



TLM - 3902

Master's Thesis in Telemedicine and E-health

**Users' Experiences with
Clinical Video Conferencing
at a Resource Centre for Rare Disorders**

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Abstract

The ambulatory consulting service is a corner stone in the services of a resource centre for rare disorders. This service is tailored to each client, and a typical clinical conference is organized as a meeting in the client's municipality. One or two professionals from Frambu travel to encounter the client and his or her relatives, together with several local service providers and often professionals from the specialized health service. Such meetings often gather 10-20 participants.

Videoconferencing is considered an alternative way of meeting, to decrease costs and time spent on travelling and to increase the number of professionals from Frambu participating at the conference. Additionally, it can lead to a broader multidisciplinary scope.

Videoconferencing is in this context a new modality, and there is a need to know how the participants assess it. Frambu is only one of several centres that offer a similar ambulatory consulting service, so results from this study should be useful in a wider area. There are only a few studies that partially can be compared with the present.

The Technology Acceptance Model (TAM) is used as theoretical framework. TAM is a theory useful to predict user acceptance of information technology, with its two determinants "perceived usefulness" and "perceived ease of use". In this context the extended model; the Unified Theory of Acceptance and Use of Technology (UTAUT), is discussed and found suitable to understand the challenges one meets in implementing new technology.

The aim of the study was to compare two modalities of conducting a clinical conference: face-to-face and videoconference. Clinical conferences from January 2008 until March 2010 were assessed, resulting in 375 informants. The participants received questionnaires to assess their satisfaction with the conference.

The main result was that both clients and providers were satisfied with the service, whether it was delivered as a videoconference or as a face-to-face meeting. Clients and providers were equally satisfied. There were no significant differences in satisfaction depending on neither the age of the participants nor on former experience with videoconferencing.

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At the bottom of this page, but at the top of my life; thanks for “surviving” my staying in Tromsø for a year, while you where all at home in Oslo; Ida, Stine and Ole.

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Introduction

The term “telemedicine” was first defined as “medicine delivered by distance” (1). The European Commission’s definition was “the delivery of healthcare services at a distance using information and communication technologies” (2). As telemedicine is a tool used with a much wider scope, a congressional briefing in 1999 in the USA produced this statement: “Telemedicine utilizes information and telecommunications technology to transfer medical information for diagnosis, therapy and education” (1).

The scope of telemedicine is much wider than only medical diagnostics, treatment and follow-up, although its origin was there. Many related areas use concepts and technologies also used in telemedicine. Two examples are e-learning and videoconferencing, which are in use “everywhere”; in universities, hospitals, organizations, companies and also in the private sphere (e.g. “Skype”).

Telemedicine services have been available in Norway for many years, and many applications are routinely in use. However it is demanding to bring the services into regular use and large-scale action (3-5).

Videoconferences

A videoconference is a live audio- and video connection between people in separate locations for the purpose of communication. Videoconferences can be set up between two or multiple locations. In its most simple way, it is possible to use standard computer equipment and free software (e.g. “Skype”). For higher quality and more sophisticated tasks, special equipment is required.

The Norwegian authorities have decided on several strategies to increase the use of ICT in health care. Through the National Health Plan for Norway (2007 – 2010), the government wants to strengthen and coordinate the focus on a more equal and fair distribution of good health (6). Last year, the Norwegian Ministry of Health and Care Services sent “The Coordination Reform”(7) to the Norwegian Parliament with the vision: “Proper treatment – at the right place and right time”. The government declared that “in the development of ICT-strategies, the aim is that electronic communication should be the normal way of communicating”(page 35) (7).



Frambu Centre for Rare Disorders

The Norwegian Directorate for Health defines a rare disorder as a disorder with a prevalence of 10/100 000 (consequently, affecting less than 500 individuals in Norway). The rare disorders for which resource centres have been established are (basically) genetic disorders associated with a need for multidisciplinary and cross-sectoral. Relatively few persons are thus affected by each disorder, but totally 30,000 individuals are affected by a rare disorder in Norway (8). Worldwide, there are about 7,000 known rare disorders (9). Consequently, rare disorders affect a lot of people. It is thus important to increase the knowledge of the disorders and their consequences to develop high quality services with a positive impact on the lives of the affected.

Frambu is one of 16 state-financed resource centres for rare disorders in Norway. These centres provide free, low-threshold services to individuals suffering from rare disorders, their relatives, and service providers from local health care services, schools and kindergartens, specialized health care services, and social welfare services. Frambu’s task is to provide information, courses and counselling services about approximately 100 different rare genetic disorders.

Individuals with rare disorders are often in need of long-term services from several categories of providers from different levels in the ordinary health-, welfare- and education system that everyone has access to. Frambu has a supplementary role that anyone can make use of. The services span the entire life cycle from childhood to old age (10).



Figure 1: Frambu is situated on a peninsula in a small lake 15 km south east to Oslo.

Information is provided through continuous courses related to specific diagnoses. Frambu is a meeting place for families and professionals. Families affected by rare disorders typically feel alone with their situation and problems, and they express a great need to meet others affected by the same diagnosis as themselves (11).

In the ambulatory consulting service, professionals from Frambu share their specialist knowledge by providing guidance and support to the local network of professionals. Thus, clients diagnosed with rare disorders and their families can receive the services and professional help they are entitled to. The consulting service is tailored to the particular client in relation to his or her local environment. A service like this literally

moves the specialists and the competence from the Centre to the residence of the clients. The clients and the service providers find the services very useful (11, 12), and this way of meeting is an effective means of establishing a good rapport between professionals, the clients, and their next of kin. The purpose of these conferences is often twofold: First, to transfer information about the disorder from the specialists to the local service providers, since lack of knowledge hampers them when trying to adapt the services for their client (11). Second, there is often a need to help facilitating the local service providers' network in the community. Clients suffering from rare disorders often have intellectual disabilities and symptoms from several organ systems. They need multidisciplinary support, which requires well-coordinated services with collaboration across professional and organizational borders. Both the family and the professionals may initiate these meetings. The professionals contact Frambu when they need more knowledge or experience, to be able to give the family reasonable support and proper follow-up.

The typical ambulatory consulting service is a co-located clinical conference organized as a meeting with one or two professionals from Frambu, the client and/or her/his next of kin, and between five and fifteen local professionals from the municipality and the specialized health services.

Explanation of Terms as Used in Thesis

Client: Person with a rare disorder using Frambu's services.

Service provider: A professional, for instance a teacher, a physiotherapist, an occupational therapist, a psychologist, or a physician.

Rare disorder: A disorder is rare if less than 10/100.000 suffer from it.

Ambulatory consulting service: Service where employees from Frambu give guidance to clients, relatives, and other people from the health service in clinical conferences. They are held either locally (i.e. near the client) or as a videoconferencing service.

Motivation

The ambulatory consulting service is costly, both in terms of time spent on travelling and expenses of travelling, and staying in the municipality over night. Frambu yearly conducts between 100 and 120 clinical conferences with communities all around Norway. Since 2007, about 25 of them have been conducted as videoconferences. Increased use of videoconferences can reduce the cost (i.e. travel expenses) of each conference and thereby raise the total number of conferences held. In this sense, videoconferencing could be a cost-effective alternative with significant potential. Although Frambu aims at providing multidisciplinary services, only one or two professionals are allowed to travel and participate in each conference. In videoconferences, this number may be increased.

Videoconferencing is a tool that must be seen in the context of Frambu's strategy, organization, knowledge, and experience. It is a new modality, different from the face-to-face meeting, and the use of videoconferencing raises several topics that will have to be examined. Therefore, it is necessary to know how the different participants assess their experience with videoconferencing and to know under what circumstances videoconferencing ought to be the preferred modality.

Frambu bought equipment for two videoconferencing studios and completed an "E(lectronic)-interaction" project in 2006. Strategies for implementing telemedicine (videoconferences) in courses and ambulatory consulting services were decided. Videoconferencing was seen as useful to gather more providers from the whole country to participate in courses held at Frambu, without spending a lot of time and money on travelling. In the ambulatory consulting service, videoconferencing was as a new modality that could be a supplement to face-to-face conferences.

Using videoconferencing as a tool for the clinical conferences was seen as a possibility for increasing the number of clinical conferences and, the number of professionals participating from Frambu. Additionally, it was supposed to decrease the travel expenses and save time. Requests for counselling services are discussed in one of three multidisciplinary teams, and the choice of modality (face-to-face or videoconference) is taken by the professional attending the particular case.

As an employee at Frambu, this background has motivated for me to study telemedicine. I hope the study can contribute to increasing knowledge, influencing attitudes, and when appropriate, increasing the actual use of the applications.



Figure 2: A typical local studio. There are two screens; on the one they see the specialist from Frambu (right screen), on the other they see themselves (left screen).



Figure 3: Four professionals in the studio at Frambu. This is a typical sample with a special teacher, psychologist, physician and a social worker.

Purpose of the study

There is a need of more knowledge about the two different modalities that can be offered at clinical conferences. I want to compare the various participant experiences and attitudes to videoconferences and face-to-face conferences (i.e. co-located). Are there patterns or elements that are significant to how the services are assessed by the clients and the service providers?

The main question is how satisfied the different participants were with the conference. In the study's questionnaire, satisfaction was examined in terms of the content, the usefulness in light of the expectations, and interpretation of the communication, the dialogue, and the atmosphere in the venue.

