589'82N689 (#5!-&% 1 !3LM : : !\*%7#&#5!#2'8' , F! &#-#&9!'!+2, !\$#&9%2!%&!C%5, !' (+! 1 +, ! 1 +82'+82!%&!&+29 1 8'!\$#&9%2+4! (#+4' (!82-%& 1 +'8%2!/!

B#& 1 9! . 9#5!%!0#9\*8C#!L5#2'8' , !M&%\*%'8%2!X%-!L2587856+4!M+'8#2'fA4828\*8+2d!@2'8' , Y!!

**De-Identification of protected health information**!+9!5#-82#5!C, !3LM : : !M&87+\* , ! " 64#\_! > (#+4' (!82-%& 1 +'8%2!' (+!5%#9!2%'!85#2'8- , !+2!82587856+4!+25! ; 8' (!&#9\$#\*%'!%&! ; (8\* (!' (#&#!89! 2%!&#+9%2+C4#1C+989!'!C#48#7#!' (+!' (!#82-%& 1 +'8%2!\*+2!C#!69#5!'!85#2'8- , !+2!82587856+4! 89!2%'!82587856+44, !85#2'8-8+C4#! (#+4' (!82-%& 1 +'8%2/?! " # 68&# 1 #2'9!-%&!5#]85#2'8-8\*+'8%2! 82\*465#!XDY!**statistical method**!69#!%-!N#2#&+44, !+\*%#\$'#5!9+'89'8\*+4!+25!9\*8#2'8-8\*! \$&82\*8\$4#9!+25! 1 #' (%59!-%&!&#25#&&2N!82-%& 1 +'8%2!2%'!82587856+44, !85#2'8-8+C4#1C, !+!\$#&9%2! ; 8' (!+\$&%\$&8+\*#!=2% ; 4#5N#!+25!#J\$#&8#2\*#d!5#'#& 1 8282N!' (+!' (!#&89=89!78&, !9 1 +44! (+!' (!#82-%& 1 +'8%2!\*%645!C#!69#5F!+4%2#!%&!82!\*% 1 C82+'8%2! ; 8' (!%' (#&!&#+9%2+C4, !+7+84+C4#! 82-%& 1 +'8%2!F!C, !+2!+2'8\*8\$+'#5!&#\*8\$82'!'!85#2'8- , !+2!82587856+4! ; (%!89!+!96C!#\*%'!%-!' (! 82-%& 1 +'8%2d!+25!5%\*6 1 #2'9!' (! 1 #' (%59!+25!&#964'9!%-!' (!#!+2+4, 989!' (+!V69'8-, !96\* (! 5#'#& 1 82+'8%2d!%&!XGY!**safe harbor method**\_! ; (#&#!9\$#\*8-8\*!85#2'8-8#&9!%-!' (!#82587856+4!%&! %-!&#4+'87#9F!# 1 \$4%, #&9F!%&! (%69# (%45! 1 # 1 C#&9!%-!' (!#82587856+4F!+&#!&# 1 %7#5F!82\*46582N! D!I9\$#\*8-8\*!#4# 1 #2'9!\$!69!+2, !%' (#&!628'6#!85#2'8- , 82N!26 1 C#&F!\* (+&+\*#889'8\*F!%&!\*%5#! #J\*#\$!+9!\$#& 1 8''#5!-%&!&#]85#2'8-8\*+'8%2!C, !' (!' \*%7#&#5!#2'8' , !/Re-identification!%-!5#] 85#2'8-8#5!5+'+!89!\$#& 1 8''#5!C, !' (!' \*%7#&#5!#2'8' , !9%!4%2N!+9!' (! 1 #+29!%-!85#2'8-8\*+'8%2!89! 2%'!5#&87#5!-&% 1 !%&!&#4+'#5!'!%&! (#!82-%& 1 +'8%2!+25!' (!' \*%7#&#5!#2'8' , !5%#9!2%'!69#!%&!

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

Enhanced Protections for Uses of Health Data: !

:!)'# ; +&59(8\$!<&+ 1 # ; %&=-!-%!>) #\*%25+&,!. 9#9?!%~!@##'&%28\*+4,!A%4##\*#5!+25!B&+29 1 8''#5!3#++' (!0+' +!

589\*4%9#!' (#!\*%5#!%&!+2,!% (#&!\$6&\$%9#!+25!5%#9!2%'!589\*4%9#!' (#! 1 #\* (+289 1 !-%&!&#] 85#2'8-8\*+'8%2!XKW!A< " !gDZK/WDKX+YFCYF!+25!X\*YY!

