

Appendix 4

Illinois Foundation for Quality Health Care

Electronic Health Information Exchange Consumer Focus Group Summary

**Sharp Research
March 2007**

Objectives

- Assess consumers' current use of personal health records and their exposure to electronic health records
- Understand consumers' perceptions about ownership of their medical records
- Understand consumers' use of computers
- Discussion regarding concerns related to privacy and security measures involved with online exchanges of confidential information
- Assess consumers' perceptions about the implementation of a national electronic health information exchange (EHIE)
- Discussion of benefits and concerns regarding privacy and security of such a process
- Discussion of type of unique patient identification that should be used in an EHIE

Methodology

- Four (4) focus group sessions were conducted with consumers on Wednesday, March 7, and Thursday, March 8, at Home Arts Guild Research Center
- Participants were required to have visited a doctor or health care facility within the past 12 months (either for someone they care for or themselves)
- Focus group participants were recruited (12 participants were recruited per group):
- Two groups with participants aged 60 plus: One (1) group of 11 and one (1) group of 12 showed up
- Two groups with participants aged 24-59: One (1) group of 11 and one (1) group of 12 showed up
- Moderator Marybeth Sharp conducted the group with the assistance of a moderator's guide developed by Sharp Research and IFQHC

Organization of Results

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- General Health Findings
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Executive Summary

General Health Care

Participants, in general, seem not to feel frustrated with the process of completing medical history forms when visiting a new physician's office. A little frustration was noted if they were required to complete these forms when they went to their primary care physician's office for annual check-ups; despite noted minor frustration, most saw this as a standard process. There was minor concern that the information they provide on medical history forms is inaccurate or incomplete.

Several participants maintain personal healthcare records. These can be copies of their actual health records, or another form of documentation they have developed on a computer to keep track of their medical procedures and medications. A few participants who provide care to others keep track of information that is necessary in caring for these people, such as medication records and some medical history.

When asked if they had heard of electronic health records, a few participants indicated they had and were even able to provide an accurate description of an electronic health record. Several participants indicated they have seen electronic health records in the offices of their own physicians. Many like the idea of electronic health records; they believe they will provide more accurate records and eliminate lost records. While many like and see benefits in electronic health records, they also want to ensure that these records remain part of the confidential "patient-doctor relationship." The use of a computer to record medical information leads some people to perceive that the medical visit itself will become automated and physicians will spend less time with patients.

The majority of participants currently receive hard copy prescriptions from their physicians' offices. A few have received a prescription generated by computer.

Participants were asked who was the owner of their healthcare data. The initial answer by most participants was "me." After discussing their actual access to these records, they soon changed their answer to the "hospital/medical facility were the owners" but they were able to get copies of this information when needed.

"Safety and Privacy" of Computers

Almost all participants use computers on a regular basis. Some are still a bit hesitant about "safety and privacy" when it comes to exchanging their personal and confidential information online, but the majority feel comfortable that the sites they use for online purchases and personal business are quite secure.

Electronic Health Information Exchange

Participants were provided with a definition of "Electronic Health Information Exchange" and asked to discuss concerns and perceived benefits related to the implementation of such a process. While the majority of participants reacted positively to an "electronic health record," many immediately expressed concern with an "electronic health information exchange" that would allow thousands of people to gain access to their healthcare information.

The perceived benefits of the process include immediate access to health information in the event of an emergency and a reduction in errors from lost or misplaced records.

The concerns associated with the process include increased access to personal/confidential healthcare information (a concern expressed especially by those who might have particularly confidential information such as mental illness) and hackers breaking into the system. There was also a concern that organizations, such as insurance companies and employers, may gain access to this information. The fear of insurance companies and employers obtaining this information made people believe that it could affect insurance premiums and coverage and also limit job opportunities.

While many participants see this process as being “inevitable” in the future of health care, they would still like to have some control over it. They would like to have the ability to provide authorization before any exchange of their health information is permitted.

Many participants would like to gain access to their own healthcare data via the electronic health information exchange. They felt that the ability to read their own records on line would be an appealing attribute.

When asked what type of patient identification number should be associated with electronic health records, the majority did not want to see their Social Security number used; they preferred having a “unique patient identification” number created.

