Center for Technology and Aging

ADOPT Toolkit

Accelerating Diffusion of Proven Technologies

Evaluating the Effectiveness of Remote Patient Monitoring to Reduce Readmissions

in a Medi-Cal Waiver Program

This tool was submitted by the California Association of Health Services at Home as a part of their *Evaluating the Effectiveness of RPM Technologies in Medi-Cal Waiver Programs* project supported by the Center for Technology and Aging, Remote Patient Monitoring Diffusion Grants Program, 2010-2011. Additional information is available at toolkit.techandaging.org

Project Statement

California Association of Health Services at Home's goal with this project is to convince Californian's Medi-Cal program to authorize and reimburse for RPM technology. The strategy is to conduct a carefully structured and evaluated pilot project in the Medi-Cal Waiver Program. This is a population of aged and chronically ill patients cared for at home in lieu of a skilled nursing facility or acute hospital. An additional advantage of conducting the pilot program in the Medi-Cal Waiver Program is that it does not require federal approval and can be implemented rapidly.

a. Goals

Primary Goal:

☐ To evaluate the effectiveness of remote patient monitoring (RPM) for reducing patient hospitalizations, including 30 days rehospitalizations, ED visits, and health care costs (including hours of LVN care) compared to usual care in a high risk group of adults ≥ 60 years of age with mixed chronic disease. [Time Frame: 6 months]

Secondary Goals:

☐ To evaluate the usability and acceptability of the RPM system among patients and their informal caregivers (e.g., family) and among formal caregivers (e.g. LVN's). [Time Frame: 6 months]

☐ To evaluate the effectiveness of RPM for improving patient functional status, quality of life, quality of care, and patient (and caregiver) attitudes, behaviors, and compliance compared to usual care among individuals ≥ 60 years of age with mixed chronic disease, and their primary formal and informal caregivers. [Time Frame: Baseline, 6 months]

b. Strategy

1. The project will utilize the Intel Health Guide PHS6000.
2. The Intel Health Guide PHS6000 was selected because in addition to its monitoring functions it also has an on-line interface and two way audio and video.
3. We believe the capabilities of the Intel Health Guide PHS6000 will maximize the opportunity to substitute RPM for nursing hours and improve outcomes.

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Opportunities

Home Health Agencies are already serving these types of patients.

Home Health Agencies are experienced with RPM.

The OASIS-C data set provides a rich set of data.

The Medi-Cal Program is searching for opportunities to control costs.

Barriers

Home Health Agencies find it is difficult to deploy monitors and monitor the patients.

It may be difficult to convince the Medi-Cal Program to authorize and reimburse for RPM after the pilot project. We have selected home health agencies to participate in the project that are serving Medi-Cal Waiver patients and are familiar with RPM. We are designing our evaluation plan around the OASIS-C data set.

We have convinced Medi-Cal to participate in the pilot project and our goal is to expand the program based on the pilot project results. We will overcome the difficulties agencies have installing and monitoring the technology by having Intel assist with the installation and will use a third party to monitor the patients: Health Watch Monitoring Company. The targeted segment who will benefit from the project will be patients in the Medi-Cal Waiver Program who are at least sixty years of age. During the pilot phase 50 patients will benefit. This could grow to 1,715 within one year and to 60,000 Medi-Cal patents who receive home care within five years. We will work with Department of Health Care Services staff who administer the Medi-Cal waivers to identify the fifty patients in the experimental group and fifty in the control group based on criteria developed by our evaluation consultants.

CAHSAH has submitted the following forms and templates as examples of what they used for both the experimental and control group during the course of the study. These tools can be used by other organizations that are looking to implement the same type of project.

Medi-Cal Remote Patient Monitoring Project
Data Collection Protocol

1. Determine if patient is eligible for study based on inclusion criteria:
    a. Medi-Cal eligible (waiver or regular)
    b. Age 40 or older
    c. Meets one of the following:
        i. Diagnosis of CHF, COPD or Diabetes; or
        ii. Three or more co-morbidities; or
        iii. Three or more ER visits or hospitalizations over the last six months.
2. Determine if patient meets environmental requirements by administering telephone survey: Intel Personal Health System Eligibility and Site Survey Checklist (Attachment 1).
3. Obtain verbal consent (See Participant Consent Form, Attachment 2)
4. Email potential participants to Mary Adorno (madorno@cahsah.org) for randomization into experimental and control groups (See Attachment 3 for Randomization Protocol).
5. Mary Adorno will email you back with assignments to the experimental or control group.
6. Collect OASIS data on both the experimental and control group (See Attachment 10 – OASIS Data Collection Protocol).
7. If the patient is assigned to the control group, obtain written informed consent from the patient (Attachment 2), informal caregiver (Attachment 4) and the agency nurse (also Attachment 4).
8. Create a secure file for each person in the control group. Place the signed participant consent, caregiver consent for the informal caregiver, and caregiver consent for the agency nurse in this file.
9. Administer the Initial Patient Survey (Attachment 7), the Initial Informal Caregiver Survey (Attachment 8) and the Initial Nurse Survey (Attachment 9) to the control group. Place completed surveys in the Secure File.
10. If the patient is assigned to the experimental group, complete the Patient Demographic Form (Attachment 5), call the Oxford telehealth staff at 800-749-6555, and tell them you are faxing the Patient Demographic Form, medications list and physician's order with parameters (Attachment 6) to:

    Oxford fax number 417-841-2854

11. The Oxford telehealth staff will enter patient demographics, assign protocols, create work order, and fax work order to the appropriate agency.
12. Agency staff will prepare the Health Guide for installation in the home.

13. Obtain written informed consent from the patient (Attachment 2), informal caregiver (Attachment 4), and the agency nurse (Attachment 4).
14. Once the Health Guide is installed in the patient's home and the first session is completed, call Oxford at 800-749-6555 to confirm transmission.
15. Create a Secure File for each person in the experimental group. Place the signed participant consent, caregiver consent for the informal caregiver, and caregiver consent for the agency nurse in this file.
16. Administer the Initial Patient Survey to the patient (Attachment 7). File this survey in the Secure File.
17. Administer the Initial Informal Caregiver Survey to the informal caregiver (Attachment 8). If there is no informal caregiver, indicate this in the Secure File.
18. Complete the Initial Nurse Survey (Attachment 9). File this in the Secure File.
19. Patients will be monitored for 6 months, until discharged, or until they voluntarily leave the study. If a patient leaves the study, notify both Mary Adorno and Oxford.
20. If a patient is hospitalized, notify Oxford. If they return to service after hospitalization, continue monitoring. If they return to the hospital and are discharged, notify both Mary Adorno and Oxford.
21. If a patient is discharged or reaches the end of the 180 day monitoring period, complete the Experimental Group Final Patient Survey (Attachment 11). Also complete the Experimental Group Final Informal Caregiver Survey (Attachment 12) and the Experimental Group Final Nurse Survey (Attachment 13).
22. At the end of the project (August 13, 2011) administer the Control Group Final Patient Survey (Attachment 14), Control Group Informal Caregiver Survey (Attachment 15) and Control Group Final Nurse Survey (Attachment 16) to the Control Group.
23. At the end of the study, send all study data to the Project Evaluation Team at:

XXXXXXXXXXX

The project file should consist of the following documents:

a. Experimental Group Patient Consent
b. Control Group Patient Consent
c. Experimental Group Informal Caregiver Consent
d. Control Group Informal Caregiver Consent
e. Experimental Group Nurse Consent
f. Control Group Nurse Consent
g. Control Group Initial Patient Survey
h. Control Group Initial Informal Caregiver Survey
i. Control Group Initial Nurse Survey
j. Experimental Group Initial Patient Survey
k. Experimental Group Initial Informal Caregiver Survey

l. Experimental Group Initial Nurse Survey
m. Experimental Group Final Patient Survey
n. Experimental Group Final Informal Caregiver Survey
o. Experimental Group Final Informal Formal Caregiver Survey
p. Control Group Final Patient Survey
q. Control Group Final Informal Caregiver Survey
r. Control Group Final Nurse Survey
s. Experimental Group Patient Baseline OASIS
t. Experimental Group Patient Intermediate OASIS, if any
u. Experimental Group Patient Final OASIS
v. Control Group Patient Baseline OASIS
w. Control Group Patient Intermediate OASIS, if any
x. Control Group Patient Final OASIS

Intel® Personal Health System Eligibility and Site Survey Checklist

Purpose: This telephone survey will be completed to determine if a potential member/patient meets eligibility requirements to participate in the pilot investigating the use the Intel® Personal Health System. Eligibility will be determined by physical and behavioral patient factors. The site survey focuses on environmental requirements.