**Limited Data Set**!+9!5#-82#5!C,!3LM : : !M&87+\* ,! " 64#\_!\$&%'#\*#5! (#+4' (!82-%& 1 +'8%2!' (+! #J\*465#9!+4!588#\*#185#2'8-8#&9!%-!' (#!82587856+4!%&!%-!&#4+'87#9F!# 1 \$4% , #89F!%&! (%69# (%45! 1 # 1 C#&9!%-!' (#!82587856+4!+9!5#-82#5!82!3LM : : a9!M&87+\* ,! " 64#a9!5#-82'8%2!%-!5#] 85#2'8-8\*+'8%2!except!\*8' ,F!) '+#F!+25!P8\$!\*%5#d!+4!#4# 1 #2'9!%-!5+'9!&#4+'#5!%!' (#! 82587856+4d!+25!+2,!% ('&!628`6#!85#2'8- ,82N!26 1 C#&F!\* (+&+\*#889'8\*F!%&!\*%5#!2%'!82\*465#5! 82!' (#!3LM : : !5#-82'8%2!%-!5#]85#2'8-8\*+'8%2!XKW!A< " !gDZK/WDKX#YY!

**Anonymization**!+9!96C 1 8''#5!%!' (#!3#+4' (!L2-%& 1 +'8%2!B#\* (2%4%N,!)' +25+&59!M+2#4! X3LB)MY!C,! ('!M%\$64+'8%2!3#+4' (!B#\* (28\*+4!A% 1 1 8''##!6\$%2!' (#!&#\*% 1 1 #25+'8%2!%-!' (#! : 1 #88\*+2!3#+4' (!L2-%& 1 +'8%2!A% 1 1 628' ,!X : 3LAY!R8%96&7#844+2\*#!0+'+!) '#882N! A% 1 1 8''##!XU+ ,!DDF!GHH!Y\_!+!\$&%\*#99!%-!># 1 %7+4!+25!+NN&#N+'8%2!&#`68&# 1 #2'9!-%&! 5+'+!7+&+C#9!r8/#/F!\$&%\*#\*#5! (#+4' (!82-%& 1 +'8%2s!96C 1 8''#5!%!'!+!C8%96&7#844+2\*#! 82-%& 1 +'8%2!9,9' # 1 XRL)Y!r82!+\*%&5+2\*#! ; 8' (!' (#!3LM : : !M&87+\* ,! " 64#!KW!A< " ! gDZK/WDEXCY!' (+!\$#& 1 8'9!+!\*%7#&#5!#2'8' ,!'!69#!%&!589\*4%9#!\$&%\*#\*#5! (#+4' (!82-%& 1 +'8%2! ; (#2!&#`68&#5!C,!4+ ; s! ; (#&#!9% 1 #!5# 1 %N&+\$ (8\*!5+'+!#4# 1 #2'9!%-!82'##&9!'r%&582+&84 ,! &# 1 %7#5!625#&!' (#!3LM : : !5#-82'8%2!%-!5#]85#2'8-8\*+'8%2s!2#5!%!C#!&# +82#5!82!%&5#&!%! +\*\*6&+!#4,!#7+46+'#!' (#!5+'+!%!5#'#\*!\$%#2'8+4!' (&#+'9!%!\$6C48\*! (#+4' (!/?!!