Following each discussion, participants were asked how they would like to have their healthcare records maintained – in an electronic healthcare exchange process or in a paper copy. Thirty-nine of 46 indicated they would select the electronic process; four would like a paper copy; one did not care which format; one wanted both the paper and electronic format; and one was interested in electronic but wanted more information.

General Healthcare Findings

Healthcare Visits Findings:

- Out of forty-six participants, only one indicated he did not currently have a primary care physician.
- Participants were asked if they found the process of having to complete a medical history form upon entering a new doctor's office or updating their medical history when revisiting their current doctor's office frustrating.
 - The majority of participants felt this was a standard process when visiting any new doctor's office.
 - A couple indicated it was frustrating to have to complete the information every year for their annual visit with their primary care physician.
 - Those who have been going to the same physician for many years simply tell them "nothing has changed."
- Most participants were not concerned that they were forgetting information when completing medical history forms.
 - Several did not have a concern because they rely on their primary physician to forward copies of their medical records to any new physician.
 - A couple of participants indicated the form is so thorough that it usually addresses everything.
 - Only a few participants expressed concern regarding information they just did not know, such as the medical history of their ancestors or information pertaining to someone in their care, for example their parent or child.

Supporting Quotations:

"I switched practices and did not like the new doctor who took over the practice... so next time I have to go to a doctor I have some recommendations to follow up on for a new physician." (60+ Group)

"It is standard to complete these [medical history] forms every time you go to a doctor the first time." (60+ Group)

"I expect it each time that I go...it is something they want to know and maybe something came up since last time I went to the doctor's office." (60+ Group)

"I find it frustrating...I go once a year for an annual physical and I have to fill it out every time." (24-59 Group)

"When I am referred to a specialist, I have my primary care physician make sure they send over a copy of [my medical records] and I tell [the specialist] I do not need to fill out the forms because they already have a copy of my records from my physician. Why should I do something that is not worth my time?" (60+ Group)

"I always have my physician make a copy of my records and they give it to me to take to a new physician." (60+ Group)

"The questionnaire list [medical history form] is so long that if you follow it all the way through there is little chance that you are going to miss something." (24-59 Group)

"I filled out [medical history form] recently and it asked how old my grandparents were when they died. I had to call my parents because I would not have even gotten it close." (24-59 Group)

"The person I take care of is allergic to aspirin so I have to make sure I mark that down all the time." (24-59 Group)

Personal Healthcare Records Findings:

- A few participants in each group indicated they kept some type of personal healthcare records. In many of these cases, these personal health records are carried to the various doctor and health care appointments.
 - Several obtain actual copies of their physician/medical visits and referred to those as their personal health records.
 - A couple of participants developed a “simple” program on their computer (Microsoft Word was mentioned) and document all their visits, medical procedures, and a listing of all their medications.
- A few participants also maintain “pertinent” personal health information documents for someone they look over and assist to medical visits.
 - In many cases this was for a parent they were caring for and needed to maintain medication and medical treatment information.
 - Several participants also noted keeping copies of their children’s records, specifically immunization records.

Supporting Quotations

“I keep my [copies] of my files back from 1985.... I also ask for a copy of the [medical history] form that I fill out and [office visit information] because I want to keep track of my blood pressure and weight, so I ask for copies and I saved them all.” (60+ Group)

“On my computer...I keep track of all of my medical issues that I have had in my lifetime, like surgeries or problems that I had that did not require surgery. One side has my medications and supplements, and I take these with me and hand them this sheet. I have even done this in the operating room. I update the information and put a date on it to make sure it is the latest version.” (60+ Group)

“My mom was on a lot of medications so I kept a copy in my wallet [of all her medications] because we were in the hospital once a month and it was easier than carrying her bottles of medications with me. I kept the information on a little piece of paper laminated in my wallet.... It was easier to give it to them in the ER.” (24-59 Group)

“I keep copies of [my dad’s] records – photocopies of records and we keep all his medications documented.” (24-59 Group)

“I keep copies of my children’s immunization records.” (24-59 Group)

“It would probably be a smart thing to do [maintain personal health records] but I do not do it.” (24-59 Group)

Electronic Healthcare Records Findings:

- When participants were asked if they ever heard of electronic healthcare records, several provided a description of what they had already seen in their physicians’ offices and some indicated they had seen/read about electronic healthcare records on the Internet or in journals, or heard about it on television.
- A description of electronic health records was read to the group and they were asked to discuss the benefits and concerns regarding such a process. Many participants liked the idea of electronic health records and felt the medical field was late in getting this up and running. Perceived benefits to this type of process include:
 - Elimination of duplicate tests (X-rays, MRIs, etc.)
 - Elimination of lost/destroyed medical records (in cases of misplaced/misfiled records, securing files from damage such as water or fire, etc.)
 - More confidential than having hard copy file lying around the office or sitting by the examining room door

Supporting Quotations

"An electronic health record] is health information kept electronically in a centralized data file that is accessible, with firewalls, to specific individuals who are cleared to access that information. If they [physicians] had [electronic records] it would be easy to transfer medical records; instead of making a hard copy of the file, you could just pull it up on the computer." (60+ Group)

"I never heard of [electronic health records] but I think we should have it because when I started treatment for cancer I started at one place and had to go to another place. ... I had a big folder and when I went to visit my primary doctor, they misplaced my folder." (60+ Group)

"I heard of [electronic health records]...clinics and hospitals are on electronic systems, not all, but [electronic records] should be a better way to keep up with compliance and regulations – I think it is more confidential than having your medical record on the door so someone can walk by and look at it." (24-59 Group)

"I read about electronic health records in journals and on the Internet." (24-59 Group)

Electronic Healthcare Records in Physician Offices Today Findings:

- When asked if their physician's office is currently using electronic health records, there was a mix of responses and confusion about whether their "actual health records" were electronic. Several indicated their physicians had computers in the examining rooms, others thought the nurses or staff entered data into a computer, and some indicated the healthcare records were still on paper.
- When asked how they feel about doctors using computers during an exam, there was concern from a few that it might eliminate any "personal touch" that is involved in a doctor-patient relationship, while others felt it would be the same if a doctor were taking notes during the exam – "What's the difference if they are writing it down or typing it?"
 - Those participants who did not want a computer in the examining room did not seem to mind that the records were electronic as long as the physician was paying attention to them during the visit and putting the data in the computer afterwards.
 - More often participants in the 60+ group seemed to prefer the more "personal touch" component to an office visit versus participants in the 24-59 age group, who were more concerned with the accuracy and privacy of their records.
- Participants were asked about the type of prescriptions they receive from their doctor's office, whether they are handwritten on a tablet of paper, electronic copy, or automatically sent via email to the pharmacist.
 - The majority of participants across all groups indicated they are receiving a handwritten copy of their prescription.
 - Only a few have received a computer printout of their prescription.
 - Those who have the prescription sent directly to the pharmacist could not determine whether it was via email, fax, or phone.
 - One participant indicated he receives a hard copy that he has to mail to his benefit plan.

Supporting Quotations

"I would be upset if my doctor was typing on a computer during the middle of my visit." (60+ Group)

"A very important part of medicine is listening to the patient's needs. If a doctor is on a computer, then he is not really focusing on what the patient is telling him – I think it is a distraction. If the person wants to make notes and go on computer after the visit that is fine." (60+ Group)

"My doctor is a young doctor...he asks questions and types them in [the computer]. I would rather see what he is typing since you can't read their handwriting." (60+ Group)

"My only concern with it [electronic health records] is who would have access to that information." (24-59 Group)

"I went to my doctor and he started typing on his computer with his back to me and that seemed a bit strange, so as long as he was facing me it would not be bad." (24-59 Group)

"I don't have a problem with my doctor typing his notes on a computer... my old doctor's office had a flood and all the records were destroyed so they should be up with the program on having files on a computer." (24-59 Group)

"I get my prescription called into the drugstore or a hard copy is given to me." (60+ Group)

"My physician [today at my visit] was putting something in the computer and when I checked out I was given a prescription [printed from the computer]." (24-59 Group)

"I was taken to the ER in Sweden...and they gave me a form printed [on a computer] in Swedish with my prescription." (60+ Group)

Ownership of Healthcare Data Findings:

- The initial perception of many participants when asked who was the owner of their healthcare data was "me." However, as the groups began to discuss the processes involved in getting copies of their health records, transferring their health information to other physicians' offices, and the inability to actually change this data, their viewpoints changed.
- Some believe ownership should have to do with who pays for the information.
- Participants noted they are able to obtain copies of their health records but cannot take the originals.
- Patients do not have the ability to make changes or add notes to their healthcare records; therefore, they are not owners of this data.