The concept of the ambulatory consulting service; a simple model

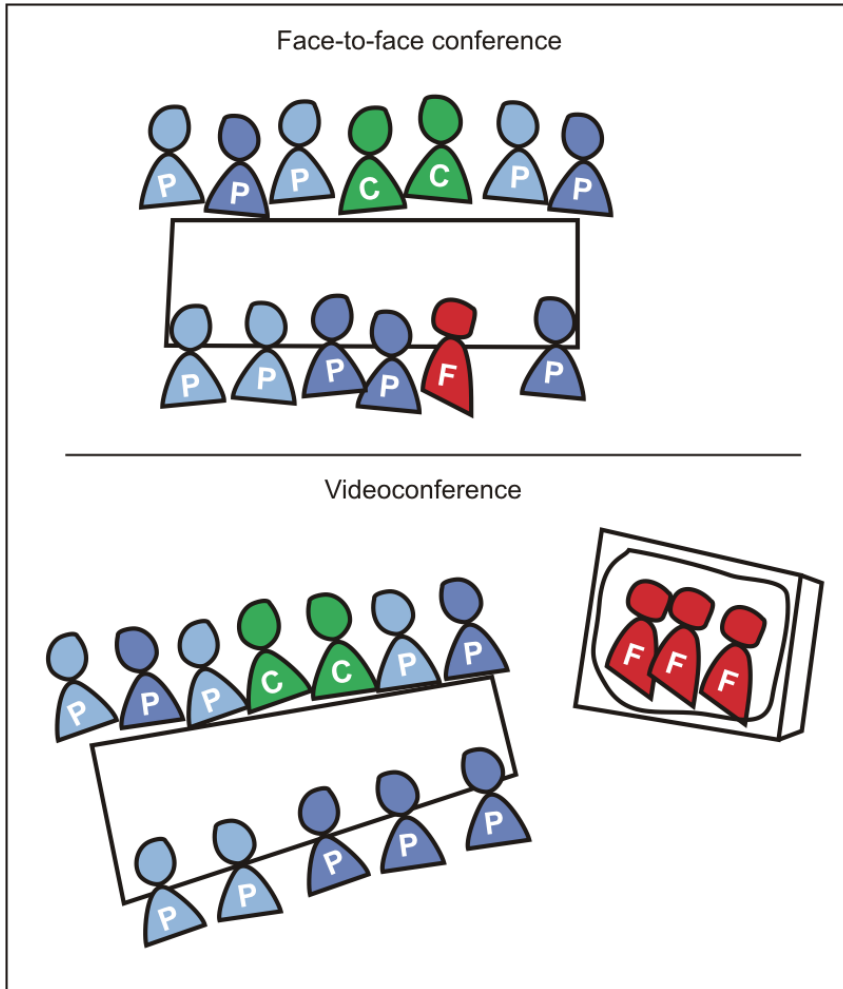


Figure 4: The typical concept of the ambulatory consulting services' two modalities; face-to-face conference (upper) and videoconference (lower). In the figure, the clients are green (C), the providers are blue (P), and the providers from Frambu are red (F). In the videoconferences, on average three providers from Frambu participated, while the average number in face-to-face conferences was 1,6.

Hypotheses

Drawing on prior relevant studies, I hypothesized that:

- Professionals and clients participating in videoconferences are as satisfied as those participating in co-located clinical conferences (13).
- The clients and their next of kin are more satisfied than the professionals with clinical conferences conducted as videoconferences (14, 15).
- Younger participants are more satisfied than older participants with clinical conferences conducted as videoconferences (15, 16).
- Participants with former experience with videoconferences are more satisfied than first time participants (15).

Relevant literature

To prepare the study, I searched for literature where face-to-face consultations were compared with videoconferences; I was especially interested in studies assessing user satisfaction of telemedicine services. I was also looking for papers that could bring in other perspectives to my study, e.g. about communication and the human factor.

The main searches were done in Medline and PsychInfo. The search strings combined "satisfaction" and "usefulness" with various terms such as "telemedicine", "videoconference", and "face-to-face". Although search strings were used, the review process should be described as unsystematic according to the rigid criteria of, for instance the Cochrane Collaboration (17). As a supplement, Google Scholar was used to catch papers from other fields that could be interesting, especially computer science and communication skills in telecommunication.

Two reviews published in 2000 gave a useful perspective of the field. In the first review, Mair and Whitten reviewed studies between 1966 and 1998 (18). This paper is a not new, but important, since it offers an opportunity to follow an historical development. In their review, 32 studies are identified, but because of methodological deficiencies they found it difficult to generalize. Nevertheless, their conclusions are that “teleconsultations are acceptable to patients in a variety of circumstances, but issues relating to patient satisfaction require further exploration of both clients and providers” (18). Two main arguments were emphasized: First, “it would seem that the patients found teleconsultations acceptable; noted definite advantages, particularly increased accessibility of specialist expertise, less travel required and reduced waiting times” (page 1518-1519). Second, the patients were not familiar with this mode of health care delivery, i.e. the communication between patient and provider via videoconference.

In this first review, four issues that need addressing were identified: 1) What types of consultations are suitable for teleconsulting? 2) What are the effects of this mode of health-care delivery on the doctor-patient relationship? 3) How do communicative issues affect the delivery of health care via telemedicine, and what are the effects of telemedicine consultations? 4) What are the possible limitations of telemedicine in clinical practice? The second review (13) indicates that those patients receiving health consultations by videoconferencing are equally satisfied as those receiving them face-to-face.

Several studies compare videoconferences and face-to-face meetings with different aims and concepts. In Kansas, school professionals supporting students with chronic illness produced 45 presentations, each of them of about 60 minutes duration (19). The study had 1389 informants; 919 on FTF and 417 in VC. Overall, all participants were satisfied, but FTF participants were significantly more satisfied than VC participants. To what degree the participants felt comfortable was important for their satisfaction (19). In a UK study, parental satisfaction was assessed related to the delivery of specialist

advice for paediatric cardiology in videoconferences versus face-to-face meetings. The patients were babies needing urgent cardiac evaluation. 100 parents participated in the study, where the satisfaction with specialist consultations provided face-to-face and by videoconference were compared. Parents who participated in videoconferences were more satisfied than parents who were in face-to-face consultations (16).

Some studies show that clients and providers vary in their satisfaction assessment. In a communication aid centre in Bristol, UK, counselling services to clients, relatives, and local providers were conducted with videoconferencing. They found that “the participants felt that videoconferencing was an acceptable method of delivering a remote AAC service (augmentative and alternative communication) in terms of assessment and reviews”(page 419) (15). The clients gave the most positive feedback, while the providers (speech and language therapists) were the most critical because of some technological problems and because they felt uncomfortable about communicating in videoconferences, which was a new experience for them (15).

The studies mentioned above, were all quantitative and performed with questionnaires. To gain deeper insight in what lies behind “patient satisfaction” and “dissatisfaction” was the aim of a qualitative study with 28 participants from the UK (20). The patients were randomized to either undergo a conventional outpatient consultation with a hospital specialist, or a joint teleconsultation, where the patient was together with his GP and saw the specialist in a videoconference. They conclude that “patients generally welcome the increased convenience and punctuality, but they do not want these aspects to take the precedence over the quality of clinical care” (page 89). Several of the patients felt that they received more undivided attention from the specialist during a videoconference, and that the presence of the GP increased the quality of the meeting. Some of the patients, however, felt insecure and perceived the meeting as having a “long distance” quality. Patients that needed

examination preferred that this be done by the specialist himself, and not by the GP relaying findings to the specialist (20).

A Norwegian teledermatology study had two topics: 1) How was the diagnostic agreement between face-to-face consultations and videoconferences? 2) How was the doctor-patient relationship and patient satisfaction assessed? All patients participated in both a face-to-face consultation and a videoconference, and both the dermatologists and the GP had previous experience in videoconferencing. 26% of the patients preferred teleconsultations, 66% assessed them equal, and only 8% preferred the face-to-face consultations (21).

A study from Japan (14) emphasizes communication skills to be important when patients and physicians assess their satisfaction with videoconferences. The patients were given both face-to-face consultations and videoconferences as patient consultations; the patients were satisfied with the telemedicine consultations, whereas the doctors were not. The physicians spent more time on the face-to-face consultations than on the videoconferences, and the number of words written in the patients' medical records was greater for the face-to-face consultations. The physicians struggled with patient communication in the videoconferences. Training programs for doctors to improve communication skills and ability to express empathy in telemedicine consultations are suggested (14).

A different approach is presented in a study where the focus was on the content of the consultations. The study had two phases; first, interviews with clients and service providers telling their opinions about the FTF and VC conversations. Second, the consultations were observed and registered for both content and behaviour of the participants (22). On basis of media theory, the researchers assumed that the patients would prefer to use rich media when communicating equivocal information and leaner media when the message is less equivocal (22). The degree of a media's capacity to transmit complex information, decides what media people chose for

different communication. Face to face is the richest, videoconferencing is the second richest, while synchronous audio, email, and text-based chat is lower on the list (23-25). In this study one of the hypothesis stated: "Equivocal conversations topics will be discussed more often in FTF than in telemedicine sessions" (page 102), but this hypothesis was not supported when the sessions were analyzed. Another result was that doctors and nurses interpreted the equivocality of the sessions different than the patients; the "individual richness perceptions are dynamic" (page 102), one example is that patients were more likely to choose videoconference when they needed rapid contact with the physician (22).

To achieve success with telemedicine applications, it is important to take the human factor into consideration (26). "Nine human factors contributing to the user acceptance of telemedicine applications: a cognitive-emotional approach", is the title of Buck's paper (26). Her focus is on "matters related to the cognitive-emotional situation of the users involved in telemedicine" (page 55). The benefit of the application has to be clear for the users; they must immediately understand the importance of the products, and "it's necessary to give users incentives which make them want to work with the telemedicine application" (page 56)(26). All participants must feel that they are being taken seriously; they have to feel they have control and enjoy confidence. Losing control can be threatening to the providers. Doctors tend to feel that the application is in charge of the consultation (27). When clients and providers physically are divided, as in a telemedicine application, it is recommended to create "an atmosphere of safety and confidence" (page 57) to take care of the emotional needs of the patient (26).

A recent published Norwegian report describes the health service's acquaintance and contact with the centres for rare disorders in Norway. The research institute, Synovate, has done interviews on telephone with 139 providers in the local health services and the specialized health services in Norway (12). The study describes when and why the informants contact a resource centre. The most frequent situation is when a person is

recently diagnosed, or when there is a worsening in the medical condition. The other situations for contacting a resource centre are in transitions between kindergarten, school, high school, and employment, and in connection with moving out from parents to their own home. The resource centres are multidisciplinary staffed, and the informants answered questions about which professionals they had been in contact with. Physicians were the most frequently contacted profession, then follows physiotherapists, nurses, social workers, occupational therapists, and educational professionals(12). Those of the informants, who had participated in videoconferences, were satisfied with the professional content, and thought that videoconferences were suitable for clinical conferences. Almost half of the informants told they were less active in videoconference than in face-to-face conferences (12).

Telemedicine is a tool to improve communication between primary and secondary care (28). Several papers describe how telemedicine is a tool for collaboration and learning across organizational borders (29), and that telemedicine is not a barrier for cooperation; for the most it seems to work quite well (30). Regular use of videoconferences between professionals at different locations and with different specialties can open access to different repertoires of knowledge and experience (29). The teamwork may be improved by factors like experience and education (30).

The literature describes a substantial amount of telemedicine applications and modalities carried out as projects and assessed as feasible to implement in daily routine. Nevertheless, I find that when it comes to “real life”, implementation of telemedicine applications do not increase as expected or follow the initial enthusiasm that are seen in the projects. Two literature studies were conducted to search for the characteristics or determinants of successfully implemented applications.