**Pseudonymization**!+9!96C 1 8''#5!%!' (#!3#+4' (!L2-%& 1 +'8%2!B#\* (2%4%N,!)' +25+&59! M+2#4!X3LB)MY!C,! ('!M%\$64+'8%2!3#+4' (!B#\* (28\*+4!A% 1 1 8''##!6\$%2!' (#! &#\*% 1 1 #25+'8%2!%-!' (#! : 1 #88\*+2!3#+4' (!L2-%& 1 +'8%2!A% 1 1 628' ,!X : 3LAY!R8%96&7#844+2\*#! 0+'+!) '#882N!A% 1 1 8''##!XU+ ,!DDF!GHH!Y\_!+!\$+&'8\*64+&! , \$#!%-!+2%2 , 1 8P+'8%2!' (+!C%' (! &# 1 %7#9!' (#!+99%\*8+'8%2! ; 8' (!+!5+'+!96C!#\*#!+25!+559!+2!+99%\*8+'8%2!C# ; ##2!+! \$+&'8\*64+&!9#!%-!\* (+&+\*#889'8\*9!&#4+'82N!%!' (#!5+'+!96C!#\*#!+25!%2#!%&! 1 %&#! \$9#65%2 , 1 9/?! : 49%F!>' (#!\$&%\*#99!%-!96\$4 ,82N!+2!+4'##2+'87#!85#2'8-8#&! (+!\$#& 1 8'9!+! \$+'82'!'!C#!&#-##&#5!%!C,!+!=# ,!' (+!96\$&#99#9! (8f (&#!+\* '6+4!85#2'8-8\*+'8%2! 82-%& 1 +'8%2!/?! : !\$6C48\*! (#+4' (!+N#2\* ,! 1 + ,!69#!>\$9#65%2 , 1 8P+'8%2!' (&%6N (!r+s!&69'#5! ' (&5!\$+& ,!r'%s!96\$&%&!&#]85#2'8-8\*+'8%2F!/!/!96\* (!+9!-%&!7#&8-8\*+'8%2!+25!7+485+'8%2!%-!5+'+! 82'N&8' ,F!\* (#\*#82N!-%&!969\$#\*#5!56\$48\*+'#!&#\*%&59F!#2+C482N!&#`6#9'9!-%&!+558'8%2+4! 5+'+F!482=82N!%!96\$4# 1 #2'!&#9#&+\* (!82-%& 1 +'8%2!7+&+C#F!\*% 1 \$48+2\*#!+658'F!82-%& 1 82N! 5+'+!96C!#\*#!%-!98N28-8\*+2'!-82582N9F!+\*848+'#!-%44% ; ]6\$!&#9#+&\* (F!+25!4+ ; !#2-%&\*# 1 #2'/?!

**Data aggregation**!+9!5#-82#5!C,!3LM : : !M&87+\* ,!&64#\_!> ; 8' (!&#9\$#\*!'!%\$&%'#\*#5! (#+4' (! 82-%& 1 +'8%2!\*##+'#5!%&!&#\*#87#5!C,!+!C6982#99!+99%\*8+'#!/!/!/r89s!' (#!\*% 1 C8282N!%-!96\* (! \$&%\*#\*#5! (#+4' (!82-%& 1 +'8%2!/!/!/! ; 8' (!' (#!\$&%\*#\*#5! (#+4' (!82-%& 1 +'8%2!/!/!/!%-!+2%' (#&! \*%7#&#5!#2'8' ,F!%!\$#& 1 8'!5+'+!+2+4 ,9#9!' (+!&#4+'#!%!' (#! (#+4' (\*+&#!%\$#&+'8%29!%-!' (#! &#9\$#\*#87#!\*%7#&#5!#2'8'8#9?!XKW!A< " !gDZK/WHDY! : !\*% 1 1 %2!9+'89'8\*+4!5#-82'8%2!%-!5+'+! +NN&#N+'8%2!89!>+2 ,!\$&%\*#99!82! ; (8\* (!82-%& 1 +'8%2!89!N+' (#&#5!+25!#J\$&#99#5!82!+! 96 1 1 +& ,!-%& 1 F!-%&!\$6&\$%9#9!96\* (!+9!9+'89'8\*+4!+2+4 ,989?!XO+'+! e +&# (%69#!L29'8'6' #F! U+ ,!GHHWF! ; ; ; /!5 ; 8/%&NfM6C48\*+'8%29f e (+ e %&=9!+\*\*#99#5!DDfKfH!Y!

B#& 1 9! . 9#5!%!0#9\*8C#M#& 1 8998%2!%!: \*\*#99f . 9#f089\*4%9#!

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data :**

:!)'# ; +859(\$!<8+ 1 # ; %&=-%&!>) #\*%25+&,!. 9#9?!%~!@#\*'8%28\*+4, !A%4#\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+ '+  
!  
!