Supporting Quotations

"I should be the owner...I paid for it [health care records]." (60+ Group)

"Under the law, ownership has to do with custody and custody is in the hands of the institution – we as patients have a right to obtain copies...but we do not have custody so under the law we do not have ownership." (60+ Group)

"I think I can ask for my records to be transferred to a doctor and they may not physically give it to me but I know they have a set sent to the other office. I am the implied owner but I do not think I have rights to actually physically hold it." (24-59 Group)

"I would say the hospital is the owner because you do not get the originals." (24-59 Group)

"If we were the owner we would be able to change our records and we are not able to change it." (24-59 Group)

General Attitudes About the Safety and Privacy of Computers

Use of Computers Findings:

- All but one of 46 participants currently use computers; the one nonuser indicated he just enrolled in a computer class. The majority of participants use their computers and online services extensively. Only a few tend to use the computer infrequently, typically for email or to look up information on the Internet.
- The majority of participants who use their computers frequently also admitted they use the Internet for the exchange and transfer of personal and confidential information, such as product/service purchases, and online banking/financial business.

- Participants who are comfortable using the Internet for online purchases and financial transactions were comfortable because they know what to do or look for in terms of safety precautions
 - Most are comfortable making purchases online if it is with a reputable company or if they can determine it is a “secure site.” They determine it to be a secure site if it has a “secure lock” or “SSL encryption.”
- A few participants who purchase products online indicated they have a credit card designated for online purchases. In case fraud occurs, the credit card can be cancelled easily.
- In addition, many participants indicated they are always concerned about secure sites and fraud in general, so they make sure to monitor all purchases that show up on their credit cards, whether the purchases were made online or in a store.
- A few participants in the 60+ group expressed more concern that their Social Security numbers are tied to everything versus concern about safety on the Internet. One stated: “Our lives are really an open book tied to our Social Security number.”
- A couple of participants also expressed concern about the risk of identity theft, which can be associated with putting your personal information online.

Supporting Quotations

“I order online.... I do not keep financial records out there but I have a separate credit card that I use for online purchases.” (60+ Group)

“It’s our generation that is so concerned – young people put everything out there [on the Internet].” (60+ Group)

“I do not think twice about [using the Internet] as long as it is a real site and company.” (24-59 Group)

“I have not written a check in two years. Every bill is paid online by bank or their website.” (24-59 Group)

“I only use the computer for Internet and WebMD.” (24-59 Group)

“I take it for granted that major companies are secure and have a safe site. For smaller companies I am lucky—I am in the profession and know what to look for, like secure lock or SSL encryption. I buy stuff all the time online and I think it is more secure than paying in person in a restaurant.” (24-59 Group)

“I have a philosophy – if someone wants to get in [to data files], they are going to get in, no matter how secure you try to make yourself.” (24-59 Group)

“My purse was stolen and my bank account was wiped out. I always hear how easy it is for people to steal your identity.” (24-59 Group)

General Attitudes About Electronic Health Information Exchange

Electronic Health Information Exchange Findings:

- Participants were provided with a copy of the following definition of an electronic health information exchange and asked to discuss the benefits and concerns regarding this definition:
 - A “secure and private” electronic health exchange of health information (your medical history). This would allow healthcare providers to share personal health information and would include all healthcare providers such as hospitals, public health facilities, pharmacies, laboratories, and imaging centers who had the authorization to access this information. For example, if you went to another doctor’s within the state OR in another state and provided a piece of information, possibly a patient identification number, your medical history would come up electronically for the physician to review (e.g., it would show all recent physician visits, medications that you are and have been on, recent and historical medical conditions that you were treated for, etc.). This would allow doctors to

update your records at the time of each visit and this information would then be in your records for access.

- While many participants like the idea of having electronic health records in a physician's office, many became concerned about the notion that access to this information would now be expanded outside the physician's office or the hospitals/medical facilities to "thousands" of other people.