The most important determinants of a successful implementation are technology and acceptance, which decide 66% of the success, while organization, financing, and legislation comprise 34% (31). Available support and training are important for the

users. If the users experience problems with the application, this often leads to demotivated users. The consideration phase, which comes after the initial enthusiasm, is very important if the application is to be sustainable (31). A telemedicine application must have an aim that the users agree with, and want to contribute to solve. Whether a telemedicine application is a success or not does not only depend on the technological feasibility or success, but to a large extent on the users' different interpretations and discussions. This social negotiation should not be underestimated as a determinant to predict the system's success rate (32). Often when new technology is introduced, it brings along a controversy in the organization about what are the main tasks to be solved and how to do it. "Implementation is a process of mutual transformation"(page 143) (33). To succeed is not only a technical matter, but a result of what is decided on the floor and by the managers, and all the users need evidence for benefit (32).

Theoretical Framework

The study I have performed is related to Frambu, a resource centre for rare disorders. Their use of telemedicine consists of videoconferences for in-house courses and clinical conferences in the centre's ambulatory consulting services. The latter is the topic of this study. Videoconferencing is introduced as a new modality of the consulting services, as an alternative to the traditional co-located clinical conferences. From a theoretical point of view, this can be seen as applying new technology and the Technology Acceptance Model (TAM) (34) will be a suitable framework for discussing what happens, what are the driving forces and what factors hamper this activity. Videoconferencing is a new technology in the context of clinical conferences at a resource centre for rare disorders. This technology is in this study introduced to a setting where most of the participants have prior experience with co-located, face-to-face conferences. New technology may be frightening to some people, for others it may be exciting. When introducing computers and systems or applications into peoples' working life, it is important to understand what happens if you want the system to be implemented in daily use(33) .

Technology Acceptance Model (TAM)

The Technology Acceptance Model (TAM) is a theoretical model from the field of Information Systems, IS. TAM is an adaptation of the Theory of Reasoned Action (TRA) and is especially tailored for modelling user acceptance to the field of Information Systems (IS)(35). In industries outside health care, TAM is by many considered a gold standard, and as much as 10% of the published literature about Information Systems is related to TAM research (36). TAM has become so popular that it has been cited in research on a various type of applications; e-mail systems, e-commerce applications, groupware, database programs, hospital IS, and telemedicine systems, to mention

some (37). The TAM theory has been tested thoroughly, and the theoretical importance of perceived usefulness and perceived ease of use as determinants is shown in several diverse lines of research (34).

However, there are critical voices too, and TAM is discussed by researchers and there is mixed opinions regarding its usefulness. Some talks about “the legacy of TAM” and want a paradigm shift (38).

History/Background

In the 1970's new technological systems rapidly was implemented with too much failure and system rejecting for the organizations to stand. The need to predict system use and explain system acceptance or rejection increased (37). In MIS Quarterly I 1989 Fred Davis claimed: “Valid measurement scales for predicting user acceptance of computers are in short supply”(34). He discussed what the causes are of the fact that people accept or reject information technology, and he posited that two determinants are especially important: **perceived usefulness** and **perceived ease of use** (34). TAM can be explained very simply and can be applied in almost all relations between people and technological systems, whether it be computers, applications or other technological equipment, such as videoconferencing systems. The simplicity, or the parsimony, as Bagozzi said, is also the models Achilles' heel, because it is not possible to explain complex decisions and behaviors across all systems and organizations (38).

The main message of the designers of TAM was “we need to understand why people accept or reject computers”(page 982)(35). What is the impact of external factors on internal beliefs, attitudes, and intentions? TAM was influenced by the Theory of reasoned action (TRA) described by Fishbein and Ajzen in 1975 (35). “TRA is very general and explains behavior across a wide variety of domains” (page 983) (35). When modelling TAM, the aim was to identify a small number of fundamental variables and model the theoretical relationship between them. To test and develop TAM, Davis

developed psychometric scales for both perceived usefulness and perceived ease of use. His first scale constituted of 14 items on each topic. These scales were revised several times until he ended with a six items scale to conduct studies to validate the TAM (37).

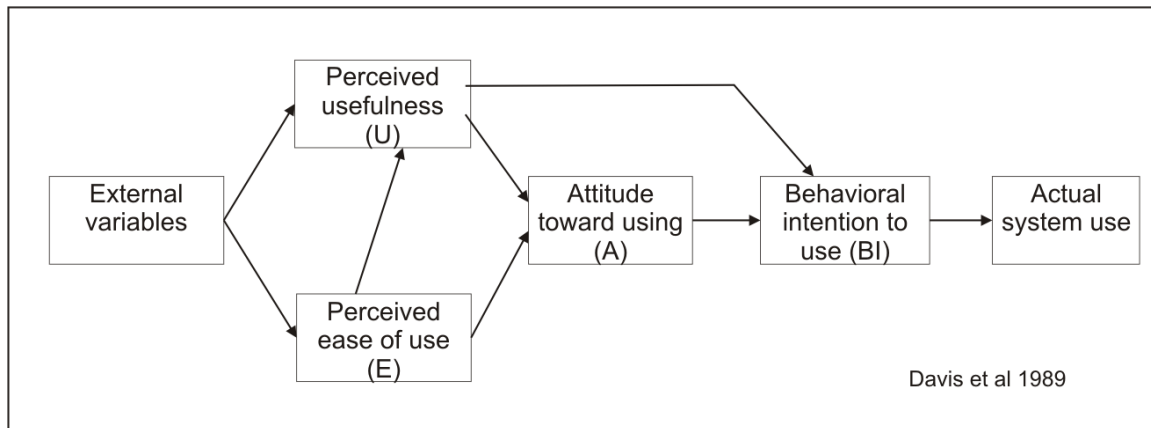


Figure 5: Technology Acceptance Model (TAM), from Davis et al. 1989

TAM posits that perceived usefulness (U) and perceived ease of use (E) are the main determinants for computer acceptance behaviour. Perceived usefulness is defined as “the prospective user’s subjective probability that using a specific application system will increase his or her job performance within an organizational context” (page 985). Perceived ease of use (E) is defined as “the degree to which the prospective user expects the target system to be free of effort” (page 985)(35). Actual system use is determined by the persons’ attitude (A) and intention (BI) to use the system, and the relation between A and BI. If anything else is equal, peoples’ intentions are to behave in a way that gives positive effect ($BI = A + U$). The most important presumption is behavioural intention to use (BI), and this is what is usually meant when referring to “acceptance”(35). The construct “external variables” might influence the beliefs of a person towards a system since it include system characteristics, user training, user participation in design, and the nature of the implementation process (39).

Davis worked on with TAM, and evolved it until the final version was presented in 1996 (39). This model differs from the original by removing the construct “attitude towards

using”, because both perceived usefulness and perceived ease of use were found to have direct influence on “behavioral intention”, which led to actual use of a system (37).

Development and Extensions of TAM

In general, TAM was supported as a model to predict usage behavior, but not to identify the reasons behind. Davis proposed the TAM2 model, with several variables added as antecedents to perceived usefulness (40), later Venkatesh proposed two groups of antecedents for perceived ease of use (41).

In 2003 Venkatesh et al. gathered in a unifying paper about TAM (42). This paper is comprehensive and quite central in the further development and understanding of the TAM model. They present a literature review and compare models; and in the end, they formulate a unified model, that is empirically validated by testing the original data from the eight models that are unified and by further adding two more datasets. The Unified Theory of Acceptance and Use of Technology (UTAUT), was formulated with four core determinants of intention and usage, and up to four moderators of key relationships. When UTAUT was tested using the original data, it was found to be better than the eight individual models. At last it was tested in two new organisations with the almost same result (adjusted R^2 of 70 percent)(42).

UTAUT is intended to be used to assess the likelihood of success when introducing new technology. This model could be useful for managers as it could help them understand what actions are necessary to work out in order to achieve a high level of acceptance. The unified model presents the basic conceptual framework that can explain individual acceptance of information technology(42) (see Figure 6).

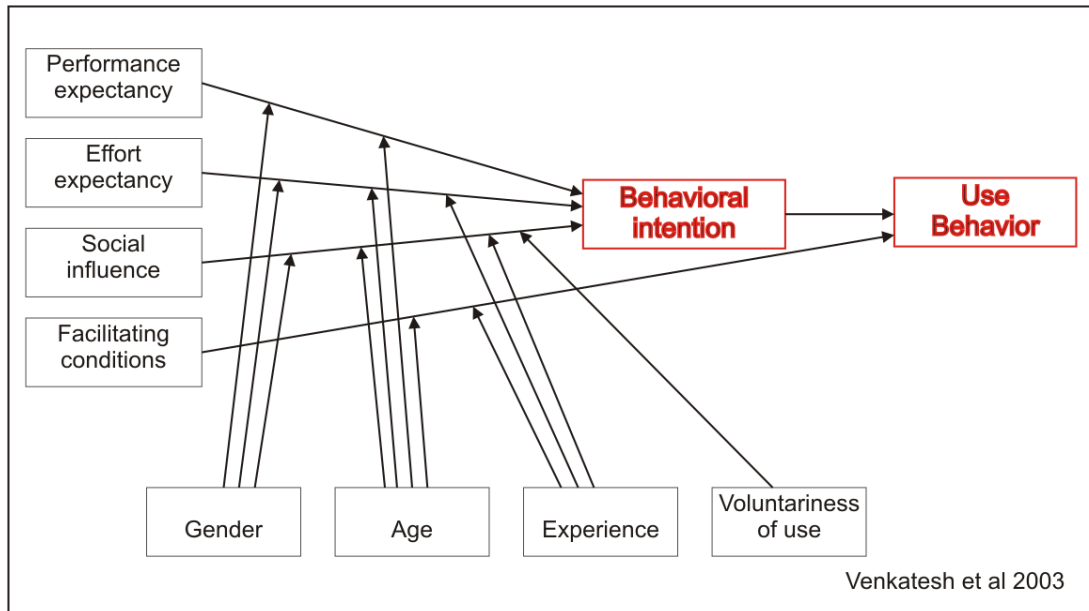


Figure 6: UTAUT Research model. Venkatesh et al 2003

The UTAUT model places perceived usefulness into a concept of *performance expectancy* and perceived ease of use into *effort expectancy*. *Social influence* is a variable that includes attitudes and influence from colleagues, leaders, and company culture that force end users to accept and use the system. Quite new in this model is the determinant *facilitating conditions* for use behavior. Facilitating conditions means how the individual believes that there are organizational and technological infrastructures that support use of the system (42).

Tests of UTAUT documents an explanation of 70% of the variance in BI and about 50% in actual use (36).