**Authorization**!+9!69#5!82!3LM : : !M&87+\* , ! " 64#!+!'KW!A< " !gDZK/WH[\_!>@J\*#\$'!+9!  
%' (#& ; 89#!\$## 1 8''#5!%&!&#` 68&#5!/!/!/!+!\*%7#&#5!#2'8' , ! 1 + , !2%'!69#!%&!589\*4%9#!\$&% '#\*'#5!  
(#+4' (!82-%& 1 +'8%2! ; 8' (%6!'!+2!+6' (%&8P+'8%2!' (+!89!7+485!625#&! ' (!r9\$#\*8-8\*+'8%29! ; 8' (82!  
' (! " 64#F!82\*46582N!98N2+'6&#!%-!82587856+4!%&!\$#89%2+4!&#&\$#9#2'+!87#sd?!+25! ' (!69#!%&!  
589\*4%96&#! 1 69'!C#!\*%2989'#2! ; 8' (!' (#!48 1 8'+!8%29!%-!' (#!+6' (%&8P+'8%2!/B (#!3LM : : !  
M&87+\* , ! " 64#!+9%!5#9\*8C#9!69#9!+25!589\*4%96&#9!&#` 68&82N!+2!%\$%&'628' , !-%&! ' (#!  
82587856+4!'!+N&##!%&!%!'%C\#\*!'!&#4+'87#!'!69#!+25!589\*4%96&#!-%&!-+\*848' , !58&#\*'%88#9!+25!  
-%&!827%47# 1 #2'!82! ' (!82587856+489!\*+&#!+25!2%'8-8\*+'8%2!\$6&\$%9#9!XKW!A< " !gDZK/WDHYd!  
+25!69#9!+25!589\*4%96&#9!-%&! ; (8\* (!+2!+6' (%&8P+'8%2!%&!%\$%&'628' , !%!'!+N&##!%&!%C\#\*!'!89!  
2%'!8#` 68&#5!XKW!A< " !gDZK/WDGYF!96\* (!+9! ; (#2!&#` 68&#5!C , !4+ ; F!-%&!\$6C48\*! (#+4' (!  
\$6&\$%9#9F!-%&! (#+4' (!%7#&98N ('!+\*'878'8#9F!'#\*'/!  
!

**Authorization**!+9!69#5!82!3LM : : !)' #\*688' , ! " 64#!+!'KW!A< " !gDZK/QH[XKY\_!>\$%48\*8#9!+25!  
\$&%\*#56&#9!-%&!rN&+2'82Ns!+\*'#99!'!#4#\*'8%28\*\$&% '#\*'#5! (#+4' (!82-%& 1 +'8%2!' (+!'+&#!  
\*%2989'#2! ; 8' (!' (#!+\$\$48\*+C4#!&#` 68&# 1 #2'9!%-!r' (#!M&87+\* , ! " 64#s/?!  
!

**Consent**!+9!69#5!82!3LM : : !M&87+\* , ! " 64#!+!'KW!A< " !gDZK/WHZXC\_Y!> : !\*%7#&#5!#2'8' , !  
1 + , !%C'+82!\*%29#2'!%-!' (#!82587856+4!'!69#!%&!589\*4%9#!\$&% '#\*'#5! (#+4' (!82-%& 1 +'8%2!'%!  
\*+&&, !%6!'!&#+ 1 #2'F!\$+ , 1 #2'F!%&! (#+4' (\*+&#!%\$##+'8%29!/A%29#2'!/!/!/9 (+4!2%'!C#!  
#--#\*'87#!'!%\$#& 1 8'!+!69#!%&!589\*4%96&#!%-\$&% '#\*'#5! (#+4' (!82-%& 1 +'8%2! ; (#2!+2!  
+6' (%&8P+'8%2!/!/!/89!&#` 68&#5!%&! ; (#2!+2%' (#&!\*%258'8%2! 1 69'!C#! 1 #!'!-%&!96\* (!69#!%&!  
589\*4%96&#!'!%C#!\$## 1 899C4#/?!B (89!9#\*'8%2!-6&' (#&!5#9\*8C#9!' (+!+!\*%7#&#5!#2'8' , ! 1 + , !

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS  
Enhanced Protections for Uses of Health Data: !**

:!

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS  
Enhanced Protections for Uses of Health Data: I