Name _____ ID#_____

Survey completed by_____ Date _____

Physical Requirements (with or without caregiver support)

- ☐ Participant has adequate sensory ability to operate the Intel® Health Guide (hearing, vision)
- ☐ Participant is willing to monitor weight and/or blood pressure and answer questions from the Intel® Health Guide as scheduled

Cognitive Requirements

- ☐ Participant/caregiver has sufficient cognitive function to follow simple instructions, touch screen to respond to questions using the Intel® Health Guide
- ☐ Participant/caregiver comprehends that information will be sent to organization's care management system
- ☐ Participant/ caregiver can understand and read instructions in English

Environmental Requirements

- ☐ Home has high-speed broadband internet access or a working telephone line
- ☐ Has grounded 3-pronged outlet in home near planned site for location of Intel® Health Guide
- ☐ Has adequate space (minimum two square feet) to place Intel® Health Guide, scale (if applicable) and blood pressure monitor close to phone or broadband site (counter, table or desk).
- ☐ Has minimum of two square feet on the floor to place scale (if applicable). (Will want to have a chair in this area to sit while completing health session.)

Obtain Verbal Agreement/Consent

- ☐ Reviewed consent form with participant over the phone
- ☐ Preferred time to schedule health session (must be on the hour or ½ hour)

Considerations for Location of Personal Health System Device in Home

- Adequate space for unit to sit securely on a table, desk or counter
- Adequate space on floor for a weight scale
- User has room to sit comfortably when using
- Fan noise will not be disturbing (humming sound)
- In 'living' section of home where unit will not be ignored
- Safe distance from flammable sources and liquids
- Access to grounded 3-prong power source
- Cables and power cords can be routed to minimize trip hazard

CONSENT TO ACT AS A HUMAN RESEARCH SUBJECT (Participant)

Evaluating the Effectiveness of Remote Patient Monitoring Technologies in Medi-Cal Waiver Programs

You are being asked to participate in a research study. Participation in this study is completely voluntary. Please read the information below and ask questions about anything that you do not understand before deciding if you want to participate.

RESEARCH TEAM AND SPONSORS

Principal Investigator:

Joseph H. Hafkenschiel, Executive Director
California Association for Health Services at Home (CAHSAH) Foundation
3780 Rosin Court, Suite 190
Sacramento, CA 95834
(916) 641-5795, ext 118
(916) 641-5881 (fax)
jhafkenschiel@cahsah.org

A DESCRIPTION OF THE RESEARCH STUDY:

The purpose of this research study is to evaluate the effectiveness of Remote Patient Monitoring (RPM) technologies among people with chronic illness. In this study, the RPM technology that will be investigated is an electronic monitor placed in patients' homes that monitors such things as weight and blood pressure and that notifies the appropriate health care providers, if warranted. We want to learn whether people who use RPM technologies to help manage their chronic illness have better health outcomes than people who receive standard care.

We also want to evaluate how informal caregivers (such as family members who provide care) and formal caregivers (such as staff from a home health agency) feel about RPM technologies – for example, whether or not the technologies help them provide better care. For this reason if you choose to participate in the study, we will invite your informal and formal caregivers to provide their opinions about the RPM technologies and their caregiving experiences.

PARTICIPANTS

You will be eligible to participate if you:

1. Are age 40 or older, speak English, and fall into one of the following categories:
   a. Have a primary diagnosis of congestive heart failure, chronic obstructive pulmonary disease or diabetes; or
   b. Have three or more co-morbidities; or
   c. Have three or more emergency room visits or hospitalizations over the last six months.
2. Do not have a diagnosis of dementia or evidence of cognitive impairment.
3. Are able to participate fully in all aspects of the study.
4. Grant authorization to your medical records.
5. Live in a home or apartment that has a telephone line.

6. Have an informal caregiver and a formal caregiver who speak English and who consent to participate in the study.

This study will include approximately 100 participants from 5 to 6 home health agencies in Northern, Central, and Southern California.

PROCEDURES:

There is no medical treatment involved in this study. If you agree to participate in the study, the following will take place:

1. You will be selected in consultation with a case manager from a home health agency, and enrolled in the study if you give written informed consent and meet the eligibility criteria.
2. You may be randomly assigned to receive the RPM monitor. Half of the study participants will be selected for the study group who will receive monitors and fifty subjects will be selected for the control group (who will not receive monitors). The duration of the project will be six months.
3. You will be asked to complete brief questionnaires at the beginning and end that ask about your health status, illness management, and health care, your views on the use of technology for health monitoring, and your socio-demographic background.
4. If you are randomly assigned to receive the RPM monitor, it will be installed in your home in a convenient location and you will be taught how to use it to assist you with management of your chronic illness. The monitor provides a large touch screen and simple user interface. The monitor obtains information from medical devices such as weight and blood pressure as well as from surveys provided to the patient. Data from the monitor will be reviewed by a health care monitoring company and your home health nurse may contact you based on those data. It is important for you to understand that ***the monitor is not Personal Emergency Response System and should not be used for emergencies***. The monitor will be removed at the conclusion of the study.
5. If you are randomly assigned to receive the RPM monitor, your informal and formal caregivers will be asked about their opinions about the RPM technologies and their care giving experiences.
6. Relevant data from all participants' medical records will be abstracted from the Outcome and Assessment Information Set, Version C (OASIS-C). OASIS-C is collected at admission and discharge from all Medicaid and Medicare patients. OASIS-C is a database that is used to keep track of things such as a patient's diagnosis, symptoms, limitations of function, and medical risks.

RISKS AND DISCOMFORTS

The possible risks and/or discomforts associated with the procedures described in this study include:

- **Detection of previously unknown health condition.** There is a small risk that the RPM may detect a health condition and the resulting intervention may not be timely or effective.
- **Emotional Risk.** You may feel uncomfortable talking about your personal and health information. You can refuse to answer questions that make you feel uncomfortable. You can choose not to discuss issues that are too difficult or you may stop participation at any time.
- There may be risks to being in this study that are not currently known. You will be informed of any changes in the way the study will be done and any additional identified risks to which you may be exposed.

BENEFITS

Benefits to Participants

The possible benefits you may experience include potentially receiving six months of Remote Patient Monitoring. To the extent that Remote Patient Monitoring may result in reduced hospital admissions, reduced emergency department visits, improved quality of life and improved quality of care, you may benefit from these as well.

Benefits to Others or Society

The possible benefits to others are better health outcomes if the Remote Patient Monitoring technology helps people manage their chronic illness more effectively. The benefits to society include reduce health care costs if people with chronic illnesses experience better health outcomes. The study results also will add to scientific knowledge about the use of health information technology.

ALTERNATIVES TO PARTICIPATION

Alternative medical monitoring and information exchange with the participant's treatment team is available as part of their routine care. Monitoring and communication using the RPM monitor is only available to the participant if they take part in the study.

COMPENSATION, COSTS AND REIMBURSEMENT

Compensation for Participation

You will not receive any compensation for participating in this study.

Costs

There is no cost to you for participation in this study.

Reimbursement

You will not be reimbursed for any out of pocket expenses.

Compensation for Injury

As the research involves minimal risk, no treatment or any form of compensation for injury will be provided. It is important that you report any suspected study-related illness or injury to the research team listed at the top of this form immediately.

WITHDRAWAL OR TERMINATION FROM THE STUDY AND CONSEQUENCES

You are free to withdraw from this study at any time. **If you decide to withdraw from this study, you should notify the research team immediately.** The research team may also end your participation in this study if you do not follow instructions, if your safety and welfare are at risk, or the study sponsor decides to stop the study.