Several meta-analysis of papers published on TAM have tried to consolidate the result from TAM-studies. One of them (King and He from 2006), conclude that TAM is a valid and robust model that is widely used; "TAM has come to be one of the most widely used models in IS, in part because of its understandability and simplicity" (page 740)(43).

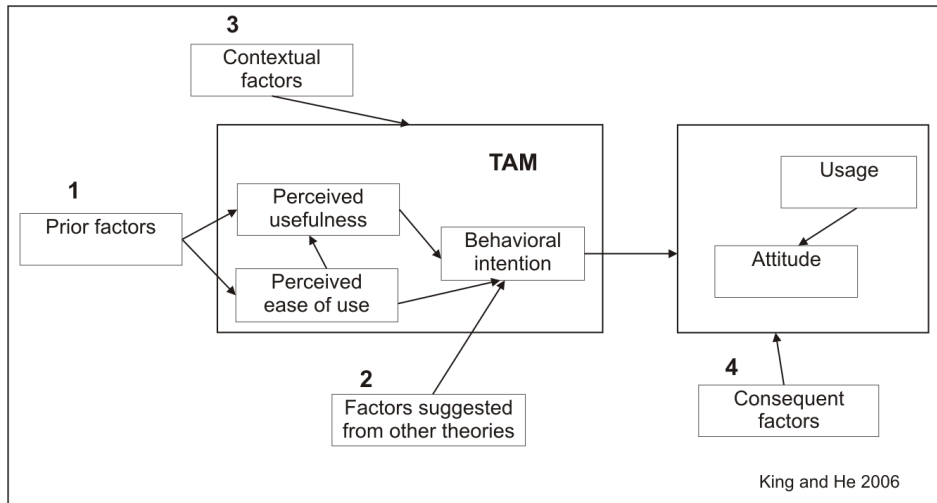


Figure 7: King and He extend TAM with four categories.

The figure above shows how King and He (43) see TAM as the “core” of a broader evolutionary structure that has experienced four major categories of modifications:

1. Inclusion of external precursors (prior factors)
2. Incorporation of factors suggested from other theories
3. Inclusion of contextual factors (gender, culture, etc.)
4. Inclusion of consequence measures (attitude, perceptual and actual usage)

In their conclusions, King and He find that TAM is a powerful and robust model. They also posit that the effect of Davis’ determinant “perceived ease of use”, on behavioural intention is primary through perceived usefulness (43).

Some researchers claim that TAM has come to its return point, and there is time for a paradigm shift (38). Bagozzi, who was Davis’ co-author in 1992, claims that the extensions and developments have led to a broadening, but not a deepening, of the model (38). Nevertheless, the majority of research papers still support TAM, either in its original or in an extended form. A recently published review (2010) concluded that “the most impressive is that the relationship between perceived usefulness and the intention to use or actual use of health IT was significant in every test” (page 166) (36). TAM appears to be a strong theory, currently valid in health care context.

Methods

When doing studies of the real world, researchers have different approaches and different goals with the studies. Depending on what and how to study, there are two main approaches; the quantitative and the qualitative/interpretive, or in other terms, fixed or flexible design (44). The strength of a quantitative study is its ability to create evidence that is both valid and reliable, and which can be tested and retested by new groups of researchers. Studies often have large numbers of participants – often hundreds, or in very big studies, thousands of participants.

The quantitative approach was chosen for this study, but that was not the obvious choice in the early planning process. The limitation of the sample size was an important factor in these discussions. Was it possible to gather enough information to achieve valid and reliable data? On the other side, the majority of previous studies with similar aims were based on questionnaires and a quantitative method.

Prior to this study, I had made some preliminary investigations. I was an observer at two videoconferences conducted by the ambulatory consulting service from Frambu, I made in-depth interviews with three providers from Frambu about their experiences with videoconferences, and I was part of an exchange of experiences with ten of the staff from Frambu who had participated in videoconferences. This previous experience was useful when it came to choice of method and in the preparation of the questionnaires.

Inclusion and Exclusion Criteria

Participants in the ambulatory consulting service provided from Frambu between January 2008 and March 2010 were included:

- If the conference was conducted either as face-to-face conference in the municipality or as videoconference
- If the conference was related to one client (or more if member of same family)

As clients count both the individual with the disorder and his/her parents, and other close relatives (i.e. siblings, grandparents), if they were present at the conference.

Two exclusion criteria were determined:

- If the individual with the disorder had died after the clinical conference, the parents were excluded
- If the family were not able to read and understand Norwegian

On basis of these criteria, an estimate for possible participants was made.

Numbers of face-to-face conferences in the study period was estimated to be 210 and videoconferences to be 27. The numbers of clients to ask was expected to be 450, while the number of providers was more uncertain. But with a mean of 7 participants, and a reduction because some professionals had participated in several conferences, there ought to be between 1.000 and 1.500 to ask in total.

Questionnaire

To find answers to my hypotheses, using questionnaires seemed to be an appropriate method. Certain instruments have been made to measure patient satisfaction, but they will not give answers to my questions about usefulness and satisfaction of this particular application. To make a questionnaire especially for this study, I searched the literature for questionnaires tested for validity and reliability and that could be used as a point of departure. However, as there is no standard questionnaire for telemedicine studies of this kind, I had to develop a specific questionnaire for the present study.

Relevant Literature on Usefulness and Satisfaction Questionnaires

The focus in this study was on usefulness and satisfaction. I found a lot of studies that aimed at measuring people's satisfaction with telemedicine services. Most often, patient satisfaction was the focus of the study, but there were also studies on professionals' satisfaction.

The questionnaire; "Telemedicine Satisfaction Questionnaire" (TSQ) is validated (45), and the questionnaire is tested on patients with diabetes. "Telemedicine Satisfaction and Usefulness Questionnaire" (TSUQ) was developed in the USA and both the development and quality assurance has been described. Psychometric analyses were conducted to assure the reliability and validity (46). I have used four of their statements in my own questionnaire. The TSUQ is based on a number of other questionnaires, but their main source is "Telemedicine Perception Questionnaire" (TMPQ) from The American Telemedicine Association (47).

A literature review on questionnaires on acceptance and satisfaction concludes with a recommendation of 13 topics that could be covered in studies for that purpose (48). I have checked this list to ensure my questionnaire covers relevant items for my purpose. From a study done in the UK, I found a number of questions/statements that were formulated closely to what I need in my study. I have chosen seven statements from this questionnaire (16). A study from Kansas compares videoconferencing with meeting face-to-face when specialists educate/supervise teachers of children with disabilities (19). I have included five of their statements in my questionnaire. From a study with focus on communication experiences as a factor on satisfaction (14), I have included two statements.

Topics in the Questionnaire

The aim was that the main topics would be reflected in the questions (49). Through my preliminary interviews, observations of videoconferences, and the literature search, these four topics emerged as important to explore:

- Outcome – are the participants satisfied
- Usefulness – assessed by the participants
- Communication skills/communication between participants
- Additionally for videoconferences:
Technology – does it work properly – is the quality of audio and video acceptable?

Two Questionnaires – one for Clients and one Providers

The initial idea was to use equal questionnaires for clients and providers; however, in order to formulate the questions and statements as precisely as possible, it was more appropriate to develop two questionnaires, both consisting of three sections:

1. Information about the informant (age, county) and the particular service (how, when, and why was this service offered).
Questions to answer or checkboxes.
2. Statement about the informants' perceived usefulness and satisfaction. The rating scale was: "strongly disagree", "disagree", "neither agree nor disagree", "agree" and "strongly agree".
The clients got 15 statements to assess. Those who participated in co-located meetings got two additional statements, while those who participated in videoconferences got six. Four of the common statements are statements used in earlier studies, while all the six additional questions for videoconferences are present in earlier studies.
The providers got 13 statements for all, and the same additional statements for co-located meetings and videoconferences.
3. Statements on how to improve the services to increase perceived usefulness and satisfaction. 7 common statements to all and the possibility to make comments in free text. The providers who participated in videoconferences, got three more questions about support and technology.

The first version of the questionnaire was piloted in a group of colleagues at Frambu and with two parents who had participated in a co-located service meeting. The testing identified weaknesses and ambiguous questions and assured that every question was easy to understand. After this testing, the questionnaires were proofread by colleagues. (Appendix 1 and 2)

Scale

All the relevant questionnaires I found use a five items Likert scale to assess statements. I have chosen the same (49). It was considered important to use generic scales to allow comparison with other studies.

Two Main Categories of Informants

As far as possible, providers and clients got the same questions, but some changes had to be made to make the questionnaires unambiguous and clear in wording. The two target groups had to be handled differently. The clients had to sign an informed consent form prior to the return of the questionnaire. To assure the anonymity of the clients, and at the same time reduce the inconvenience to them, the clients got paper-based questionnaires, while the providers got the questionnaires electronically.

Frambu had records of all the clients; thus their names and addresses were easy to find. The providers who had participated in the same conferences, were not registered. Only the numbers of providers were available. To get in contact with them was an extensive job. First; one had to get in contact with the local provider who was the main contact for Frambu. Second, she or he had to gather the names and email-addresses of all the local providers and send them to Frambu.

Clients

The research protocol was sent to the Regional Committee for Medical and Health Research Ethics (REK) for approval. Their decision was that this study aimed at obtaining knowledge about experiences and attitudes to the videoconferencing service. This study was therefore not comprised by the Norwegian Act for Health Research (Helseforskningsloven) (Appendix 3).

To ensure that the parents' and clients' privacy was appropriately protected, this study has also been examined and recommended by the Norwegian Social Science Data Service (NSD) (Appendix 4). NSD pointed out the importance of handling my two different roles as an employee at Frambu and a researcher at the same place. To ensure that clients' and relatives' privacy was secured, I was not allowed to see the records. Frambu generously offered the job of a consultant who searched the records, sent the envelopes with information and questionnaires, and gathered e-mail addresses of the service providers by phone.

Parents and clients got a package containing an information letter, an informed consent form, the questionnaire, and two lottery tickets (Flax-lodd). In the package there were also two envelopes. The smallest one was for the consent form. The bigger envelope was addressed and postage was prepaid. When finished filling out the questionnaire, they placed it together with the small envelope in the bigger one and returned it to Frambu.

At Frambu, the consultant registered who answered and archived the consent forms; afterwards I got the anonymous questionnaires. Then there was no possibility for me to recognize the identity of the informants. I recorded the answers in SPSS, and when all questionnaires were registered, I brought the questionnaires to the University of Tromsø, for safe storage.