! ) # , +159 (8) < 1 1 # % 1 % 2 1 # \* % 2 5 4 5 , 1 8 # 9 2 ! % 1 0 # \* % 2 1 # + 1 1 A % 4 # \* # 5 ! + 2 5 ! B & + 2 9 ! 1 # # 5 ! 3 # + 1 1 ( 1 0 + 1  
! / 6 & 8 9 5 8 \* ' 8 % 2 + 4 ! + 2 5 ! % & N + 2 8 P + ' 8 % 2 ! \$ & 8 7 + \* , ! \$ % 4 8 \* 8 # 9 ! ' ( + ' ! N & + 2 ' ! % & ! ; 8 ' ( ( % 4 5 ! \* % 2 9 # 2 ' ! ' % ! % 2 # ! % & !  
1 % & # ! 8 5 # 2 ' 8 - 8 # 5 ! # 2 ' 8 ' 8 # 9 ! 8 2 ! + 1 5 # - 8 2 # 5 ! & % 4 # d ! ' % ! \$ # & - % & 1 ! % 2 # ! % & ! 1 % & # ! % \$ # & + ' 8 % 2 9 ! X # / N / F !  
\* % 4 4 # \* ' F ! + \* \* # 9 9 F ! 6 9 # F ! 5 8 9 \* 4 % 9 # F ! + 1 # 2 5 F ! % & ! 5 # 4 # ' # Y d ! % 2 ! + 2 ! 8 2 9 ' + 2 \* # ! % & ! ' , \$ # ! % - ! L L 3 L d ! - % & ! + !  
\$ 6 & \$ % 9 # ! 9 6 \* ( ! + 9 ! ' & # + ' 1 # 2 ' F ! \$ + , 1 # 2 ' F ! % \$ # & + ' 8 % 2 9 F ! & # 9 # + & \* ( F ! \$ 6 C 4 8 \* ! ( # + 4 ' ( F ! ` 6 + 4 8 ' , !  
1 # + 9 6 & # 9 F ! ( # + 4 ' ( ! 9 ' + ' 6 9 ! # 7 + 4 6 + ' 8 % 2 ! C , ! ( 8 & 5 ! \$ + & ' 8 # 9 F ! % & ! 1 + & = # ' 8 2 N d ! 6 2 5 # & ! \* # & ' + 8 2 !

ZG!



**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(\$!<&+ 1 # ; %&=-%&!>) #\*%25+&,!. 9#9?!%-!@4#\*'&%2!+44,!A%44#\*'#5!+25!B&+29 1 8''#5!3#+4'(!0+'+  
!  
!

**Research**F!+9!5#-82#5!C,!3LM : :!M&87+\* ,!" 64#\_!>+!9,9'# 1 +'8\*!827#9'8N+'8%2F!82\*46582N!  
&#9#+&\* (!5#7#4%\$ 1 #2'F!'#9'82NF!+25!#7+46+'8%2F!5#98N2#5!'!5#7#4%\$!%&!\*%2'&8C6'#!'!%!  
N#2#&+48P+C4#!=2% ; 4#5N#/?!XKW!A< " !gDZK/WHDY!B (89!5#-828'8%2!89!

# NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

## Enhanced Protections for Uses of Health Data: !

:!)'# ; +859(\$!<8+ 1 # ; %&=-!-%&!>) #\*%25&,&! . 9#9?!%~!@##\*%&28\*+4, !A%4##\*#5!+25!B&+29 1 8'#5!3#+4' (!0+ +!  
! SMM!89!%- '#2! 1 89'+=#24, !&#-##&&#5!'!%+!9!>3LM : : !\*%29#2'F?! ; (#&#!8!89!not 82'#25#5!'!%C#!  
#8' (#&!+!\*%29#2'!%&!+6' (%&&P+'8%2!-%& 1 !'!%C'+82!+2!82587856+4a9!\$## 1 8998%2!-%&!69#9!+25!  
589\*4%96&#9!%~!\$&% '#\*#5! (#+4' (!82-%& 1 +'8%2!/  
!

**Privacy Policy**F! ; 8' (!&#9\$#\*#!'!% ; #C98#9F!89!+!2%'8\*#!&#N+&582N!\$&87+\* , !8996#9!+25!  
\*(%8\*#!%2! (% ; !\$#89%2+4!82-%& 1 +'8%2!89!69#5!/ . 25#&! (#!<#5#&+4!B&+5#!A% 1 1 8998%2! : \*'F!  
' (#!A% 1 1 8998%2!>N6+&59!+N+829!62+&82#99!+25!5#\*#\$'8%2!C, !#2-%&\*82N!\*% 1 \$+28#9x!  
\$&87+\* , !\$&% 1 89#9!+C%6'! (% ; !' (#, !\*%44##\*#F!69#1+25!9#\*6#!\*%296 1 #89x!\$#&9%2+4!  
82-%& 1 +'8%2/?! . 25#&! (#! \ &+ 1 1 ]i#+\* (]R48# , !: \*'F!' (#!A% 1 1 8998%2! (+9!8 1 \$4# 1 #2'#5!  
&64#9!\*%2\*##282N!82+2\*8+4!\$&87+\* , !2%'8\*#9!+25!' (#!+5 1 8289'&+'87#F!'#\* (28\*+4!+25!\$( , 98\*+4!  
9+~#N6+&582N!%~!\$#&9%2+4!82-%& 1 +'8%2F!+25!8'!+NN&#9987#4, !#2-%&\*#9!+N+829!\$##'#J'82N!  
r69#1%~!+49#!\$&#'#29#9s!B (#!A% 1 1 8998%2!+49%!\$&% '#\*9!' \*%296 1 #&!\$&87+\* , !625#&! (#!<+88!  
A&#58'! "#\$%&'82N! : \*'!+25!' (#!A (845&#2x9!O2482#!M&87+\* , !M&% '#\*8%2! : \*'!  
X ; ; ; /-\*/N%7f\$&87+\* , f!+\*\*#99#5!DDfGHfH IY!!  
!!

