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**SICKLE CELL DISEASE TREATMENT DEMONSTRATION PROGRAM  
 INDIVIDUAL UTILIZATION QUESTIONNAIRE**

<b>Subject ID Label:</b> _____	<b>Site:</b> _____
<b>Today's Date:</b>  __ _  -  __ _  - 20  __ _  <b>Data Collector:</b> _____	<b>Date Client Enrolled:</b>  __ _  -  __ _  - 20  __ _  <b>Respondent:</b> 1 <input type="checkbox"/> Sickle Cell Client    2 <input type="checkbox"/> Other    3 <input type="checkbox"/> Both
<b>Interview:</b> 1 <input type="checkbox"/> Baseline    2 <input type="checkbox"/> Follow-up	

FOR EACH QUESTION, PLEASE INDICATE WHETHER THE INFORMATION WAS OBTAINED FROM (1) SELF-REPORT BY THE SICKLE CELL CLIENT OR HIS/HER PROXY (E.G., CAREGIVER), (2) A CLIENT DATABASE, **AND/OR** (3) THE CLIENT'S MEDICAL RECORDS.

<b>Baseline Interview Only [FOR FOLLOW-UP → BEGIN WITH QUESTION 5]</b>	
<b>1. What is (your/the client's) date of birth?</b>  __ _  -  __ _  -  __ _  <small>Month      Day      Year</small>	<b>Q.1 →</b> 1 <input type="checkbox"/> Self report 2 <input type="checkbox"/> Database 3 <input type="checkbox"/> Medical record
<b>2. (Are you/Is the client):</b> 1 <input type="checkbox"/> Male    2 <input type="checkbox"/> Female	<b>Q.2 →</b> 1 <input type="checkbox"/> Self report 2 <input type="checkbox"/> Database 3 <input type="checkbox"/> Medical record
<b>3. What is (your/the client's) ethnic background?</b> 1 <input type="checkbox"/> Hispanic                      2 <input type="checkbox"/> Non-Hispanic	<b>Q.3 →</b> 1 <input type="checkbox"/> Self report
<b>4. What is (your/the client's) race? (MARK ALL THAT APPLY)</b> 1 <input type="checkbox"/> Black/African American                      4 <input type="checkbox"/> Asian 2 <input type="checkbox"/> White    5 <input type="checkbox"/> American Indian or Alaska Native 3 <input type="checkbox"/> Native Hawaiian or Other Pacific Islander	<b>Q.4 →</b> 1 <input type="checkbox"/> Self report

5. Including (yourself/the client), how many people live in the household?

□□□

Q.5 →

- 1  Self report
- 2  Database
- 3  Medical record

6. What is the highest grade of school that (you/the client) completed?

- |  |  |
|--|--|
| 0 <input type="checkbox"/> Not school age                        | 6 <input type="checkbox"/> Post-High School Training other than College (Vocational, Technical, etc) |
| 1 <input type="checkbox"/> Currently in Grade School             | 7 <input type="checkbox"/> Some College  |
| 2 <input type="checkbox"/> Currently in Middle School            | 8 <input type="checkbox"/> Graduated from College  |
| 3 <input type="checkbox"/> Currently in High School              | 9 <input type="checkbox"/> Post-Graduate   |
| 4 <input type="checkbox"/> Less than High School Graduate or GED |  |
| 5 <input type="checkbox"/> High School Graduate or GED           |  |

Q.6 →

- 1  Self report
- 2  Database
- 3  Medical record

7. What type(s) of medical insurance (do you/does the client) have? (CHECK ALL THAT APPLY)

- |  |   |
|--|---|
| 1 <input type="checkbox"/> Medicaid                                      | 5 <input type="checkbox"/> Medicare HMO |
| 2 <input type="checkbox"/> State Children's Health Insurance Plan (CHIP) | 6 <input type="checkbox"/> Private      |
| 3 <input type="checkbox"/> Medicaid HMO                                  | 7 <input type="checkbox"/> No insurance |
| 4 <input type="checkbox"/> Medicare                                      | 8 <input type="checkbox"/> Other ↓      |
| -8 <input type="checkbox"/> DON'T KNOW                                   |   |
- 7a. Specify: \_\_\_\_\_

Q.7 →

- 1  Self report
- 2  Database
- 3  Medical record

8. Please use this card (GIVE INCOME CARD) and tell me the number 1 through 11 that best represents your household yearly income from January 1<sup>st</sup> through December 31<sup>st</sup> of last calendar year, (SAY APPROPRIATE YEAR). Please include all sources of income.