Providers

The questionnaire made for the professionals was made almost like the one for parents; only small changes were made. Since there was no need for a separate written consent, it was possible to use an electronic questionnaire. Frambu has a license to use the electronic questionnaire system “Questback”, and this was used as a tool for the questionnaire. The research consultant at Frambu made lists with e-mails to the providers, and I imported the e-mails into Questback. After importing the e-mails into Questback, their anonymity was automatically fully secured (50, 51). Even though I had access to Questback, it was not possible to see who of the recipients had answered the questionnaire. After fourteen days, a reminder was sent electronically from Questback to the recipients who had not yet given any response. It is possible to reject to answer the questionnaire. If a recipient rejects, a reminder is not sent.

Providers employed at Frambu were a subgroup of providers, and their answers could therefore be included and compared to the providers from the municipalities. Many of them had experience with videoconferencing, but still about one third had not. They were told to assess the latest videoconference they had participated in, or the latest face-to-face conference, for those who still had not attended a videoconference.

Data Preparation and Analyses in SPSS

For the providers, it was suitable both to collect and analyze the data electronically. For the providers, data was collected in a web-based Questback form sent to them by e-mail. From Questback, the providers’ data was imported directly to SPSS (Statistical Package for the Social Sciences). The data from the clients’ questionnaires were manually transferred to SPSS by the research consultant, while I checked each questionnaire afterwards. Some of the questionnaires were not completely filled in; between 5 and 10 were missing on each statement. The missing data were excluded in the analysis.

The following analyzes were descriptive to get knowledge about the groups of informants to be compared. Since the VC-group and FTF group were not random selected, the descriptive data could show to what degree they were similar, and what differences that were between them.

An exploratory factor analysis was performed on the test scores from the questionnaire to examine whether the items should be summed in one or several subscale scores. As the analysis had no intention to relate common variance among item scores to a latent construct, but rather to maximize observed explained variance, a principal component method for extracting factors was chosen. Then, the four hypotheses were tested on the factor score(s) with analysis of variance (one-way ANOVA and multivariate ANOVA) and correlation analysis.

Results

The total numbers of clinical conferences included in the study, were 19 videoconferences and 115 face-to-face conferences conducted in the period January 2008 to March 2010. Based on these conferences, questionnaires were sent to 240 clients, 453 local service providers, and 31 providers at Frambu, totally 724 participants.

Descriptive results

Informants

Clients: 27 participated in videoconferences and 95 in face-to-face conferences

Providers: 79 participated in videoconferences and 151 in face-to-face conferences

Providers from Frambu: 16 participated in videoconferences and 7 in face-to-face conferences

Totally 375 informants participated in the study.

6 questionnaires were excluded because the respondents had not participated in a conference or had given answer about another service provided.

Questionnaires, informants and response rate

	Questionnaires sent	Informants	Response rate
Clients	240	122	50,8
Face-to-face	199	95	47,7
Videoconferences	41	27	65,9
Providers	453	230	52,1
Face-to-face		151	
Videoconferences		79	
Providers Frambu	31	23	74,2
Face-to-face		7	
Videoconferences		16	

Table 1: Table showing number of questionnaires sent to the different categories, number of informants that participated and the response rate in each of the informant category.

Crosstabulation: Informantkategori * modality

		Modality		Total
		Video-conference	face-to-face	
Informant category	Clients	27	95	122
	Provider	79	151	230
	Provider at Frambu	16	7	23
Total		122	253	375

Table 2: Overview of the informant categories. Clients (N=122) were mainly parents; 72 mothers, 41 fathers, 2 persons with the diagnosis and, 7 were other relatives.

The providers received an electronic questionnaire. It was likely that some of the local providers could have participated in several conferences, or had other contacts with Frambu during the two year study period, so we had to be sure that they knew exactly which conference they were asked about. To ensure the answer was related to one specific conference, they received an e-mail with information about the date and the diagnosis of the person the conference was about. A reminder was sent electronically after fourteen days.

Most of the videoconferences were conducted from September 2009 to March 2010. This period represents 77 of the 113 informants. In 2008, there were 21 informants that had participated in videoconferences. The data collection was done in the retrospective and started in October 2009.

When the conference were conducted

		Modality		Total
		Video-conference	face-to-face	
When did the conference take place?	2008 – January	1	8	9
	2008 - February	0	4	4
	2008 – March	3	9	12
	2008 - April	5	5	10
	2008 – May	4	10	14
	2008 - June	1	6	7
	2008 - September	2	10	12
	2008 - October	3	14	17
	2008 - November	2	9	11
	2008 - December	0	4	4
	2009 - January	3	8	11
	2009 – February	0	7	7
	2009 - March	1	23	24
	2009 - April	9	9	18
	2009 – May	1	7	8
	2009 - June	0	13	13
	2009 – July	0	1	1
	2009 - August	1	11	12
	2009 - September	6	4	10
	2009 - October	21	33	54
	2009 - November	8	10	18
	2009 - December	22	5	27
	2010 – January	0	10	10
	2010 - February	18	9	27
	2010 - March	2	8	10
Total		113	237	350

Table 3: Monthly distribution of when the informants participated in the conferences they assessed. 25 informants (6.7 %) did not answer this question.

Diagnoses

The list gives an overview of how the distribution of informants was related to different diagnoses. The participants in face-to-face conferences have answered in

relation to 22 (N=227) different rare disorders, while the participants in videoconferences have answered in relation to 15 (N=103) different disorders. 45 participants (12 %) are missing, because they did not state the name of the diagnosis. The highest number is from conferences related to DiGeorge syndrome (22q11 deletion syndrome), with 35 informants from as much as seven videoconferences.

The diagnosis represented in the clinical conferences

		Modality		
		Video-conference	Face-to-face	Total
Diagnosis	Angelman syndrome	12	22	34
	Cri-du-chat syndrome	0	7	7
	DiGeorge syndrom	32	3	35
	Duchenne muscular dystrophy	0	4	4
	Dystrophy myotonica/CMT/LimbGirdle	4	15	19
	Fragile x Syndrome	1	9	10
	Klinefelter syndrome	14	10	24
	Klippel-Trenaunay syndrome	0	3	3
	Mitochondrial Diseases	0	6	6
	Progressive neurological diseases	6	6	12
	Neurofibromatosis, type 1	11	9	20
	Noonan syndrome	2	13	15
	Prader-Willi syndrome	6	47	53
	Rett syndrome	0	5	5
	Rubinstein-Taybi syndrome	0	8	8
	Smith-Magebus syndrome	6	13	19
	Sotos syndrome	1	8	9
	Rare Chromosome disorders	1	9	10
	Turner syndrome	5	10	15
	Williams syndrome	2	20	22
	Total	103	227	330

Table 4: Table showing the number of informants related to each of the diagnosis. 45 participants (12 %) did not state the name of the diagnosis.

Geography

It is no link between the particular conference and the informants; therefore it is not possible to know exactly which conferences the particular informants are related to. To get the most correct distributing of the conferences in the health regions (Figure 8), only answers from clients are included. Related to each conference, only two clients were present, why the number of providers could vary a lot.

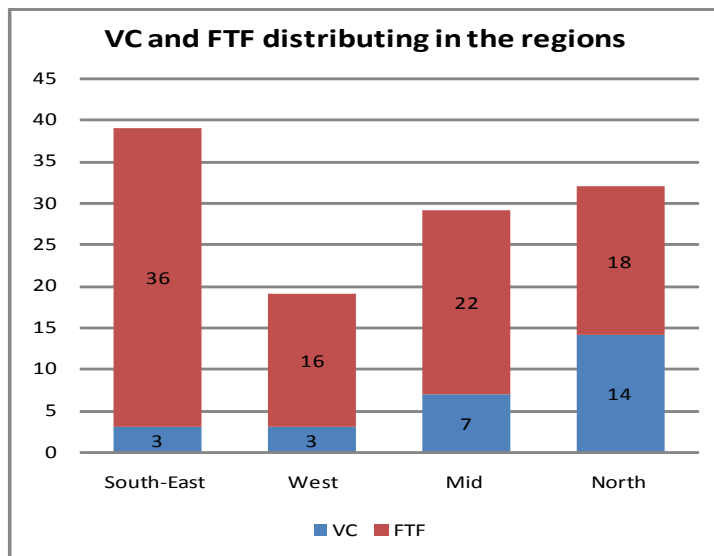


Figure 8: In this figure the distribution between the counties are shown. It is based on the clients' answers (N = 118), 4 (3.3%) are missing.

The counties in northern Norway have the highest proportion of informants from videoconferences, Nordland 34.6% (N = 9) and Troms 19.2% (N = 5). Their proportion of face-to-face conferences are 6.5 % and 8.7 %. Face-to-face conferences are most frequently conducted in Akershus 15.2 % (N = 14) and Oslo 8.7 % (N = 8). In these counties no videoconferences were conducted.

Age

The mean age of the individuals with the disorders, is 13 years both in videoconferences and in face-to-face conferences.

Age of the individuals with the disorder

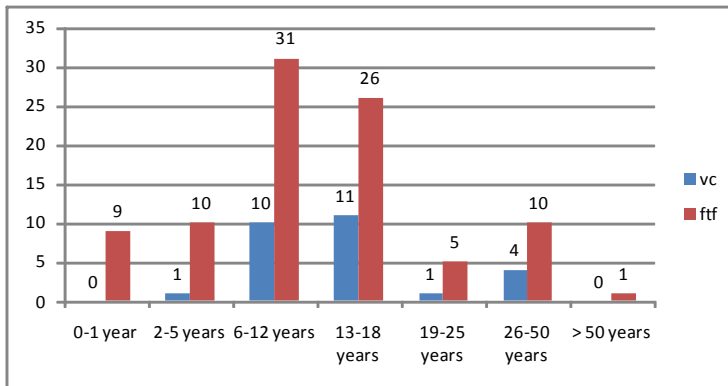


Figure 9: Graph showing age of the person with disorder (N = 119, 3 are missing). The mean age was 13 years. This is based on information from clients.

The spread of age of the person with the disorder, seem to follow the same pattern for videoconferences and face-to-face conferences. The highest numbers of patients are in the age groups from 6 to 18 years. However, when the conferences regarded children younger than one year, all were conducted as face-to-face conferences.