If you experience any of the side effects listed in the Risks and Discomforts section or if you become ill during the research, you may need to be withdrawn from the study, even if you would like to continue. The research team will let you know if it is not possible for you to continue. The decision may be made to protect your safety and welfare or because it is necessary for the research to withdraw people who certain conditions during the course of the study.

If you withdraw or are removed from the study, the researcher may ask you to return for a final close-out visit or evaluation or complete an exit telephone interview.

CONFIDENTIALITY -- Data from the monitor will be reviewed by a health care monitoring company. Clinically relevant data may be disclosed to your home health agency and, if warranted, your primary care provider.

Identifiable Data about Participants: All identifiable information that will be collected about you will be removed and replaced with a unique numeric code. A list linking the code and your identifiable information will be kept separate from the research data. Only the research team will have access to that information. Your name will not be used in any public reporting of data. All data collected for the project will be subject to the same confidentiality procedures which apply to the OASIS-C data set, which is currently collected on all Medi-Cal patients. Data analysis will be conducted by an independent team of consultants outside of the California Association for Health Services at Home (CAHSAH) Foundation.

Data Storage
All research data will be maintained in a secure location at CAHSAH. Only authorized member of the research team will have access to it. All research data will be stored electronically on a secure computer and network with encryption and/or password protection.

Data Access
The research team and regulatory entities such as the Committee for Protection of Human Subjects may have access to your study records to protect your safety and welfare. Any information derived from this research project that personally identifies you will not be voluntarily released or disclosed by these entities without your separate consent, except as specifically required by law. Research records provided to authorized entities will not contain identifiable information about you. Publications and/or presentations that result from this study will not include identifiable information about you.

Data Retention
All primary data will be destroyed three years after the end of the research project.

OTHER CONSIDERATIONS

Investigator Financial Conflict of Interest
No one on the study team has a disclosable financial interest related to this research project.

IF YOU HAVE QUESTIONS

If you have any comments, concerns, or questions regarding the conduct of this research please contact the Principal Investigator listed at the top of this form.

If you are unable to reach the Principal Investigator listed at the top of the form and have general questions, or you have concerns or complaints about the research study, research team, or questions about your rights as a research subject, please contact: Jordan Lindsey (jlindsey@cahsah.org), Director of Policy, California Association for Health Services at Home (CAHSAH) Foundation, at (916) 641-5795, ext 123 or in-person at 3780 Rosin Court, Suite 190, Sacramento, CA 95834.

You may also contact the Committee for the Protection of Human Subjects (cphs-mail@oshpd.ca.gov), California Health and Human Services Agency, at (916) 326-3660.

VOLUNTARY PARTICIPATION STATEMENT

You should not sign this form unless you have read the attached "Research Participant's Bill of Rights for Non-Medical Research" and have been given a copy of it and this consent form to keep. **Participation in this study is voluntary.** You may refuse to answer any question or discontinue your involvement at any time without penalty or loss of benefits to which you might otherwise be entitled. Your decision will not result in any penalty or loss of benefits to which you are otherwise entitled. Your signature below indicates that you have read the information in this consent form and have had a chance to ask any questions that you have about the study.

SIGNATURES

Subject

If you agree to the use and release of your Personal Health Information, please print your name and sign below. You will be given a signed copy of this form**.**

_____

Subject's Name (print)--*required*

_____ _____

Subject's Signature Date

Parent or Legally Authorized Representative (where IRB approved)

If you agree to the use and release of the above named subject's Personal Health Information, please print your name and sign below.

_____ _____

Parent or Legally Authorized Representative's Name (print) Relationship to the Subject

_____ _____

Parent or Legally Authorized Representative's Signature Date

Witness

If this form is being read to the subject because s/he cannot read the form, a witness must be present and is required to print his/her name and sign here:

_____

Witness' Name (print)

_____ _____

Witness' Signature Date

Participant's Bill of Rights for Non-Medical Research

You have been asked to participate in a research study. Any participant in a research study has the right to:

a) Be told the nature and purpose of the study.
b) Be given an explanation of what will happen during the study and of how the research participant is expected to participate.
c) Be given an explanation of any risks or discomforts that may be experienced as a result of participating in the study.
d) Be given an explanation of any benefits that may be expected from participation in the study.
e) Be told of other appropriate choices that may be better or worse than being in the study, and be told of the risks and benefits of those other choices.
f) Have the opportunity to ask questions about the study or about your participation in it, both before agreeing to participate in the study and during the course of the study.
g) Be told that you may withdraw your consent and participation in the study at any time, and that your withdrawal will not affect your services.
h) Be told that you may refuse to answer any question.
i) Be given a copy of the signed and dated consent form.
j) Be free of pressure when considering whether to consent to, and participate in, the study.
k) Be informed, upon request, about the results of the study.

CONSENT TO ACT AS A HUMAN RESEARCH SUBJECT (Caregiver)

Evaluating the Effectiveness of Remote Patient Monitoring Technologies in Medi-Cal Waiver Programs

You are being asked to participate in a research study. Participation in this study is completely voluntary. Please read the information below and ask questions about anything that you do not understand before deciding if you want to participate.

RESEARCH TEAM AND SPONSORS

Principal Investigator:

Joseph H. Hafkenschiel, Executive Director
California Association for Health Services at Home (CAHSAH) Foundation
3780 Rosin Court, Suite 190
Sacramento, CA 95834
(916) 641-5795, ext 118
(916) 641-5881 (fax)
jhafkenschiel@cahsah.org

A DESCRIPTION OF THE RESEARCH STUDY:

The purpose of this research study is to evaluate the effectiveness of Remote Patient Monitoring (RPM) technologies among people with chronic illness. In this study, the RPM technology that will be investigated is an electronic monitor placed in patients' homes that monitors such things as weight and blood pressure and that notifies the appropriate health care providers, if warranted. We want to learn whether people who use RPM technologies to help manage their chronic illness have better health outcomes than people who receive standard care.

We also want to evaluate how informal caregivers (such as family members who provide care) and formal caregivers (such as staff from a home health agency) feel about RPM technologies – for example, whether or not the technologies help them provide better care. For this reason, if you are an informal or formal caregiver to a patient who participates in the study, we will ask you to provide your opinions about the RPM technologies and your caregiving experiences.

PARTICIPANTS

You will be eligible to participate if you:

1. Are caring for a patient who elects to participate in the study.
2. Are able to participate fully in all aspects of the study.
3. Are an informal caregiver or a formal caregiver who speak English and who consent to participate in the study.

This study will include approximately 100 participants from 5 to 6 home health agencies in Northern, Central, and Southern California.

PROCEDURES:

There is no medical treatment involved in this study. If you agree to participate in the study, the following will take place:

1. If you are an informal or formal caregiver to a patient who elects to participate in the study, you will be asked about your opinions about RPM technologies and your caregiving experiences.
2. It is important for you to understand that ***the monitor is not a Personal Emergency Response System and should not be used for emergencies***. The monitor will be removed at the conclusion of the study.
3. Relevant data from all participants' medical records will be abstracted from the Outcome and Assessment Information Set, Version C (OASIS-C). OASIS-C is collected at admission and discharge from all Medicaid and Medicare patients. OASIS-C is a database that is used to keep track of things such as a patient's diagnosis, symptoms, limitations of function, and medical risks.

RISKS AND DISCOMFORTS

The possible risks and/or discomforts associated with the procedures described in this study include:

- **Detection of previously unknown health condition.** There is a small risk that the RPM may detect a health condition and the resulting intervention may not be timely or effective.
- **Emotional Risk.** You may feel uncomfortable talking about your opinions about RPM technologies and your caregiving experience. You can refuse to answer questions that make you feel uncomfortable. You can choose not to discuss issues that are too difficult or you may stop participation at any time.
- There may be risks to being in this study that are not currently known. You will be informed of any changes in the way the study will be done and any additional identified risks to which you may be exposed.