- |  |   |
|--|---|
| 1 <input type="checkbox"/> Less than \$5,000   | 8 <input type="checkbox"/> \$50,000 - \$59,999  |
| 2 <input type="checkbox"/> \$5,000 - \$9,999   | 9 <input type="checkbox"/> \$60,000 - \$79,999  |
| 3 <input type="checkbox"/> \$10,000 - \$14,999 | 10 <input type="checkbox"/> \$80,000 - \$94,999 |
| 4 <input type="checkbox"/> \$15,000 - \$19,999 | 11 <input type="checkbox"/> \$95,000 and over   |
| 5 <input type="checkbox"/> \$20,000 - \$29,999 | -8 <input type="checkbox"/> DON'T KNOW          |
| 6 <input type="checkbox"/> \$30,000 - \$39,999 | -9 <input type="checkbox"/> REFUSED             |
| 7 <input type="checkbox"/> \$40,000 - \$49,999 |   |

Q.8 →

- 1  Self report
- 2  Database
- 3  Medical record

9. What type of Sickle Cell Disease (do you/does the client) have? (COLLECT SELF-REPORT RESPONSE AND VERIFY WITH DATABASE OR MEDICAL RECORD)

- |                                       | a. <u>Self-Report</u>       | b. <u>Database/Medical Record</u> |
|---------------------------------------|-----------------------------|-----------------------------------|
| Sickle Cell Disease (SS) .....        | 1 <input type="checkbox"/>  | 1 <input type="checkbox"/>        |
| Sickle-Hemoglobin C Disease (SC)..... | 2 <input type="checkbox"/>  | 2 <input type="checkbox"/>        |
| Sickle Beta-Plus Thalassemia .....    | 3 <input type="checkbox"/>  | 3 <input type="checkbox"/>        |
| Sickle Beta-Zero Thalassemia .....    | 4 <input type="checkbox"/>  | 4 <input type="checkbox"/>        |
| Other → 9c. Specify: _____ .....      | 5 <input type="checkbox"/>  | 5 <input type="checkbox"/>        |
| DON'T KNOW .....                      | -8 <input type="checkbox"/> | -8 <input type="checkbox"/>       |

10. At what age did (you/the client) first find out that (you have/the client has) Sickle Cell Disease?

- 1  NEWBORN SCREENING    2  OTHER → 10a. Specify Age:  year(s) old  
-8  DON'T KNOW  
-9  REFUSED

Q.10 →

- 1  Self report  
2  Database  
3  Medical record

We are interested in the health care that you receive from a variety of sources. These next questions ask about visits to a primary health care provider, a sickle cell specialist, other medical specialists, and a hospital emergency department.

11. In the past 12 months, how many times (have you/has the client) gone to a primary health care provider for:

- a. Sickle cell-related problems?   
b. Non Sickle cell-related problems?

Qs.11a, b →

- 1  Self report  
2  Database  
3  Medical record

11c. Is (your/client's) primary health care provider also (your/his/her) sickle cell specialist?

- 1  Yes → SKIP TO Q.13    2  No

12. In the past 12 months, how many times (have you/has the client) gone to a sickle cell specialist (if not your primary care physician) for:

- a. Sickle cell-related problems?   
b. Non-Sickle cell-related problems?

Qs.12a, b →

- 1  Self report  
2  Database  
3  Medical record

13. In the past 12 months, how many times (have you/has the client) gone to another type of specialist for:

- a. Sickle cell-related problems?   
b. Non-Sickle cell-related problems?

Qs.13a, b →

- 1  Self report  
2  Database  
3  Medical record

14. In the past 12 months, did (you/the client) receive a referral for an eye examination?

- 1  Yes    2  No

Q.14 →

- 1  Self report  
2  Database  
3  Medical record

15. In the past 12 months, did (you/the client) make an appointment for an eye examination?

- 1  Yes → SKIP TO Q.16    2  No

Qs.15, a →

- 1  Self report  
2  Database  
3  Medical record

15a. Why wasn't an appointment made for an eye examination?

\_\_\_\_\_

\_\_\_\_\_

SKIP TO Q.17

16. Did (you/the client) go to the eye appointment?

- 1  Yes → SKIP TO Q.17    2  No

Qs.16, a →

- 1  Self report  
2  Database  
3  Medical record

16a. Why didn't (you/the client) go to the appointment?