Age of the informants (all categories included)

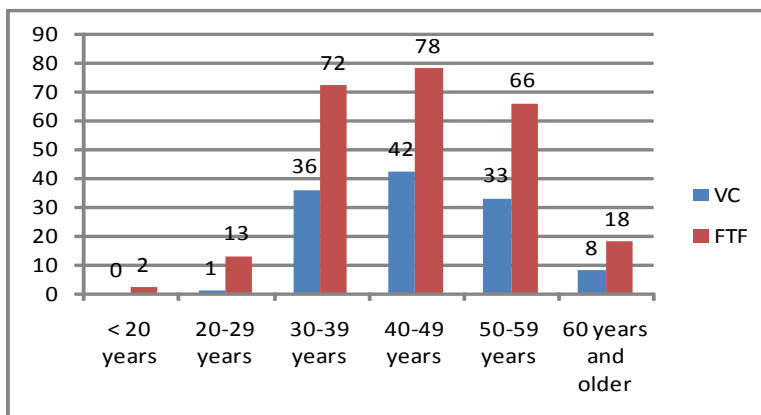


Figure 10: Graph showing age of the informants (N=371, 4 are missing)

The informants are between 20 and 60 years, with the highest amount in the group 40-49 years. The mean age is 39 years. The distribution seems to be equal for participants in videoconferences and face-to-face conferences.

Profession of the participating service providers

The informants represent professionals from different sectors; education, health and welfare, and they also represented both the local and the regional level. When looking at the distribution of the providers' profession, nearly 40 % were teachers or special teachers working in school or kindergarten. The second most frequent profession was milieu therapists and assistants, which amount to 10 %. They work in the clients' home or in school and kindergarten. 8% of the informants were health visitors or nurses.

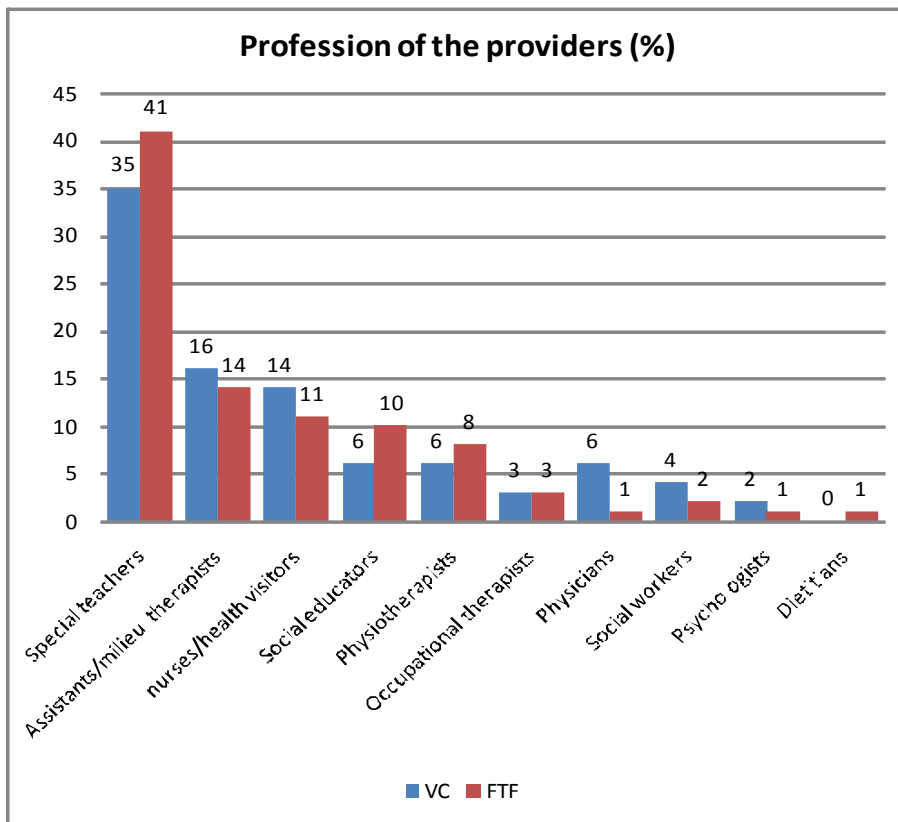


Figure 11: Table showing the profession of the providers (N = 253). Professionals from schools and kindergartens are in majority with 38.7%.

There are some differences between videoconferences and face-to-face conferences. There was a higher number of educational professionals in the face-to-face conferences than the videoconferences (41 % vs. 35 %), while physicians were more often present in videoconferences than in face-to-face conferences (6 % vs. 1%).

Relation to Frambu

Most of the clients had a previous relation to Frambu whether they participated in videoconferences or face-to-face conferences (

Figure 12). The numbers of clients without previous experience with Frambu were 3 (11 %) in videoconferences and 13 (14 %) in face-to-face conferences. The providers were new to Frambu in 57 % of both the videoconferences and the face-to-face conferences. For the Frambu-providers, this question regarded whether the client they met had previous experience with Frambu.

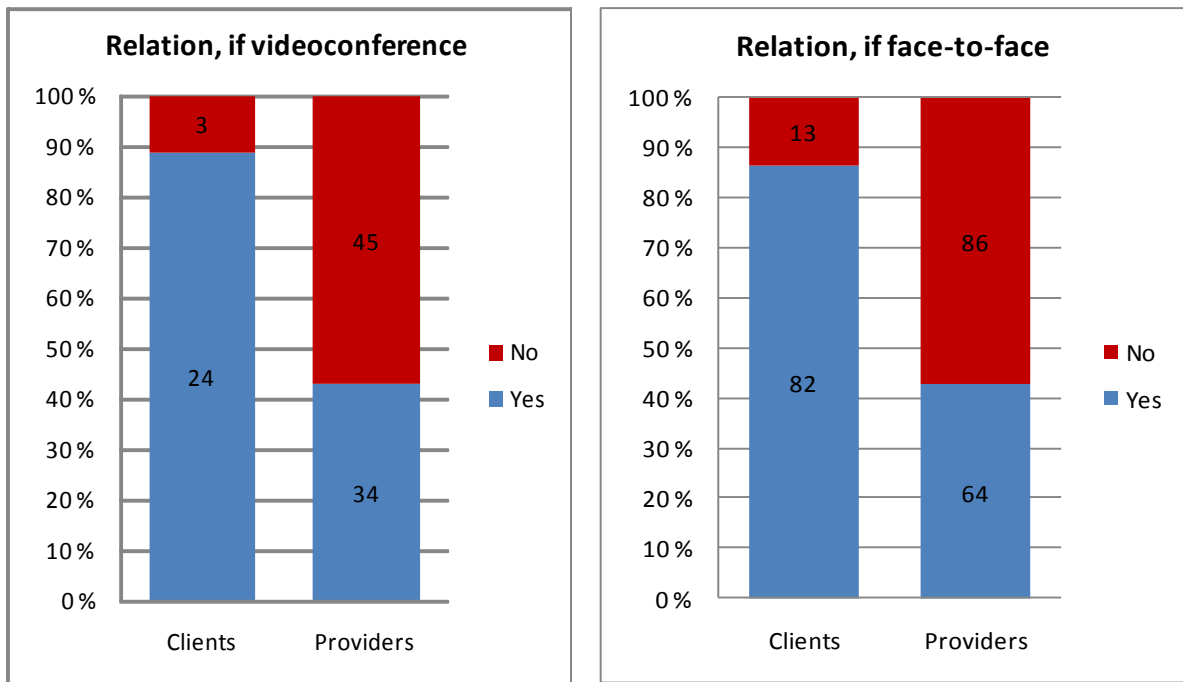


Figure 12: Graph showing previous relation to Frambu related to VC and FTF.

Figure 13 shows what sort of relation the different participants had. 74 % of the clients in videoconferences and 66 % of the clients in face-to face conferences had participated in a 5 day family course at Frambu. Almost one third (30 %) of the clients in the face-to-face conferences had already participated in at least one earlier conference. For videoconferences, this amount was somewhat lower, 22 % had participated in a face-to-face conference earlier. 4 % of the clients in videoconferences had participated in a videoconference with Frambu earlier, while 10 % of providers in videoconferences had already that experience related to Frambu. For the face-to-face conferences, only 1 % of the providers had participated in a videoconference with Frambu earlier.

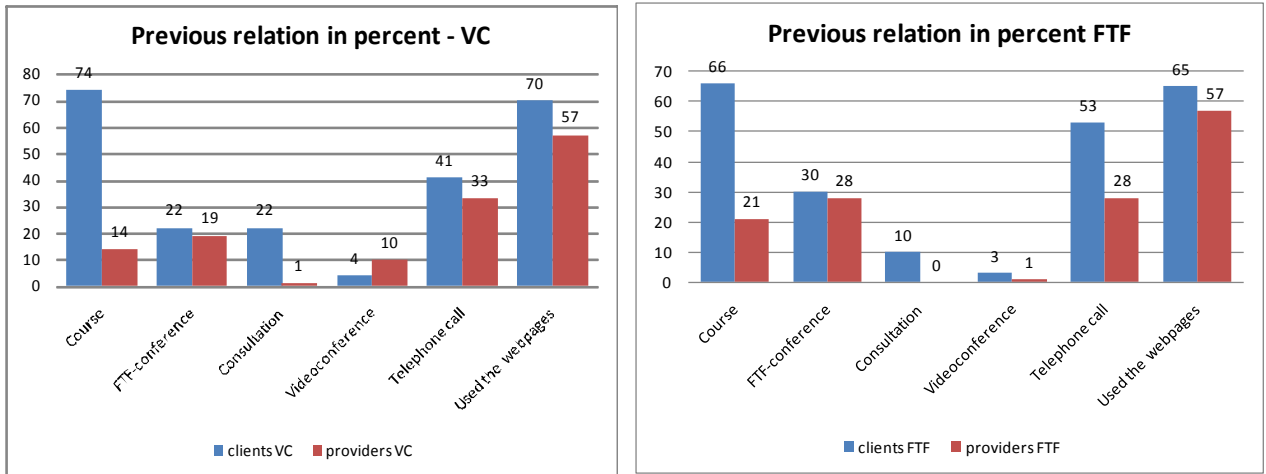


Figure 13: Two graphs that show what sort of previous relation to Frambu the different participators had. Most of the clients had participated in one or more courses at Frambu.

Videoconferences vs. Face-to-Face Conferences

The geographical distribution of the videoconferences illustrates that the majority of the videoconferences were held in the local communities with longest distance to Frambu.

In videoconferences, the average number of participants was 3.06, while in face-to-face conferences it was 1.62.

Topics for the Meeting

Nine topics were listed in the questionnaire, and the informants were allowed to choose up to three choose up to three alternatives. The results are shown in

Figure 14.