BENEFITS

Benefits to Participants

The possible benefits participants may experience include potentially receiving six months of Remote Patient Monitoring. To the extent that Remote Patient Monitoring may result in reduced hospital admissions, reduced emergency department visits, improved quality of life and improved quality of care, participants may benefit from these as well.

Benefits to Others or Society

The possible benefits to others are better health outcomes if the Remote Patient Monitoring technology helps people manage their chronic illness more effectively. The benefits to society include reduced health care costs if people with chronic illnesses experience better health outcomes. The study results also will add to scientific knowledge about the use of health information technology.

ALTERNATIVES TO PARTICIPATION

Alternative medical monitoring and information exchange with the participant's treatment team is available as part of their routine care. Monitoring and communication using the RPM monitor is only available to the participant if they take part in the study.

COMPENSATION, COSTS AND REIMBURSEMENT

Compensation for Participation
You will not receive any compensation for participating in this study.

Costs
There is no cost to you for participation in this study.

Reimbursement
You will not be reimbursed for any out of pocket expenses.

Compensation for Injury
As the research involves minimal risk, no treatment or any form of compensation for injury will be provided. It is important that you report any suspected study-related illness or injury to the research team listed at the top of this form immediately.

WITHDRAWAL OR TERMINATION FROM THE STUDY AND CONSEQUENCES

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If you experience any of the side effects listed in the Risks and Discomforts section or if you become ill during the research, you may need to be withdrawn from the study, even if you would like to continue. The research team will let you know if it is not possible for you to continue. The decision may be made to protect your safety and welfare or because it is necessary for the research to withdraw people who certain conditions during the course of the study.

If you withdraw or are removed from the study, the researcher may ask you to return for a final close-out visit or evaluation or complete an exit telephone interview.

CONFIDENTIALITY -- Data from the monitor will be reviewed by a health care monitoring company. Clinically relevant data may be disclosed to the home health agency and, if warranted, the primary care provider.

Identifiable Data about Participants: All identifiable information that will be collected about participants will be removed and replaced with a unique numeric code. A list linking the code and participants identifiable information will be kept separate from the research data. Only the research team will have access to that information. Names will not be used in any public reporting of data. All data collected for the project will be subject to the same confidentiality procedures which apply to the OASIS-C data set, which is currently collected on all Medi-Cal patients. Data analysis will be conducted by an independent team of consultants outside of the California Association for Health Services at Home (CAHSAH) Foundation.

Data Storage
All research data will be maintained in a secure location at CAHSAH. Only authorized member of the research team will have access to it. All research data will be stored electronically on a secure computer and network with encryption and/or password protection.

Data Access
The research team and regulatory entities such as the Committee for the Protection of Human Subjects may have access to study records to protect safety and welfare. Any information derived from this research project that personally identifies you will not be voluntarily released or disclosed by these entities without your separate consent, except as specifically required by law. Research records provided to authorized entities will not contain identifiable information about you. Publications and/or presentations that result from this study will not include identifiable information about you.

Data Retention
All primary data will be destroyed three years after the end of the research project.

OTHER CONSIDERATIONS

Investigator Financial Conflict of Interest
No one on the study team has a disclosable financial interest related to this research project.

IF YOU HAVE QUESTIONS

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You may also contact the Committee for the Protection of Human Subjects (cphs-mail@oshpd.ca.gov), California Health and Human Services Agency, at (916) 326-3660.

VOLUNTARY PARTICIPATION STATEMENT

You should not sign this form unless you have read the attached "Research Participant's Bill of Rights for Non-Medical Research" and have been given a copy of it and this consent form to keep. **Participation in this study is voluntary.** You may refuse to answer any question or discontinue your involvement at any time without penalty or loss of benefits to which you might otherwise be entitled. Your decision will not result in any penalty or loss of benefits to which you are otherwise entitled. Your signature below indicates that you have read the information in this consent form and have had a chance to ask any questions that you have about the study.

I agree to participate in the study. I have been given a copy of the Informed Consent Form and the Research Participant's Bill of Rights for Non-Medical Research and give consent to participate in this research project.

Caregiver Signature **Date**

Printed Name of Caregiver

Researcher Signature **Date**

Printed Name of Researcher

Participant's Bill of Rights for Non-Medical Research

You have been asked to participate in a research study. Any participant in a research study has the right to:

a) Be told the nature and purpose of the study.
b) Be given an explanation of what will happen during the study and of how the research participant is expected to participate.
c) Be given an explanation of any risks or discomforts that may be experienced as a result of participating in the study.
d) Be given an explanation of any benefits that may be expected from participation in the study.
e) Be told of other appropriate choices that may be better or worse than being in the study, and be told of the risks and benefits of those other choices.
f) Have the opportunity to ask questions about the study or about your participation in it, both before agreeing to participate in the study and during the course of the study.
g) Be told that you may withdraw your consent and participation in the study at any time, and that your withdrawal will not affect your services.
h) Be told that you may refuse to answer any question.
i) Be given a copy of the signed and dated consent form.
j) Be free of pressure when considering whether to consent to, and participate in, the study.
k) Be informed, upon request, about the results of the study.

Initial Nurse Survey
February 18, 2011

TO BE COMPLETED BY HOME HEALTH AGENCY NURSE

Date and Time:
Participant Study Number:

Thank you for taking the time to complete this survey. There are no right or wrong answers. We are interested in <u>your</u> experiences and opinions, whatever those may be. All of your responses will be kept strictly confidential. If you have any questions about the study or this questionnaire, please call Mary Adorno at (916) 641-5795 ext. 124.

These questions ask you about your familiarity and comfort level with different kinds of technology.

1. **How would you describe your familiarity with the array of technology products for homes today? Would you say you are…**

(Circle one number)

Very familiar	Familiar	Somewhat familiar	Not very familiar	Not at all familiar
1	2	3	4	5

2. **How would you describe your comfort level with using a <u>computer</u>? Would you say you are…**

(Circle one number)

Very comfortable	Comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable
1	2	3	4	5

3. **How would you describe your comfort level with using the <u>internet</u>? Would you say you are…**

(Circle one number)

Very comfortable	Comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable
1	2	3	4	5

Indicate how often you experience the feelings listed by circling the number in the box that best corresponds to the frequency of these feelings.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1) Do you feel that because of the time you spend with your patient that you don't have enough time for yourself?	0	1	2	3	4
2) Do you feel stressed between caring for your patient and trying to meet other responsibilities (work/family)?	0	1	2	3	4
3) Do you feel angry when you are around the patient?	0	1	2	3	4
4) Do you feel that your patient currently affects your relationship with family members or friends in a negative way?	0	1	2	3	4
5) Do you feel strained when you are around your patient?	0	1	2	3	4
6) Do you feel that your health has suffered because of your involvement with your patient?	0	1	2	3	4
7) Do you feel that you don't have as much privacy as you would like because of your patient?	0	1	2	3	4
8) Do you feel that your social life has suffered because you are caring for your patient?	0	1	2	3	4
9) Do you feel that you have lost control of your life since your patient's illness?	0	1	2	3	4
10) Do you feel uncertain about what to do about your patient?	0	1	2	3	4
11) Do you feel you should be doing more for your patient?	0	1	2	3	4
12) Do you feel you could do a better job in caring for your patient?	0	1	2	3	4
Total for each column	_____	_____	_____	_____	_____

Total Score _____

Please indicate your level of agreement with each of the following statements about your Telehealth experience.

	No, definitely not 1	**I don't think so 2**	**Maybe yes, maybe no 3**	**Yes, I think so 4**	**Yes, definitely 5**	**Not applicable**
1. The training and support team from my home care agency helped me understand how to operate the equipment						
2. Telehealth equipment was easy to use						
3. Telehealth equipment helped me improve my patient's health						
4. I was uncomfortable using the Telehealth technology						
5. The Telehealth equipment took too much time to use						
6. I worried about my patient's privacy with Telehealth technology						
7. Telehealth technology helped me become more involved with my patient's healthcare						
8. The care my patient received with Telehealth technology was just as good as having a nurse come to my house						
9. I would recommend Telehealth to others						

What did you like best about Telehealth?

What did you like least about Telehealth?