\_\_\_\_\_

\_\_\_\_\_

17. In the past 12 months, how many times did (you/the client) receive health care services at a hospital emergency department?

\_\_\_\_|\_\_\_\_|

Q.17 →

<input type="checkbox"/> Self report
<input type="checkbox"/> Database
<input type="checkbox"/> Medical record

18. In the past 12 months, (were you/was the client) admitted to the hospital?

1  Yes      2  No → SKIP TO Q.19

Qs.18, a-c →

<input type="checkbox"/> Self report
<input type="checkbox"/> Database
<input type="checkbox"/> Medical record

For each hospitalization, please tell me the number of nights and the reason ) you were/ the client was) in the hospital. (LIST ADDITIONAL STAYS ON BACK OF PAGE)

18a. Hospital Stay    18b. # of nights      18c. Reason

#1	____ ____	_____
		_____
#2	____ ____	_____
		_____
#3	____ ____	_____
		_____
#4	____ ____	_____
		_____
#5	____ ____	_____
		_____

19. (Are you/is the client) currently taking hydroxyurea therapy?

1  Yes → SKIP TO Q.21    2  No

Q.19 →

<input type="checkbox"/> Self report
<input type="checkbox"/> Database
<input type="checkbox"/> Medical record

20. In the past 12 months has (your/client's) physician discussed hydroxyurea therapy as an option for (you/the client)?

1  Yes      2  No

Q.20 →

<input type="checkbox"/> Self report
<input type="checkbox"/> Database
<input type="checkbox"/> Medical record

21. What is (your/client's) baseline hemoglobin level? (COLLECT SELF-REPORT RESPONSE AND VERIFY WITH DATABASE OR MEDICAL RECORD).

a. Self-Report

\_\_\_\_|\_\_\_\_|.\_\_\_\_|

-8  DON'T KNOW

b. Database/Medical Record

\_\_\_\_|\_\_\_\_|.\_\_\_\_|

-9  NO ACCESS TO DATABASE/MEDICAL RECORD

22. **BASELINE:** (Have you/Has the client) ever had the following Sickle Cell complications?

**FOLLOW-UP:** In the past 12 months, (have you/has the client) had the following Sickle Cell complications?

	<u>Yes</u>	<u>No</u>	<u>DON'T KNOW</u>
a. Pain .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
b. Sickling in the lungs .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
c. Fever .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
d. Severe infection .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
e. Stroke .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
f. Kidney damage .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
g. Leg ulcers .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
h. Sickle eye damage .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
i. Gall bladder attack .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
j. Priapism .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/> -7 <input type="checkbox"/> N/A
k. Hand-foot syndrome .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
l. Spleen problems .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
m. Seizures .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
n. Other .....	1 <input type="checkbox"/> ↓	2 <input type="checkbox"/>	-8 <input type="checkbox"/>

Qs.22a-n →

<input type="checkbox"/> Self report
<input type="checkbox"/> Database
<input type="checkbox"/> Medical record

Please Specify: \_\_\_\_\_  
 \_\_\_\_\_

23. **BASELINE:** (Have you/Has the client) ever been given regularly scheduled blood transfusions?

**FOLLOW-UP:** In the past 12 months, (have you/has the client) been given regularly scheduled blood transfusions?

1  Yes      2  No

Q.23 →

<input type="checkbox"/> Self report
<input type="checkbox"/> Database
<input type="checkbox"/> Medical record

24. **BASELINE:** (Have you/Has the client) ever been counseled on the following?

**FOLLOW-UP:** In the past 12 months, (have you/has the client) been counseled on the following?

	<u>Yes</u>	<u>No</u>	<u>DON'T KNOW</u>
a. SCD complications	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>
b. Inheritance of SCD	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>

Qs.24a, b →

<input type="checkbox"/> Self report
<input type="checkbox"/> Database
<input type="checkbox"/> Medical record

**IF CLIENT IS 6 YEARS OR OLDER, SKIP TO Q. 27**

25. Is the client taking prophylactic antibiotics (i.e., penicillin)?

1  Yes → SKIP TO Q.26      2  No

Qs.25, a →

- 1  Self report
- 2  Database
- 3  Medical record

25a. Why isn't the client taking prophylactic antibiotics?

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**SKIP TO Q.27**

26. At what age did the client start taking prophylactic antibiotics?

| 1  weeks    2  months    3  years    -8  DON'T KNOW

26a. How often is the client taking prophylactic antibiotics?