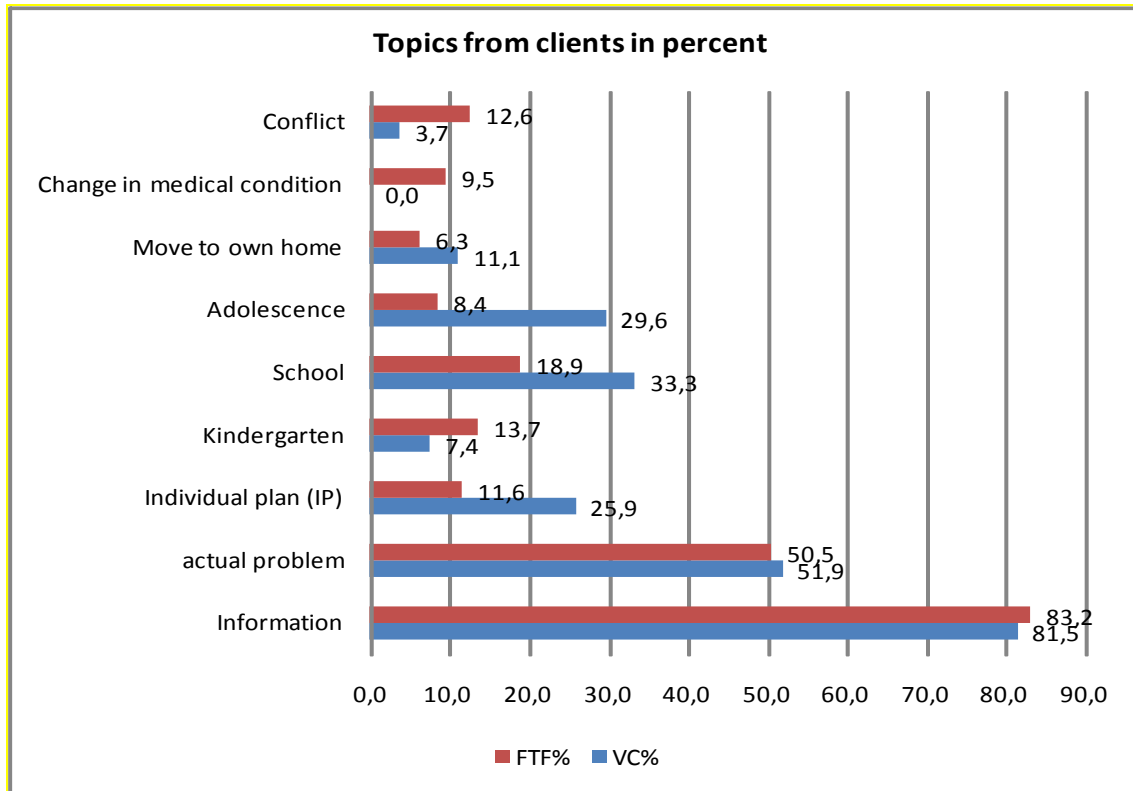


Figure 14: Main topics in the conferences. The informants were allowed to choose until three topics, therefore each topic must be assessed separately. The percentages are suited to compare VC to FTF related to each topic.

The two most frequently chosen topics “information about the diagnosis” and “discussing a current problem”, is quite equally chosen. These topics are overall the most frequent reason for the conferences, independent of modality. The percentage for videoconferences was higher when the topics were about school and adolescence and individual plan (IP), while it was higher for face-to-face conferences when the topics were kindergarten, change in the medical condition and if there were some disagree or conflict between the clients and the local service providers.

Analysis of Association

The clients answered to 15 of the statements, the local service providers answered to 13, and the providers from Frambu answered to 11 of the statements. Only the clients got statements about how they experienced being taken care of by the service providers.

Overview over Median Scores for All Statements

How did you experience the conference?	VC Clients		VC Providers		VC Frambu		FTF Clients		FTF Providers		FTF Frambu	
	N	Median	N	Median	N	Median	N	Median	N	Median	N	Median
1 - The atmosphere at the conference was relaxed	26	4,5	78	4	15	5	94	5	15	5	7	4
2 - I could talk freely with the specialists	26	4					94	5				
3 - I felt well taken care of by the professionals at the conference	26	5					93	5				
4 (Reversed) - I felt that the professionals were talking "above my head"	24	5					93	5				
5 - I got answers to my questions			78	4	15	5			151	5	7	4
6 - I made comments and asked questions	26	4,5	77	4			93	5	149	4		
7 - I got questions and/or direct requests that I replayed to	26	5	77	4	15	5	93	5	149	4	6	5
8 (Reversed) - Frambu's professional contribution did not live up to my expectations	26	5	77	5	15	5	92	5	150	5	6	4
9 (Reversed) - More professionals from Frambu should have participated	26	4,5	75	5	15	4	93	4	150	4	6	5
10 - Frambu's professionals contributed to solving the tasks we wanted	26	4	77	4	16	4	93	4	151	4	6	4
11 (Reversed) - The role of Frambu at the conference was unclear to me	25	5	77	5	15	5	93	5	151	5	6	4,5
12 - The service providers from the Municipality and from Frambu cooperated well at the conference	26	4	78	5			93	4	151	5		
13 - We had a good dialogue at the meeting	26	5	77	5	16	5	94	5	151	5	7	4
14 (Reversed) - I felt uncomfortable	26	5	77	5	16	5	92	5	150	5	6	5
15 - The break(s) contributed to valuable talks	26	4	73	4	14	4,5	89	4	143	3	5	3
16 - I am satisfied with the benefit of the conference	26	5	78	5	16	5	94	5	150	5	6	4

Table 5: Overview over median score of all statements from clients, providers, and providers from Frambu. The questionnaire had a five items Likert scale: 1= strongly disagree, 2 = disagree, 3= neither agree nor disagree, 4 agree and 5 = strongly agree. Statement 8, 9, 11, and 14 are reversed because they were negative in the questionnaire.

Table 5 indicates that the median scores are close to equal for all categories of informants, and independent of the modality of the conference. All statements were tested with a chi-square test, and there were no significant differences in how the different groups (clients, local providers, and providers from Frambu) responded.

Four hypotheses were posed in this study, regarding the topic satisfaction, and it was suitable to reduce the set of variables (see Table 5) to be able to do variance analysis. Therefore, all item scores were entered into an exploratory factor analysis. Latent components were extracted using the principal component method, thus maximizing explained variance. Using the Kaiser's criterion the analysis extracted two components with an eigenvalue above > 1 . As the correlation between the two latent components was small, the factor solution was orthogonally rotated with the Varimax procedure. The two components explained 51.7 percent of the total observed variance, which indicates an acceptable factor model. The component loadings, which indicate how strongly each item measures the respective latent component, is presented in Table 6 and visually illustrated in the factor plot in Figure 15.

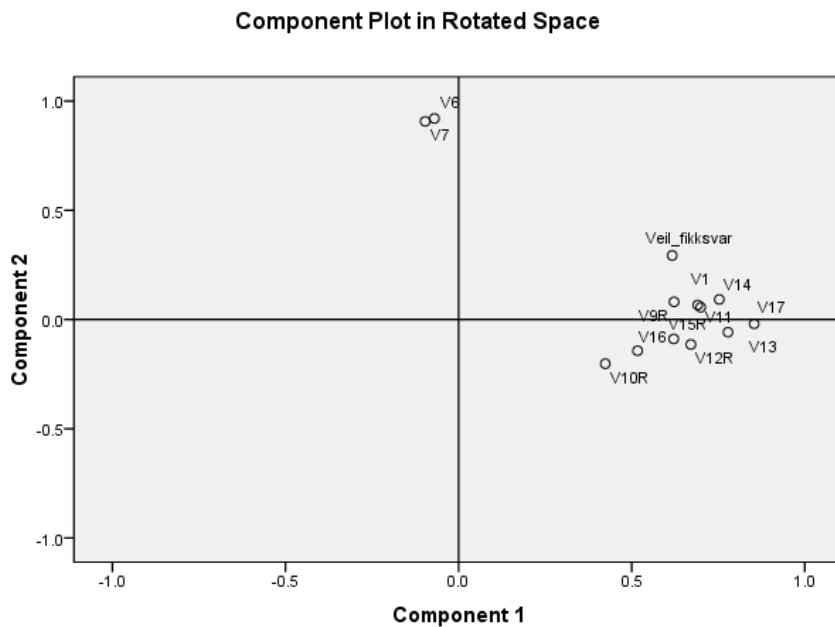


Figure 15: Graphical view of the factor analysis showing that the variables divided into two groups with Varimax rotation.

Rotated Component Matrix^a

	Component	
	1	2
V17 - I am satisfied with the benefit of the conference	.839	
V14 - We had a good dialogue at the meeting	.768	
V13 - The service providers from the Municipality and from Frambu cooperated well at the conference	.762	
V1 - The atmosphere at the conference was relaxed	.707	
V11 - Frambu's professionals contributed to solving the tasks we wanted	.693	
V12R(Reversed) - The role of Frambu at the conference was unclear to me	.644	
V9R (Reversed) - Frambu's professional contribution did not live up to my expectations	.627	
V15R(Reversed) - I felt uncomfortable	.614	
V16 - The break(s) contributed to valuable talks	.490	
V10R(Reversed) - More professionals from Frambu should have participated	.390	
V6 - I made comments and asked questions		.902
V7 - (All) I got direct questions that I replied to		.891

Extraction Method: Principal Component Analysis.
 Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 3 iterations.

Table 6: The component loadings of the factor analysis. Component no. 1 is constituted by ten items, while component no. 2 is constituted by two items.

The largest and most important component constituted a linear combination of ten variables assessing the participant's satisfaction with the conference. The smallest component, comprising only two items, indicates whether the participant's had or used the opportunity to make comments and ask questions during the conference.

Hypothesis no. 1: "Professionals and clients participating in videoconferences are as satisfied as those who participated in co-located clinical conferences (face-to-face)". Regarding the first hypothesis of this study, the components "satisfaction" and

“response” were tested with variance analyses to see what effects the independent variables modality (vc vs. ftf) and informant category had on the dependent variables.

The variance analysis, which was done to see the effect of modality on the component “satisfaction” (Sumscore Satisfaction 10 items), showed that the mean value for videoconferences was 4.36 and for face-to-face conferences 4.29 (p-value = 0.332) (Table 7). The same analysis was done to see the effect of the informant category and showed that the mean value for clients was 4.28 while the mean value for the local providers was 4.33 (p-value 0.475) (Table 8).