B#& 1 9! . 9#5!'!0#9\*8C#!@J\* (+2N#!%~!3#+4' (!L2-%& 1 +'8%2!

**Health information exchange!**X 3L@YF!+9!5#-82#5!C, !' (#!O--8\*#!%~!' (#!S+'8%2+4!  
A%#%&582+'%&!-%&!3#+4' (!L2-%& 1 +'8%2!B#\* (2%4%N, !Xb62#!GDF!GHH IYF!89!>+!#2'8' , !' (+!  
#2+C4#9!' (#! 1 %7# 1 #2'!%~!' (#+4' (!&#4+'#5!5+'+!+ 1 %2N!#2'8'8#9! ; 8' (82!+!9'+!#F!+!&#N8%2F!%&!  
+!2%2]!6&8958\*'8%2+4!\$+&'8\*8\$+2'!N&6\$/?!  
!

**Nationwide health information network!**X S 3LSYF!+9!5#-82#5!C, !' (#!O--8\*#!%~!' (#!  
S+'8%2+4!A%#%&582+'%&!-%&!3#+4' (!L2-%& 1 +'8%2!B#\* (2%4%N, !Xb62#!GDF!GHH IYF!89!>+!#2#'  
%~!2#'; %&=9a!r' (+!s!9#\*6&#4, !\*%22#\*9!' \*%296 1 #89F!\$&%785#89F!+25!' (#89! ; (%! (+7#!%&!69#!  
(#+4' (]#4+'#5!5+'+/?! e %&=82N!+996 1 \$'8%29!+49%!82\*465#!' (+!+!S 3LS! ; 844! (+7#!>2%!  
2+'8%2+4!5+'+!9'%'&#!%&!\*#2'&+48P#5!9, 9'# 1 9!+!'! (#!2+'8%2+4!4#7#4F!2%!2+'8%2+4!\$+'8#2'!  
85#2'8-8#&F!rC6'! ; 844! (+7#s!9 (+&#5!+&\* (8'#\*6&#F!X9'+25+859F!9#&78\*#9F!+25!&#` 68&# 1 #2'9YF!  
\$&%\*#99#9F!+25!\$&%\*#56&#9/?!!!  
!

**NHIN health information exchange!**X S 3L@YF!+9!5#-82#5!C, !' (#!O--8\*#!%~!' (#!S+'8%2+4!  
A%#%&582+'%&!-%&!3#+4' (!L2-%& 1 +'8%2!B#\* (2%4%N, !Xb62#!GDF!GHH IYF!89!>+!3L@!' (+!  
8 1 \$4# 1 #2'9!' (#!S 3LS!+&\* (8'#\*6&#F!\$&%\*#99#9F!+25!\$&%\*#56&#9!+25!\$+&'8\*8\$+'#9!82!' (#!  
S 3LS!A%#\$#&+'87#/?!  
!

**Health information service provider!**X 3) MYF!+9!5#-82#5!C, !' (#!O--8\*#!%~!' (#!S+'8%2+4!  
A%#%&582+'%&!-%&!3#+4' (!L2-%& 1 +'8%2!B#\* (2%4%N, !Xb62#!GDF!GHH IYF!89!>+!\*% 1 \$+2, !%&!% (##!  
%&N+28P+'8%2!' (+!96\$#\$%9!%2#!%&! 1 %&#!3L@9!C, !\$&%78582N!' (# 1 ! ; 8' (!%\$#&+'8%2+4!+25!  
'#\* (28\*+4! (#+4' (!#J\* (+2N#!9#&78\*#9/?!  
!