Supporting Quotations

"I do not like the idea [HIE] for privacy reasons but I think it is inevitable. The more people involved [in having access to health records] the more possibility information can get out. This secure access can be to 10,000 people." (60+ Group)

"I just think without adequate safeguards this would be a gross disservice to the privacy of the public. You certainly have to have the right computer experts to place safeguards in this system." (60+ Group)

"I don't think there would be anything in there [health records] that could be used against me and it is nice to know it is available in an emergency." (60+ Group)

"My mother-in-law is a retired nurse and I have two sister-in-laws that are nurses....There are things I do not want them to know. Who is going to have access?" (24-59 Group)

"I think we are trading a little bit of security for a whole lot of availability of medical information – it is a benefit but there is a tradeoff." (60+ Group)

"When we were on a trip, my son got ill and we had to go through all these things. It would have been nice to go someplace and allow them to pull up his records and give him the appropriate medication." (24-59 Group)

Electronic Health Information Exchange – Benefits Findings:

- Participants were able to identify many benefits associated with the implementation of an electronic health information exchange process. Some of these benefits include:
 - In an emergency, health information would be available immediately. This would be particularly beneficial if someone is traveling.
 - Elimination of lost or missing health records that are sent via fax or mail from one physician office to another. The files would be available immediately.
 - The long-term benefits would provide for a more efficient access to health information, a decrease in healthcare staffing needs, a decrease in manual errors (physician handwriting is not often legible), and potential for cost reductions in healthcare.
- If the health information exchange is electronic, it will be easy to track who accesses the data. When probed, participants agreed that it would be beneficial to know who has accessed their health information.

Supporting Quotations

"Wouldn't this be helpful if you are admitted to a hospital and they are able to pull up all your [health] information." (60+ Group)

"The medical industry is a high-cost industry and the reason we are charged so much is because information is not centralized or coordinated. We have everyone running around with their own information; and everyone is filling in their own information; and everyone has their own reports. The more we can eliminate some of these costs in terms of files and records would be good. But we definitely have to address the security issues involved in this process." (60+ Group)

"I had a situation when I gave birth on a holiday weekend and all my records were not sent to the hospital so both the baby and I had to redo all these tests.... If they had an electronic exchange, they could have just looked on the computer." (24-59 Group)

"I think this might reduce the costs...billing, administrative costs, and some of the overhead. I would need some Good Housekeeping Seal of Approval to make sure it is secure." (24-59 Group)

Electronic Health Information Exchange – Concerns Findings:

- The primary concern raised was a desire for assurance that the process of electronic health information exchange would truly be a "private and secure" exchange of health information.
 - The electronic health information exchange will allow more people access to extremely confidential information, such as mental illness situations.
 - The concern about hackers, who are always trying to get access to information and getting more successful in doing so. Electronic records would make it so much easier for someone to obtain information, as opposed to one hard copy.
 - More than "authorized healthcare professionals" will be able to gain access to this information, such as insurance companies and employers. Participants believe these various organizations will gain access to health information if it is electronic, and this, in turn, will affect the type of insurance coverage people get and provide employers reasons not to extend job offers.

Supporting Quotations

"I am always concerned about hackers and this takes it a step farther because it would be available worldwide." (60+ Group)

"I am not worried about who is accessing my banking information whereas patient health information is so much more interesting to look at...so I am sure hackers would love to get in there." (24-59 Group)

"If this information is out there... people will figure out how to get it." (60+ Group)

"I would not want to see someone access this outside the medical profession – especially psychiatric records." (24-59 Group)

"It might be easier for someone to access confidential electronic records, as opposed to shuffling through hard copies of medical records." (24-59 Group)

"You are talking about medical information – extremely confidential. My guess is someone who is managing IT at a high level will be able to see things because they will need to be able to get in the system to do things. Granted, there are different clearance levels, but you never know when there is a bad seed." (24-59 Group)

Electronic Health Information Exchange – Patient Authorization Findings:

- While many participants indicated the electronic health information exchange process would probably be "inevitable," it was important for patients to be required to give their authorization for other healthcare professionals to gain access to their health information.
- The majority of participants indicated the ability to view/access their own records would make the electronic health information exchange process even more appealing.
- Participants would like to see some type of limitations on who has access to data, a "role-based access," but they had difficulty providing the specifics in terms of "who" should access "what." While some discussed protecting the information by limiting the number of people who can access the information, others noted that in allowing more healthcare professionals access to the data, there may be less chance for medical errors.