How helpful have the following aspects or features of the home Telehealth device been in improving your patient's management of their medical condition?

	Extremely helpful	**Somewhat** helpful	**Not very** helpful	**Not at all** helpful	No opinion or did not use this feature
a. Reminders to take my patient's vital signs every day					
b. Automatically measuring my patient's vital signs					
c. Asking questions about my patient's health and symptoms					
d. Automatically sending my patient's vital signs and the symptoms to the care team					
e. Reminding my patient to take medications or follow other aspects of the care plan					
f. Reviewing the past vital sign history					
g. Viewing educational materials					

Please read and complete the following questions about the home Telehealth device. There are no right or wrong answers. Please mark the answer that best applies to you.

1. Overall, how much would you say that the home Telehealth device has helped you to improve your patient's management of their medical condition?

Not Helped at All	1	2	3	4	5	6	7	8	9	10	**Helped Very Much**

2. Compared to before you started using the home Telehealth device, how has your ability to manage your patient's medical condition improved in relation to the following tasks?

	Improved a lot	**Improved a little**	**No change**	**Became a bit worse**	**Became a lot worse**
a. Remembering to take medications as prescribed.					
b. Remembering to measure weight and blood pressure every day.					
c. Remembering to follow dietary instructions and restrictions.					

Please feel free to write in any additional comments, questions, or concerns:

THANK YOU SO MUCH FOR TAKING THE TIME TO COMPLETE THIS SURVEY!

Experimental Group Final Patient Survey
February 18, 2011

TO BE COMPLETED BY HOME HEALTH AGENCY NURSE
Date and Time:
Participant Study Number:

Did patient complete survey… O Alone O With Assistance (Who Assisted: _____)

Thank you for taking the time to complete this survey. There are no right or wrong answers. We are interested in <u>your</u> experiences and opinions, whatever those may be. All of your responses will be kept strictly confidential. If you have any questions about this study or this questionnaire, please call Mary Adorno at 916-641-5795, ext. 124.

The following questions ask for your views about your health *in general*. If you are unsure about how to answer a question, please give the best answer you can.

1. **In general, would you say your health is:**

(Circle one number)

Excellent	Very Good	Good	Fair	Poor
1	2	3	4	5

2. **The following items are about activities you might do during a typical day. Does *your health now limit you* in these activities? If so, how much?**

(Circle one number on each line)

Activities	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
<u>A</u>. Moderate activities, such as moving a table, pushing a vacuum cleaner	1	2	3
<u>B</u>. Climbing several flights of stairs	1	2	3

3. **During the *past 4 weeks,* have you had any of the following problems with your work or other regular daily activities *as a result of your physical health*?**

(Circle one number on each line)

	Yes	No
A. Accomplished less than you would like	1	2
B. Were limited in the kind of work or other activities	1	2

4. **During the *past 4 weeks,* have you had any of the following problems with your work or other regular daily activities *as a result of any emotional problems* (such as feeling depressed or anxious)?**

(Circle one number on each line)

	Yes	No
A. Accomplished less than you would like	1	2
B. Didn't do work or other activities as carefully as usual	1	2

5. **During the *past 4 weeks,* how much did *pain* interfere with your normal work (including both work outside the home and housework)?**

(Circle one number)

Not at all	A little bit	Moderately	Quite a bit	Extremely
1	2	3	4	5

6. **These questions are about how you feel and how things have been with you *during the past 4 weeks*. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the *past 4 weeks* …**

(Circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
A. Have you felt calm and peaceful?	1	2	3	4	5	6
B. Did you have a lot of energy?	1	2	3	4	5	6
C. Have you felt downhearted and blue?	1	2	3	4	5	6

7. During the *past 4 weeks*, how much of the time has your *physical health or emotional problems* interfered with your social activities (like visiting with friends, relatives, etc.)?

(Circle one number)

All of the time	Most of the time	Some of the time	A little of the time	None of the time
1	2	3	4	5

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8. We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

(Circle one number on each line)

A) How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
B) How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
C) How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
D) How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
E) How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
F) How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident

Question 8. Continued. Please circle one number of each line.

(Circle one number on each line)

G) How confident are you that you can reduce your physical discomfort or pain?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
H) How confident are you that you can do all the things necessary to manage your condition on a regular basis?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
I) How confident are you that you can judge when the changes in your illness mean you should visit a doctor?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
J) How confident are you that you can get family and friends to help you with the things you need (such as household chores, like shopping, cooking, or transport)?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
K) How confident are you that you can get emotional support from friends and family (such as listening or talking over your problems)?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
L) How confident are you that you can get emotional support from resources other than friends or family, if needed?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
M) How confident are you that you can get help with your daily tasks (such as housecleaning, yard work, meals, or personal hygiene) from resources other than friends or family, if needed?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
N) How confident are you that you can get information about your disease from your community resources?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident

9. Regarding your health problems, how helpless do you feel? *(Circle one number)*

Not at all helpless						Very helpless
1	2	3	4	5	6	7

10. Regarding your health problems, how helpless do you think your family member(s) feel? *(Circle one number)*

Not at all helpless						Very helpless
1	2	3	4	5	6	7

The next set of questions asks you about your familiarity and comfort level with different kinds of technology.

11. How would you describe your familiarity with the array of technology products for homes today? Would you say you are…

(Circle one number)

Very familiar	Familiar	Somewhat familiar	Not very familiar	Not at all familiar
1	2	3	4	5

12. How would you describe your comfort level with using a <u>computer</u>? Would you say you are…

(Circle one number)

Very comfortable	Comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable
1	2	3	4	5

13. How would you describe your comfort level with using the <u>internet</u>? Would you say you are…

(Circle one number)

Very comfortable	Comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable
1	2	3	4	5

14. Please indicate your level of agreement with each of the following statements about you and your family member's Telehealth experience.

	No, definitely not 1	**I don't think so 2**	**Maybe yes, maybe no 3**	**Yes, I think so 4**	**Yes, definitely 5**	**Not applicable**
1. The training and support team from my home care agency helped me understand how to operate the equipment						
2. Telehealth equipment was easy to use						
3. Since using Telehealth monitoring, I am more motivated to monitor my health						
4. Telehealth equipment helped me improve my health						
5. I was uncomfortable using the Telehealth technology						
6. The Telehealth equipment took too much time to use						
7. I worried about my privacy with Telehealth technology						
8. Telehealth technology helped me become more involved with my healthcare						
9. The care my patient received with Telehealth technology was just as good as having a nurse come to my house						
10. I would recommend Telehealth to others						

What did you like best about Telehealth?

What did you like least about Telehealth?

15. How helpful have the following aspects or features of the home Telehealth device been in improving your self management of your medical condition?

	Extremely helpful	**Somewhat** helpful	**Not very** helpful	**Not at all** helpful	No opinion or did not use this feature
a. Reminders to take my vital signs every day					
b. Automatically measuring my vital signs					
c. Asking questions about my health and symptoms					
d. Automatically sending my vital signs and symptoms to my the care team					
e. Reminding my patient to take my medications or follow other aspects of my care plan					
f. Reviewing my past vital sign history					
g. Viewing educational materials					

Please read and complete the following questions about the home Telehealth device. There are no right or wrong answers. Please mark the answer that best applies to you.

16. Overall, how much would you say that the home Telehealth device has helped you to improve your patient's management of their medical condition?

Not Helped at All	1	2	3	4	5	6	7	8	9	10	**Helped Very Much**

17. Compared to before you started using the home Telehealth device, how has your ability to manage your patient's medical condition improved in relation to the following tasks?

	Improved a lot	**Improved a little**	**No change**	**Became a bit worse**	**Became a lot worse**
a. Remembering to take medications as prescribed.					
b. Remembering to measure weight and blood pressure every day.					
c. Remembering to follow dietary instructions and restrictions.					

18. Has the use of the home Telehealth device improved your ability to communicate with members of your health care team?

Not Helped at All	1	2	3	4	5	6	7	8	9	10	**Helped Very Much**

19. Would you recommend the home Telehealth device to other patients with your medical condition?

☐ **Yes**
☐ **No**

Please feel free to write in any additional comments, questions, or concerns:

THANK YOU SO MUCH FOR TAKING THE TIME TO COMPLETE THIS SURVEY!