**National health information infrastructure!**X S 3LLYF!+9!#27898%2#5!C, !' (#!S+'8%2+4!  
A% 1 1 8'##!%2!T8'+4!+25!3#+4' (!)'+'89'8\*9!82!Information for Health: A Strategy for  
Building the National Health Information Infrastructure!S%7# 1 C#&F!DWF!GHHD! ; %645!C#!+!  
> (#+4' (!96\$#\$%&!9, 9'# 1 !c!+!\*% 1 \$&# (#2987#F! =2% ; 4#5N#]C+9#5!9, 9'# 1 !\*+\$+C4#!%~!  
\$&%78582N!82-%& 1 +'8%2!'!%~!+4! ; (%!2#5!8'!'! 1 +=#!9%625!5#\*898%29!+C%6'! (#+4' (!/!/)!B (#!

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(8\$!<8+ 1 # ; %&=-!-%&!>) #\*%25+&,!. 9#9?!%~!@4#\*'8%28\*+44,!A%44#\*'#5!+25!B&+29 1 8''#5!3#++' (!0+'+  
!  
S 3LL!82\*465#9!2%'!V69!'!#\* (2%4%N8#9!C6'F! 1 %&#!8 1 \$%&'+2'4 ,F!7+46#9F!\$&+\*'8\*#9F!  
&#4+'8%29 (8\$9F!4+ ; 9F!9'+25+&59F!9 ,9'# 1 9F!+25!+\$48\*+'8%29!' (+!96\$%\$&'!+44!~+'\*#9!%~!  
82587856+4! (#+4' (F! (#+4' (!\*+&#F!+25!\$6C48\*! (#+4' (/?!  
!  
!  
!  
B#& 1 9! : 99%\*8+'#5! ; 8' (!A%44#\*'8%29!%~!0+'+!!

**Data set**F!82!\*% 1 1 %2!69+N#!' (#&#!+&#!' ; %!5#-828'8%29 !XDY!+!489'!%~!&#\*% 1 1 #25#5!5+'+!  
#4# 1 #2'9! ; 8' (!628-%& 1 !5#-828'8%29!' (+!+&#!&#4#7+2'!-%&!+!\$+&'8\*64+&!69#!X : 1 #&8\*+2!3#+4' (!  
L2-%& 1 +'8%2!U+2+N# 1 #2'! : 99%\*8+'8%2F *Pocket Glossary*Y/!XGY!+!\*%44#\*'8%2!%~!15+'+/  
!

**Data registry**F!+!\*%44#\*'8%2!%~! (#+4' (!5+'+!&#4+'#5!'!+!9\$#\*8-8\*!589#+9#F!\*%258'8%2F!%&!  
\$&%\*#56&#!' (+! 1 +=#9!' (#!5+'+!+7+84+C4#!-%&!+2+4 ,989!+25!\*% 1 \$+&89%2!X : 1 #&8\*+2!3#+4' (!  
L2-%& 1 +'8%2!U+2+N# 1 #2'! : 99%\*8+'8%2F *Pocket Glossary*Y/!0+'+!&#N89'&8#9!' , \$8\*+44 ,!\*%44#\*'  
5+'+!82!+\*\*%&5+2\*#! ; 8' (!' (#!5+'+!9#!&#`6&# 1 #2'9!%~!+!\$+&'8\*64+&!\$&%!#\*'/!

**Data reposV # ' 9 !**



**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(\$!<+ 1 # ; %&=-%&!>) #\*%25+&,!. 9#9?!%~!@4#\*'&%2!+4, !A%4#\*'#5!+25!B&+29 1 8''#5!3#+4' (!0+'+  
!

**Appendix D: Data Stewardship Conceptu**

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(\$!<+ 1 # ; %&=-!-%&!>) #\*%25+&,!. 9#9?!%~!@4#\*'&%2!+4, !A%4#\*'#5!+25!B&+29 1 8''#5!3#++' (!0+'+  
!