Qs.26, a →

- 1  2 times per day
- 2  1 time per day
- 3  Less than 1 time per day

- 1  Self report
- 2  Database
- 3  Medical record

27. (Have you/Has the client) had:

	YES	NO	<u>DON'T</u> <u>KNOW</u>	<u>NOT</u> <u>APPLICABLE</u>
<b><u>For children only:</u></b>				
a. Developmental screening to monitor infant/ child development in areas of communication, motor, social, problem-solving and self-help skills?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
<b><u>For all participants:</u></b>				
b. A dental exam in the last year? .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
c. Hearing screening in the last year? .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
d. Vision screening in the last year? .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
e. Diabetes screening in the last year? .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
f. Blood pressure check in the last year? .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
g. TCD (Transcranial Doppler)? .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
<b><u>For adults only:</u></b>				
h. A mammogram in the in last 2 years? .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
i. A pap smear in the last 3 years? .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
j. Colon screening in the last 10 years?.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>
k. A PSA Test? .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>

Qs.27a-j

- 1  Self report
- 2  Database
- 3  Medical record

**THE FOLLOWING INFORMATION SHOULD BE OBTAINED ONLY FROM A VACCINATION CHART, CLIENT DATABASE OR CLIENT MEDICAL RECORD.**

**FOR CLIENTS AGED 6 YEARS AND YOUNGER:**

**28a. INDICATE WHETHER OR NOT THE CLIENT IS UP-TO-DATE WITH THE FOLLOWING VACCINATIONS:**

	<u>YES</u>	<u>NO</u>	<u>UNKNOWN</u>	<u>NOT APPLICABLE</u>	
(1) Diphtheria, Tetanus, Pertussis (DTaP) .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	<b>Q.28a</b> →
(2) Meningococcal (MCV4 or MPSV4) .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(3) Pneumococcal Conjugate Vaccine .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(4) Pneumococcal Polysaccharide Vaccine .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(5) Influenza .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(6) Hepatitis A (Hep A) .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(7) Hepatitis B (Hep B) .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(8) Inactivated Poliovirus (IPV) .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(9) Measles, Mumps, Rubella (MMR) .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(10) Varicella .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(11) Rotavirus (Rota) .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(12) Haemophilus influenzae type b (Hib).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	

1 <input type="checkbox"/> Vaccination Card
2 <input type="checkbox"/> Database
3 <input type="checkbox"/> Medical record

**FOR CLIENTS AGED 7 TO 18 YEARS:**

**28b. INDICATE WHETHER OR NOT THE CLIENT IS UP-TO-DATE WITH THE FOLLOWING VACCINATIONS:**

	<u>YES</u>	<u>NO</u>	<u>UNKNOWN</u>	<u>NOT APPLICABLE</u>	
(1) Diphtheria, Tetanus, Pertussis (Tdap) .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	<b>Q.28b</b> →
(2) Meningococcal (MCV4 or MPSV4) .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(3) Pneumococcal Polysaccharide Vaccine.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(4) Influenza .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(5) Hepatitis A (Hep A).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(6) Hepatitis B (Hep B).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(7) Inactivated Poliovirus (IPV).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(8) Measles, Mumps, Rubella (MMR).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(9) Varicella .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(10) Human Papillomavirus (HPV) .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	

1 <input type="checkbox"/> Vaccination Card
2 <input type="checkbox"/> Database
3 <input type="checkbox"/> Medical record

**FOR CLIENTS AGED 19 YEARS AND OLDER:**

**28c. INDICATE WHETHER OR NOT THE CLIENT IS UP-TO-DATE WITH THE FOLLOWING VACCINATIONS:**

	<u>YES</u>	<u>NO</u>	<u>UNKNOWN</u>	<u>NOT APPLICABLE</u>	
(1) Diphtheria, Tetanus, Pertussis (Td/Tdap) ..	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	<b>Q.28c</b> →
(2) Meningococcal (MCV4 or MPSV4).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(3) Pneumococcal Polysaccharide Vaccine.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(4) Influenza .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(5) Hepatitis A (Hep A) .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(6) Hepatitis B (Hep B) .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(7) Measles, Mumps, Rubella (MMR) .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(8) Varicella.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(9) Human Papillomavirus (HPV).....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	
(10) Zoster.....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	-8 <input type="checkbox"/>	-7 <input type="checkbox"/>	

1 <input type="checkbox"/> Vaccination Card
2 <input type="checkbox"/> Database
3 <input type="checkbox"/> Medical record