Supporting Quotations

"Patients' rights have to be expanded just like the medical profession wants their rights expanded. There should be no instances of a transfer of records to any sources without the authorization of the patient." (60+Group)

"I think it would be good to have access to my own records and have it all in one place." (24-59 Group)

"In terms of data to be accessed, any hospital would be given access and clinics would have different levels of access. Maybe everyone has access or maybe not...or maybe some criteria need to be set up for access." (24-59 Group)

"There is a problem with that [role-based access] because I don't think a patient can determine who should have the information, whether it is lab, staff, or a nurse." (60+ Group)

"Here is the irony – all the safeguards we are discussing, and not one of us has failed to complain about all the red tape we have to go through now and all we are doing is adding more red tape to choke the whole system. I don't care who knows my medical records and the sooner they can get the information I need the better off I am." (60+ Group)

Patient Identification with Health Information Records Findings:

- Participants were asked what type of patient identification should be associated with their electronic health information records.
 - Many did not want to see their Social Security numbers tied to this electronic health information exchange since the access would be increased. Only a few felt it would be easier to use their Social Security number since it would be one less number for them to remember.
- Participants became very creative when attempting to think of ways to "safeguard" their data. They provided several different suggested "unique patient identification" options to allow access to their health data. Some of these suggestions include:
 - A "unique number" set up to be similar to the patient's driver's license or VIN number
 - A healthcare card similar to a credit card
 - A private PIN that can only be used with the scanning of a patient's thumb or eye
 - A couple of participants even suggested inserting a microchip into every person, similar to what is being done in animals.
- When participants were asked, if they had a choice of selecting electronic health records or paper copy, which would they select:
 - Thirty-nine would select electronic health records.
 - Four would like to keep paper copy.
 - One did not care, either electronic or paper.
 - One wanted both electronic and paper records.
 - One was interested in electronic but wanted more information.

Supporting Quotations

"I think there should be a separate number [not Social Security]...it would be an additional safeguard." (60+ Group)

"You should have your own private PIN.... It can only be accessed by scanning your thumb or your eyeball." (24-59 Group)

"Use Social Security number...I do not think too many people would be interested in my medical information...a unique password is just one more thing I need to remember." (60+ Group)

"Electronic with proper safeguards in place and communication from medical profession to the patients. Would also want the patient authorization before records were made available to others." (60+ Group)

"Electronic only because it is a 24-hour thing in the event of an emergency and I really feel that they should get more information to patients [about this process]." (60+ Group)

"I would like both [electronic and paper records]; the legal field needs to have everything documented." (24-59 Group)

"Paper. I am not convinced about this and would have to think of process and security – I do not think this is a good idea." (24-59 Group)

"Electronic and would like to be able to have a copy of my own files from the electronic file." (60+ Group)

De-identifiable Health Care Data Used for Medical Research Findings:

- Participants in one of the groups were asked how they would feel if their health information, which would be de-identifiable, was used for medical research purposes. It was explained that having the information stored electronically would allow for access to a very large sample and could help in the advance of medical research.
- The majority of participants felt this was a good idea but some wanted more information about who was doing the research and how it would be used. There was concern from a couple of participants that the research was going to be done with "for profit" pharmaceutical companies and they did not like that idea.
 - Five participants would agree to having their health information used for research.
 - Three would want to know more about the use of the research before saying whether they would or would not agree to it.
 - Two would not agree to using their health information data for research.
 - One would do it only if he was paid for his information.

Supporting Quotations

"This amount of data could provide a warehouse of knowledge [for research purposes]." (24-59 Group)

"A lot of this research is done by pharmaceuticals and they do not do it for the good of us; they do it to sell us products for profit." (24-59 Group)

"They are doing great things with research." (24-59 Group)

Conclusions

- For the most part, consumers are very tuned in to today's computer technology and quite comfortable with the securities that are in place on the Internet. In order to have consumer buy-in and comfort with an electronic health information exchange process, consumers need assurances about the safeguards that will be enforced .
- The electronic health information exchange process should also be explained to consumers: who will have access to the health information, will consumers be allowed to authorize and control access to their health information, and will consumers, at some point, be allowed to access their own health information records?
- Further research should be conducted on using de-identifiable data from an electronic health information exchange for medical research purposes. There seemed to be support for this effort, but it was tested in only one group.