Experimental Group Final Informal Caregiver Survey
February 18, 2011

TO BE COMPLETED BY HOME HEALTH AGENCY NURSE
Date and Time:
Participant Study Number:

1. **Does the patient have an informal caregiver? (Circle one) Yes No**
2. **What is the informal caregiver's relationship to the patient? (Circle one) Spouse Patient Friend Sibling In-Law Other Relative Other (specify:_____)**

Did informal caregiver complete survey…

O Alone O With Assistance (Who Assisted: _____)

Thank you for taking the time to complete this survey. There are no right or wrong answers. We are interested in <u>your</u> experiences and opinions, whatever those may be. All of your responses will be kept strictly confidential. If you have any questions about this study or this questionnaire, please call Mary Adorno at 916-641-5795, ext. 124.

The following questions ask for your views about <u>your health</u> *in general*. If you are unsure about how to answer a question, please give the best answer you can.

1. **In general, would you say your health is:**

(Circle one number)

Excellent	Very Good	Good	Fair	Poor
1	2	3	4	5

2. **The following items are about activities you might do during a typical day. Does *your health now limit you* in these activities? If so, how much?**

(Circle one number on each line)

Activities	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
<u>A</u>. Moderate activities, such as moving a table, pushing a vacuum cleaner	1	2	3
<u>B</u>. Climbing several flights of stairs	1	2	3

3. **During the *past 4 weeks,* have you had any of the following problems with your work or other regular daily activities *as a result of your physical health*?**

(Circle one number on each line)

	Yes	No
A. Accomplished less than you would like	1	2
B. Were limited in the kind of work or other activities	1	2

4. **During the *past 4 weeks,* have you had any of the following problems with your work or other regular daily activities *as a result of any emotional problems* (such as feeling depressed or anxious)?**

(Circle one number on each line)

	Yes	No
A. Accomplished less than you would like	1	2
B. Didn't do work or other activities as carefully as usual	1	2

5. **During the *past 4 weeks,* how much did *pain* interfere with your normal work (including both work outside the home and housework)?**

(Circle one number)

Not at all	A little bit	Moderately	Quite a bit	Extremely
1	2	3	4	5

6. **These questions are about how you feel and how things have been with you *during the past 4 weeks*. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the *past 4 weeks* …**

(Circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
A. Have you felt calm and peaceful?	1	2	3	4	5	6
B. Did you have a lot of energy?	1	2	3	4	5	6
C. Have you felt downhearted and blue?	1	2	3	4	5	6

7. During the *past 4 weeks*, how much of the time has your *physical health or emotional problems* interfered with your social activities (like visiting with friends, relatives, etc.)?

(Circle one number)

All of the time	Most of the time	Some of the time	A little of the time	None of the time
1	2	3	4	5

8. Regarding your family member's health, how much control do you feel? (Circle one number)

Very much in control						Not at all in control
1	2	3	4	5	6	7

9. How confident are that you could take the right steps if your family member were to have an emergency related to his or her death? (Circle one number)

Very confident						Not at all confident
1	2	3	4	5	6	7

10. Regarding your family member's health problems, how helpless do you feel?

Very helpless						Not at all helpless
1	2	3	4	5	6	7

11. Regarding your family member's health problems, how helpless do you think your family member feels?

Very helpless						Not at all helpless
1	2	3	4	5	6	7

12. Below is a list of various physical and emotional tasks of caregiving, such as providing personal care, assisting with medications, monitoring symptoms, talking with health care providers, managing finances, which people often have difficulty performing. Please indicate how much difficulty you have performing the following tasks.

(circle one number on each line)

	Extremely Difficult				Not at all Difficult
A. Treatments (medications, etc…)	1	2	3	4	5
B. Personal care	1	2	3	4	5
C. Mobility (walking, exercise)	1	2	3	4	5

D.	Emotional support	1	2	3	4	5
E.	Monitoring symptoms	1	2	3	4	5
F.	Transportation	1	2	3	4	5
G.	Finances	1	2	3	4	5
H.	Household tasks (cleaning)	1	2	3	4	5
I.	Errands (shopping, etc…)	1	2	3	4	5
J.	Planning activities	1	2	3	4	5
K.	Behavioral problems, due to moodiness and irritability.	1	2	3	4	5
L.	Behavioral problems due to memory loss, loss of concentration or attention.	1	2	3	4	5
M.	Behavioral problems due to confusion, disorientation, or dementia.	1	2	3	4	5
N.	Arranging for provision of care while away	1	2	3	4	5
O.	Communicating with patient	1	2	3	4	5
P.	Finding resources	1	2	3	4	5
Q.	Communicating with healthcare professionals.	1	2	3	4	5

13. Indicate how often you experience the feelings listed by circling the number in the box that best corresponds to the frequency of these feelings.

	Never	**Rarely**	**Sometimes**	**Quite Frequently**	**Nearly Always**
1) Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
2) Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?	0	1	2	3	4
3) Do you feel angry when you are around the relative?	0	1	2	3	4
4) Do you feel that your relative currently affects your relationship with family members or friends in a negative way?	0	1	2	3	4
5) Do you feel strained when you are around your relative?	0	1	2	3	4
6) Do you feel that your health has suffered because of your involvement with your	0	1	2	3	4

relative?					
7) Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
8) Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
9) Do you feel that you have lost control of your life since your relative's illness?	0	1	2	3	4
10) Do you feel uncertain about what to do about your relative?	0	1	2	3	4
11) Do you feel you should be doing more for your relative?	0	1	2	3	4
12) Do you feel you could do a better job in caring for your relative?	0	1	2	3	4

Total for each column _____ _____ _____ _____ _____

Total Score _____

The next set of questions asks you about your familiarity and comfort level with different kinds of technology.

14. How would you describe your familiarity with the array of technology products for homes today? Would you say you are…

(Circle one number)

Very familiar	Familiar	Somewhat familiar	Not very familiar	Not at all familiar
1	2	3	4	5

15. How would you describe your comfort level with using a <u>computer</u>? Would you say you are…

(Circle one number)

Very comfortable	Comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable
1	2	3	4	5

16. How would you describe your comfort level with using the <u>internet</u>? Would you say you are…

(Circle one number)

Very comfortable	Comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable
1	2	3	4	5

17. Please indicate your level of agreement with each of the following statements about your Telehealth experience.

	No, definitely not 1	I don't think so 2	Maybe yes, maybe no 3	Yes, I think so 4	Yes, definitely 5	Not applicable
1. The training and support team from my home care agency helped me understand how to operate the equipment						
2. Telehealth equipment was easy to use						
3. Telehealth equipment helped me improve my family member's health						
4. Telehealth equipment helped me improve my family member's health						
5. I was uncomfortable using the Telehealth technology						
6. The Telehealth equipment took too much time to use						
7. I worried about my family member's privacy with Telehealth technology						
8. Telehealth technology helped me become more involved with my family member's healthcare						
9. The care my family member received with Telehealth technology was just as good as having a nurse come to my house						
9. I would recommend Telehealth to others						

What did you like best about Telehealth?

What did you like least about Telehealth?

18. How helpful have the following aspects or features of the home Telehealth device been in improving your family member's management of their medical condition?

	Extremely helpful	**Somewhat** helpful	**Not very** helpful	**Not at all** helpful	No opinion or did not use this feature
a. Reminders to take vital signs every day					
b. Automatically measuring vital signs					
c. Asking questions about health and symptoms					
d. Automatically sending my vital signs and symptoms to the family member care team					
e. Reminding my patient to take medications or follow other aspects of their care plan					
f. Reviewing past vital sign history					
g. Viewing educational materials					

19. Please read and complete the following questions about the home Telehealth device. There are no right or wrong answers. Please mark the answer that best applies to you.

Overall, how much would you say that the home Telehealth device has helped you to improve your family member's management of their medical condition?

Not Helped at All	1	2	3	4	5	6	7	8	9	10	**Helped Very Much**

1. Compared to before you started using the home Telehealth device, how has your ability to manage your family member's medical condition improved in relation to the following tasks?