**Appendix E: Abbreviations Used in this Report**

- ! : 3LA!c! : 1 #&&\*+2!3#++' (!L2-%& 1 +'8%2!A% 1 1 62! , !
- ! : 3LU : !c! : 1 #&&\*+2!3#++' (!L2-%& 1 +'8%2!U+2+N# 1 #2'! : 99%\*8+'8%2!
- ! : 3 " ^!c! : N#2\* , !-%&!3#++' ( \*+&#! " #9#+&\* (!+25!^6+4! , !
- ! : UL : !c! : 1 #&&\*+2!U#5!+4!L2-%& 1 +'8\*9! : 99%\*8+'8%2!
- ! : ) M!c! : \$\$4!+ '8%2!) #&7!#!M&%7!5#&!
- ! R3L!c!R!6#!3#++' (!L2'#4!N#2\*#!
- ! AA3LB!c!A#&'8-8\*+'8%2!A% 1 1 899!2!-%&!3#++' ( \*+&#!L2-%& 1 +'8%2!B#\* (2%4!N, !
- ! A0A!c!A#2'#&9!-%&!0!89#+9#!A%2'&%4!+25!M&#7#2'8%2!
- ! A< " !c!A%5#!%~!<#5#&+4! " #N64+'8%29!
- ! AU ) !c!A#2'#&9!-%&!U#5!+&#!+25!U#5!+85! ) #&7!#9!
- ! AOMM : !c!A+4!-%&2!+!O2!4!2#!M&87+\* , !M&%'#\*'8%2! : \*'!
- ! @3 " !c!@4#\*'&%2!3#++' (!

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +859(8\$!<8+ 1 # ; %&=-!-%&!>) #\*%25+&, !. 9#9?!%~!@##\*'%&28\*+44, !A%44##\*'#5!+25!B&+29 18''#5!3#+4' (!0+'+  
!  
3LB!c!3#+4' (!L2-%& 1 +'8%2!B#\* (2%4%N, !  
!  
3LB) M!c 3#+4' (!L2-%& 1 +'8%2!B#\* (2%4%N, !)' +25+&59!M+2#4!  
!  
3) M!c!3#+4' (!L2-%& 1 +'8%2!) #&78\*#!M&%785#&!  
!  
LL3L!c!L2587856+44, !L5#2'8-8+C4#!3#+4' (!L2-%& 1 +'8%2!  
!  
LOU!c!L29'8'6'#!%-!U#58\*82#!  
!  
L " R!c!L29'8'6'8%2+4! " #78# ; !R%+&5!  
!  
SA3) !c!S+'8%2+4!A#2'##!-%&!3#+4' (!)' +'89'8\*9!  
!  
SAM0M!c!S+'8%2+4!A%62\*84!-%&!M&#9\*88\$'8%2!O&6N!M&%N&+ 1 9!  
!  
SAT3) !c!S+'8%2+4!A% 1 1 8''##!%2!T8'+4!+25!3#+4' (!)' +'89'8\*9!  
!  
S3L@!c!S3LS!3#+4' (!L2-%& 1 +'8%2!@J\* (+2N#!  
!  
S3LL!c!S+'8%2+4!3#+4' (!L2-%& 1 +'8%2!L2-&+9'86\*'6&#!  
!  
S3LS!c!S+'8%2 ; 85#!3#+4' (!L2-%& 1 +'8%2!S#' ; %&=!  
!  
SL3!c!S+'8%2+4!L29'8'6'#!9!%-!3#+4' (!  
!  
SMM!c!S%'8\*#!%-!M&87+\* , !M&+\*'8\*#9!  
!  
S^<!c!S+'8%2+4!^6+48' , !<%&6 1 !  
!  
OA " !c!O--8\*#!-%&!A8784! " 8N( '9!  
!  
O3A : !c!O&N+28P#5!3#+4' (!A+&#! : &&+2N# 1 #2'!  
!  
O3 " M!c!O--8\*#!-%&!36 1 +2! " #9#+&\* (!M&%'#\*'8%29!!  
!  
OSA!c!O--8\*#!%-!' (#!S+'8%2+4!A%&582+'%&!-%&!3#+4' (!L2-%& 1 +'8%2!B#\* (2%4%N, !  
!  
MRU!c!M(+& 1 +\* , !R#2#-8'9!U+2+N#&!  
!  
M3L!c!M&%'#\*'#5!3#+4' (!L2-%& 1 +'8%2!  
!  
M3 " !c!M#&9%2+4!3#+4' (!" #\*%&5!  
!  
M^L!c!AU) !R#'##&!^6+48' , !L2-%& 1 +'8%2!M&%\#\*#!

**NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS**

**Enhanced Protections for Uses of Health Data: !**

:!)'# ; +&59(\$!<+ 1 # ; %&=-%&!> ) #\*%25+&, ! . 9#9?!% -!@#\*'&%2!+44, !A%4#\*'#5!+25!B&+29 1 8''#5!