	Improved a lot	**Improved a little**	**No change**	**Became a bit worse**	**Became a lot worse**
a. Remembering to take medications as prescribed.					
b. Remembering to measure weight and blood pressure every day.					
c. Remembering to follow dietary instructions and restrictions.					

Please feel free to write in any additional comments, questions, or concerns:

THANK YOU SO MUCH FOR TAKING THE TIME TO COMPLETE THIS SURVEY!

Experimental Group Final Nurse Survey
February 18, 2011

TO BE COMPLETED BY HOME HEALTH AGENCY NURSE

Date and Time:
Participant Study Number:

Thank you for taking the time to complete this survey. There are no right or wrong answers. We are interested in <u>your</u> experiences and opinions, whatever those may be. All of your responses will be kept strictly confidential. If you have any questions about the study or this questionnaire, please call Mary Adorno at (916) 641-5795 ext. 124.

These questions ask you about your familiarity and comfort level with different kinds of technology.

1. **How would you describe your familiarity with the array of technology products for homes today? Would you say you are…**

(Circle one number)

Very familiar	Familiar	Somewhat familiar	Not very familiar	Not at all familiar
1	2	3	4	5

2. **How would you describe your comfort level with using a <u>computer</u>? Would you say you are…**

(Circle one number)

Very comfortable	Comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable
1	2	3	4	5

3. **How would you describe your comfort level with using the <u>internet</u>? Would you say you are…**

(Circle one number)

Very comfortable	Comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable
1	2	3	4	5

4. Indicate how often you experience the feelings listed by circling the number in the box that best corresponds to the frequency of these feelings.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1) Do you feel that because of the time you spend with your patient that you don't have enough time for yourself?	0	1	2	3	4
2) Do you feel stressed between caring for your patient and trying to meet other responsibilities (work/family)?	0	1	2	3	4
3) Do you feel angry when you are around the patient?	0	1	2	3	4
4) Do you feel that your patient currently affects your relationship with family members or friends in a negative way?	0	1	2	3	4
5) Do you feel strained when you are around your patient?	0	1	2	3	4
6) Do you feel that your health has suffered because of your involvement with your patient?	0	1	2	3	4
7) Do you feel that you don't have as much privacy as you would like because of your patient?	0	1	2	3	4
8) Do you feel that your social life has suffered because you are caring for your patient?	0	1	2	3	4
9) Do you feel that you have lost control of your life since your patient's illness?	0	1	2	3	4
10) Do you feel uncertain about what to do about your patient?	0	1	2	3	4
11) Do you feel you should be doing more for your patient?	0	1	2	3	4
12) Do you feel you could do a better job in caring for your patient?	0	1	2	3	4

Total for each column _____ _____ _____ _____ _____

Total Score _____

Please feel free to write in any additional comments, questions, or concerns:

THANK YOU SO MUCH FOR TAKING THE TIME TO COMPLETE THIS SURVEY!

Control Group Final Patient Survey
February 18, 2011

TO BE COMPLETED BY HOME HEALTH AGENCY NURSE
Date and Time:
Participant Study Number:

Did patient complete survey… O Alone O With Assistance (Who Assisted: _____)

Thank you for taking the time to complete this survey. There are no right or wrong answers. We are interested in <u>your</u> experiences and opinions, whatever those may be. All of your responses will be kept strictly confidential. If you have any questions about this study or this questionnaire, please call Mary Adorno at 916-641-5795, ext. 124.

The following questions ask for your views about your health *in general*. If you are unsure about how to answer a question, please give the best answer you can.

1. **In general, would you say your health is:**

(Circle one number)

Excellent	Very Good	Good	Fair	Poor
1	2	3	4	5

2. **The following items are about activities you might do during a typical day. Does *your health now limit you* in these activities? If so, how much?**

(Circle one number on each line)

Activities	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
<u>A</u>. Moderate activities, such as moving a table, pushing a vacuum cleaner	1	2	3
<u>B</u>. Climbing several flights of stairs	1	2	3

3. **During the *past 4 weeks,* have you had any of the following problems with your work or other regular daily activities *as a result of your physical health*?**

(Circle one number on each line)

	Yes	No
A. Accomplished less than you would like	1	2
B. Were limited in the kind of work or other activities	1	2

4. **During the *past 4 weeks,* have you had any of the following problems with your work or other regular daily activities *as a result of any emotional problems* (such as feeling depressed or anxious)?**

(Circle one number on each line)

	Yes	No
A. Accomplished less than you would like	1	2
B. Didn't do work or other activities as carefully as usual	1	2

5. **During the *past 4 weeks,* how much did *pain* interfere with your normal work (including both work outside the home and housework)?**

(Circle one number)

Not at all	A little bit	Moderately	Quite a bit	Extremely
1	2	3	4	5

6. **These questions are about how you feel and how things have been with you *during the past 4 weeks*. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the *past 4 weeks* …**

(Circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
A. Have you felt calm and peaceful?	1	2	3	4	5	6
B. Did you have a lot of energy?	1	2	3	4	5	6
C. Have you felt downhearted and blue?	1	2	3	4	5	6

7. During the *past 4 weeks*, how much of the time has your *physical health or emotional problems* interfered with your social activities (like visiting with friends, relatives, etc.)?

(Circle one number)

All of the time	Most of the time	Some of the time	A little of the time	None of the time
1	2	3	4	5

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8. We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

(Circle one number on each line)

A) How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
B) How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
C) How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
D) How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
E) How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
F) How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident

Question 8. Continued. Please circle one number of each line.

(Circle one number on each line)

G) How confident are you that you can reduce your physical discomfort or pain?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
H) How confident are you that you can do all the things necessary to manage your condition on a regular basis?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
I) How confident are you that you can judge when the changes in your illness mean you should visit a doctor?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
J) How confident are you that you can get family and friends to help you with the things you need (such as household chores, like shopping, cooking, or transport)?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
K) How confident are you that you can get emotional support from friends and family (such as listening or talking over your problems)?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
L) How confident are you that you can get emotional support from resources other than friends or family, if needed?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
M) How confident are you that you can get help with your daily tasks (such as housecleaning, yard work, meals, or personal hygiene) from resources other than friends or family, if needed?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident
N) How confident are you that you can get information about your disease from your community resources?	not at all confident	1—2—3—4—5—6—7—8—9—10	totally confident

9. Regarding your health problems, how helpless do you feel? *(Circle one number)*

Not at all helpless						Very helpless
1	2	3	4	5	6	7

10. Regarding your health problems, how helpless do you think your family member(s) feel? *(Circle one number)*

Not at all helpless						Very helpless
1	2	3	4	5	6	7

The next set of questions asks you about your familiarity and comfort level with different kinds of technology.

11. How would you describe your familiarity with the array of technology products for homes today? Would you say you are…

(Circle one number)

Very familiar	Familiar	Somewhat familiar	Not very familiar	Not at all familiar
1	2	3	4	5

12. How would you describe your comfort level with using a <u>computer</u>? Would you say you are…

(Circle one number)

Very comfortable	Comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable
1	2	3	4	5

13. How would you describe your comfort level with using the <u>internet</u>? Would you say you are…

(Circle one number)

Very comfortable	Comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable
1	2	3	4	5

Please feel free to write in any additional comments, questions, or concerns:

THANK YOU SO MUCH FOR TAKING THE TIME TO COMPLETE THIS SURVEY!

Control Group Final Informal Caregiver Survey
February 18, 2011

TO BE COMPLETED BY HOME HEALTH AGENCY NURSE
Date and Time:
Participant Study Number:

1. **Does the patient have an informal caregiver? (Circle one) Yes No**
2. **What is the informal caregiver's relationship to the patient? (Circle one) Spouse Patient Friend Sibling In-Law Other Relative Other (specify:_____)**

Did informal caregiver complete survey…

O Alone O With Assistance (Who Assisted: _____)

Thank you for taking the time to complete this survey. There are no right or wrong answers. We are interested in <u>your</u> experiences and opinions, whatever those may be. All of your responses will be kept strictly confidential. If you have any questions about this study or this questionnaire, please call Mary Adorno at 916-641-5795, ext. 124.

The following questions ask for your views about <u>your health</u> *in general*. If you are unsure about how to answer a question, please give the best answer you can.

1. **In general, would you say your health is:**

(Circle one number)

Excellent	Very Good	Good	Fair	Poor
1	2	3	4	5

2. **The following items are about activities you might do during a typical day. Does *your health now limit you* in these activities? If so, how much?**

(Circle one number on each line)

Activities	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
<u>A</u>. Moderate activities, such as moving a table, pushing a vacuum cleaner	1	2	3
<u>B</u>. Climbing several flights of stairs	1	2	3

3. **During the *past 4 weeks,* have you had any of the following problems with your work or other regular daily activities *as a result of your physical health*?**

(Circle one number on each line)

	Yes	No
A. Accomplished less than you would like	1	2
B. Were limited in the kind of work or other activities	1	2

4. **During the *past 4 weeks,* have you had any of the following problems with your work or other regular daily activities *as a result of any emotional problems* (such as feeling depressed or anxious)?**

(Circle one number on each line)

	Yes	No
A. Accomplished less than you would like	1	2
B. Didn't do work or other activities as carefully as usual	1	2

5. **During the *past 4 weeks,* how much did *pain* interfere with your normal work (including both work outside the home and housework)?**

(Circle one number)

Not at all	A little bit	Moderately	Quite a bit	Extremely
1	2	3	4	5

6. **These questions are about how you feel and how things have been with you *during the past 4 weeks*. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the *past 4 weeks* …**

(Circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
A. Have you felt calm and peaceful?	1	2	3	4	5	6
B. Did you have a lot	1	2	3	4	5	6

of energy?						
C. Have you felt downhearted and blue?	1	2	3	4	5	6

7. During the *past 4 weeks*, how much of the time has your *physical health or emotional problems* interfered with your social activities (like visiting with friends, relatives, etc.)?

(Circle one number)

All of the time	Most of the time	Some of the time	A little of the time	None of the time
1	2	3	4	5

8. Regarding your family member's health, how much control do you feel? (Circle one number)

Very much in control						Not at all in control
1	2	3	4	5	6	7

9. How confident are that you could take the right steps if your family member were to have an emergency related to his or her death? (Circle one number)

Very confident						Not at all confident
1	2	3	4	5	6	7

10. Regarding your family member's health problems, how helpless do you feel?

Very helpless						Not at all helpless
1	2	3	4	5	6	7

11. Regarding your family member's health problems, how helpless do you think your family member feels?

Very helpless						Not at all helpless
1	2	3	4	5	6	7

12. Below is a list of various physical and emotional tasks of caregiving, such as providing personal care, assisting with medications, monitoring symptoms, talking with health care providers, managing finances, which people often have difficulty performing. Please indicate how much difficulty you have performing the following tasks.

(circle one number on each line)

		Extremely Difficult				Not at all Difficult
A.	Treatments (medications, etc…)	1	2	3	4	5
B.	Personal care	1	2	3	4	5
C.	Mobility (walking, exercise)	1	2	3	4	5
D.	Emotional support	1	2	3	4	5
E.	Monitoring symptoms	1	2	3	4	5
F.	Transportation	1	2	3	4	5
G.	Finances	1	2	3	4	5
H.	Household tasks (cleaning)	1	2	3	4	5
I.	Errands (shopping, etc…)	1	2	3	4	5
J.	Planning activities	1	2	3	4	5
K.	Behavioral problems, due to moodiness and irritability.	1	2	3	4	5
L.	Behavioral problems due to memory loss, loss of concentration or attention.	1	2	3	4	5
M.	Behavioral problems due to confusion, disorientation, or dementia.	1	2	3	4	5
N.	Arranging for provision of care while away	1	2	3	4	5
O.	Communicating with patient	1	2	3	4	5
P.	Finding resources	1	2	3	4	5
Q.	Communicating with healthcare professionals.	1	2	3	4	5

13. Indicate how often you experience the feelings listed by circling the number in the box that best corresponds to the frequency of these feelings.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1) Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
2) Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?	0	1	2	3	4
3) Do you feel angry when you are around the relative?	0	1	2	3	4

4) Do you feel that your relative currently affects your relationship with family members or friends in a negative way?	0	1	2	3	4
5) Do you feel strained when you are around your relative?	0	1	2	3	4
6) Do you feel that your health has suffered because of your involvement with your relative?	0	1	2	3	4
7) Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
8) Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
9) Do you feel that you have lost control of your life since your relative's illness?	0	1	2	3	4
10) Do you feel uncertain about what to do about your relative?	0	1	2	3	4
11) Do you feel you should be doing more for your relative?	0	1	2	3	4
12) Do you feel you could do a better job in caring for your relative?	0	1	2	3	4

Total for each column _____ _____ _____ _____ _____

Total Score _____

The next set of questions asks you about your familiarity and comfort level with different kinds of technology.

14. How would you describe your familiarity with the array of technology products for homes today? Would you say you are…

(Circle one number)

Very familiar	Familiar	Somewhat familiar	Not very familiar	Not at all familiar
1	2	3	4	5

15. How would you describe your comfort level with using a <u>computer</u>? Would you say you are…

(Circle one number)

Very comfortable	Comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable
1	2	3	4	5

16. How would you describe your comfort level with using the <u>internet</u>? Would you say you are…

(Circle one number)

Very comfortable	Comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable
1	2	3	4	5

Please feel free to write in any additional comments, questions, or concerns:

THANK YOU SO MUCH FOR TAKING THE TIME TO COMPLETE THIS SURVEY!

Control Group Final Nurse Survey
February 18, 2011

TO BE COMPLETED BY HOME HEALTH AGENCY NURSE

Date and Time:
Participant Study Number:

Thank you for taking the time to complete this survey. There are no right or wrong answers. We are interested in <u>your</u> experiences and opinions, whatever those may be. All of your responses will be kept strictly confidential. If you have any questions about the study or this questionnaire, please call Mary Adorno at (916) 641-5795 ext. 124.

These questions ask you about your familiarity and comfort level with different kinds of technology.

1. **How would you describe your familiarity with the array of technology products for homes today? Would you say you are…**

(Circle one number)

Very familiar	Familiar	Somewhat familiar	Not very familiar	Not at all familiar
1	2	3	4	5

2. **How would you describe your comfort level with using a <u>computer</u>? Would you say you are…**

(Circle one number)

Very comfortable	Comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable
1	2	3	4	5

3. **How would you describe your comfort level with using the <u>internet</u>? Would you say you are…**

(Circle one number)

Very comfortable	Comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable
1	2	3	4	5

4. Indicate how often you experience the feelings listed by circling the number in the box that best corresponds to the frequency of these feelings.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1) Do you feel that because of the time you spend with your patient that you don't have enough time for yourself?	0	1	2	3	4
2) Do you feel stressed between caring for your patient and trying to meet other responsibilities (work/family)?	0	1	2	3	4
3) Do you feel angry when you are around the patient?	0	1	2	3	4
4) Do you feel that your patient currently affects your relationship with family members or friends in a negative way?	0	1	2	3	4
5) Do you feel strained when you are around your patient?	0	1	2	3	4
6) Do you feel that your health has suffered because of your involvement with your patient?	0	1	2	3	4
7) Do you feel that you don't have as much privacy as you would like because of your patient?	0	1	2	3	4
8) Do you feel that your social life has suffered because you are caring for your patient?	0	1	2	3	4
9) Do you feel that you have lost control of your life since your patient's illness?	0	1	2	3	4
10) Do you feel uncertain about what to do about your patient?	0	1	2	3	4
11) Do you feel you should be doing more for your patient?	0	1	2	3	4
12) Do you feel you could do a better job in caring for your patient?	0	1	2	3	4

Total for each column _____ _____ _____ _____ _____

Total Score _____

Please feel free to write in any additional comments, questions, or concerns:

THANK YOU SO MUCH FOR TAKING THE TIME TO COMPLETE THIS SURVEY!