The effect of the service modality (VC vs. FTF) on the factors “response” and “satisfaction”

Descriptives

		N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum	Between-Component Variance
						Lower Bound	Upper Bound			
Sumscore Response 2 items	videoconference	103	3.7184	1.30735	.12882	3.4629	3.9740	1.00	5.00	
	face-to-face	240	4.1646	.99738	.06438	4.0378	4.2914	1.00	5.00	
	Total	343	4.0306	1.11663	.06029	3.9120	4.1492	1.00	5.00	
	Model	Fixed Effects			1.09930	.05936	3.9139	4.1474		
	Random Effects				.23740	1.0141	7.0471			.09114
Sumscore Satisfaction 10 items	videoconference	94	4.3628	.55280	.05702	4.2495	4.4760	1.80	5.00	
	face-to-face	227	4.2890	.64507	.04281	4.2046	4.3734	1.90	5.00	
	Total	321	4.3106	.61954	.03458	4.2426	4.3786	1.80	5.00	
	Model	Fixed Effects			.61959	.03458	4.2426	4.3786		
	Random Effects				.03458 ^a	3.8712 ^a	4.7500 ^a			-.00017

a. Warning: Between-component variance is negative. It was replaced by 0.0 in computing this random effects measure.

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
Sumscore Response 2 items	Between Groups	14.345	1	14.345	11.870	.001
	Within Groups	412.084	341	1.208		
	Total	426.429	342			
Sumscore Satisfaction 10 items	Between Groups	.362	1	.362	.943	.332
	Within Groups	122.462	319	.384		
	Total	122.824	320			

Table 7: Descriptive data of the two sumscores related to the service modalities videoconferences and face-to-face conferences (upper). This one-way ANOVA shows a significant effect of the informant category on the factor “response”, but no effect on the factor “satisfaction” (lower).

The effect of the informant categories on the factors "response" and "satisfaction"

Descriptives

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum	Between-Component Variance	
					Lower Bound	Upper Bound				
Sumscore Response 2 items	Clients	119	4.3025	.97906	.08975	4.1248	4.4803	1.00	5.00	
	Provider	224	3.8862	1.15957	.07748	3.7335	4.0388	1.00	5.00	
	Total	343	4.0306	1.11663	.06029	3.9120	4.1492	1.00	5.00	
	Model			Fixed Effects	.05942	3.9137	4.1475			
			Random Effects	.21603	1.2857	6.7756			.07889	
Sumscore Satisfaction 10 items	Clients	112	4.2768	.67343	.06363	4.1507	4.4029	1.80	5.00	
	Provider	209	4.3287	.58952	.04078	4.2483	4.4091	1.90	5.00	
	Total	321	4.3106	.61954	.03458	4.2426	4.3786	1.80	5.00	
	Model			Fixed Effects	.62001	.03461	4.2425	4.3787		
			Random Effects	.03461 ^a	3.8709 ^a	4.7503 ^a			-.00129	

a. Warning: Between-component variance is negative. It was replaced by 0.0 in computing this random effects measure.

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
Sumscore Response 2 items	Between Groups	13.472	1	13.472	11.125	.001
	Within Groups	412.956	341	1.211		
	Total	426.429	342			
Sumscore Satisfaction 10 items	Between Groups	.197	1	.197	.511	.475
	Within Groups	122.627	319	.384		
	Total	122.824	320			

Table 8: Descriptive data of the two sumscores related to the informant categories client and provider (upper). This one-way ANOVA shows a significant effect of the informant category on the factor "response", but no effect on the factor "satisfaction" (lower).

These one-way ANOVA analyses showed no significant effect of informant category or modality on the component "satisfaction", therefore a two-way ANOVA analysis was performed (Table 9). Since we had two dependent variables, we had to analyse if there was a significant effect of interaction with the two independent variables (modality and informant category) when they were tested on the dependent variable (sumscore of satisfaction). No effect of the interaction between modality and informant category was found (p-value =0.557).

There were not found significant differences in clients' and providers' assessment of videoconferences vs. face-to-face conferences, as postulated in hypothesis no. 1, and this hypothesis is supported.

Tests of Between-Subjects Effects: "Satisfaction"

Dependent Variable: Sumscore Satisfaction 10 items

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	.638 ^a	3	.213	.552	.647	.005
Intercept	4065.962	1	4065.962	10548.794	.000	.971
Informant category	.259	1	.259	.672	.413	.002
Modality (VC_FTF)	.128	1	.128	.332	.565	.001
Informant category * modality (VC_FTF)	.133	1	.133	.346	.557	.001
Error	122.186	317	.385			
Total	6087.390	321				
Corrected Total	122.824	320				

a. R Squared = ,005 (Adjusted R Squared = -,004)

Table 9: Two-way ANOVA with sumscore satisfaction as dependent variable was tested for interaction with the two independent variables modality and informant category.

Tests of Between-Subjects Effects: "Response"

Dependent Variable: Sumscore Response 2 items

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	26.854 ^a	3	8.951	7.594	.000	.063
Intercept	3781.068	1	3781.068	3207.863	.000	.904
Informantcategory	12.435	1	12.435	10.550	.001	.030
VC_FTF	5.674	1	5.674	4.813	.029	.014
Informantcategory * VC_FTF	2.237	1	2.237	1.898	.169	.006
Error	399.575	339	1.179			
Total	5998.750	343				
Corrected Total	426.429	342				

a. R Squared = ,063 (Adjusted R Squared = ,055)

Table 10: Two-way ANOVA with sumscore respons as dependent variable was tested for interaction with the two independent variables modality and informant category.

However, for the component "response", both the effect of informant category and modality is significant. Clients' mean value was 4.30, while providers' was 3.89 (p-value 0.001) (Table 8). Testing for the effect of modality (videoconference vs. face-to-face)

showed that the mean value in videoconferences was 3.72 and in face-to-face conferences 4.16 (p-value = 0.001) (Table 7). The clients gave a higher score to the two statements "I made comments and asked questions" and "I got questions that I answered to" than the providers, and the participants in face-to-face conferences gave higher score than participants in videoconferences. A two-way ANOVA was performed (Table 10) to see if there was a significant effect of interaction with the two independent variables (modality and informant category) when they were tested on the dependent variable (sumscore of response). Though there were significant effects of both modality and informant category, there was no effect of the interaction between them.

These results, related to the factor response, were not seen as important for interpreting the topic satisfaction and were of less importance for the hypothesis.

Hypothesis no. 2: "The clients and their next of kin are more satisfied than the professionals with clinical conferences conducted as videoconferences".

The results of a variance analysis (one-way ANOVA) of possible effects on satisfaction by the informant category, where only the participants in videoconferences were included, did not show significant differences in how clients and providers assess the satisfaction statements in the questionnaire. Clients' mean value was 4.28, while providers' was 4.39 (p = 0.362) (Table 11). Based on this analysis, the second hypothesis was not supported.

However, there was a significant difference in the effect of informant category on the dependent variable response. The mean value from the clients was 4.21 and from the providers 3.55 (p-value = 0.025) (Table 11). The variable response is seen as an indication on the activity during the conferences, and not as a predictor for satisfaction, and it is not relevant for hypothesis no. 2.

The effect of informant category on the factors “satisfaction” and “response” when only videoconferences are included

		N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
						Lower Bound	Upper Bound		
Sumscore Satisfaction 10 items	Clients	25	4.2760	.68208	.13642	3.9945	4.5575	1.80	5.00
	Provider	69	4.3942	.49997	.06019	4.2741	4.5143	2.80	5.00
	Total	94	4.3628	.55280	.05702	4.2495	4.4760	1.80	5.00
Sumscore Response 2 items	Clients	26	4.2115	.91840	.18011	3.8406	4.5825	1.50	5.00
	Provider	77	3.5519	1.38028	.15730	3.2387	3.8652	1.00	5.00
	Total	103	3.7184	1.30735	.12882	3.4629	3.9740	1.00	5.00

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
Sumscore Satisfaction 10 items	Between Groups	.256	1	.256	.838	.362
	Within Groups	28.163	92	.306		
	Total	28.420	93			
Sumscore Response 2 items	Between Groups	8.456	1	8.456	5.149	.025
	Within Groups	165.879	101	1.642		
	Total	174.335	102			

Table 11: One-way ANOVA testing effects of informant category on the variables satisfaction and response. Only videoconferences are included.

Hypothesis no. 3: “Younger participants are more satisfied than older participants with clinical conferences conducted as videoconferences”.

A correlation analysis was done to see if there was a relationship between the variables for satisfaction and response and the participants’ age. Pearson’s correlation coefficient was used to understand the variance between the two variables. The correlations between age and satisfaction and response were both non-significant, and the third hypothesis was not supported.

Correlations between age, satisfaction, and response

		Age of the participant	Sumscore Response 2 items	Sumscore Satisfaction 10 items
Age of the participant	Pearson Correlation	1.000	-.046	.005
	Sig. (2-tailed)		.645	.964
	N	120	102	93
Sumscore Response 2 items	Pearson Correlation	-.046	1.000	.081
	Sig. (2-tailed)	.645		.439
	N	102	103.000	94
Sumscore Satisfaction 10 items	Pearson Correlation	.005	.081	1.000
	Sig. (2-tailed)	.964	.439	
	N	93	94	94

Table 12: Pearson’s correlation between the age of the participants and the variables satisfaction (sumscore) and response (sumscore), were both non-significant. Only participants in videoconferences were included.

Hypothesis no. 4: “Participants with former experience with videoconferences are more satisfied than first time participants”.

Of the participants in the videoconferences (N = 122), 61 % had former experience with the modality. Independent samples t-test was done to compare the score of the variable satisfaction between the two groups of participants from videoconferences; those with former experience to those without former experience. Student’s t-test (independent samples t-test) was performed and showed a mean score for experienced participants of 4.37. The inexperienced scored 4.35 on satisfaction (p -value = 0.824), which showed no significant difference between the experienced and the inexperienced participants in the videoconferences. The fourth hypothesis is not supported.

Group Statistics: experienced participants vs. inexperienced (only videoconferences)

	Prev. experience	N	Mean	Std. Deviation	Std. Error Mean
Sumscore Response 2 items	Ja	57	3.7105	1.17999	.15629
	Nei	46	3.7283	1.46328	.21575
Sumscore Satisfaction 10 items	Ja	51	4.3745	.55312	.07745
	Nei	43	4.3488	.55864	.08519

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Sumscore Response 2 items	Equal variances assumed	4.349	.040	-.068	101	.946	-.01773	.26039	-.53428	.49881
	Equal variances not assumed			-.067	85.666	.947	-.01773	.26641	-.54737	.51190
Sumscore Satisfaction 10 items	Equal variances assumed	1.039	.311	.223	92	.824	.02567	.11504	-.20280	.25415
	Equal variances not assumed			.223	89.031	.824	.02567	.11514	-.20310	.25445

Table 13: Independent samples t-test showed no significant difference between the experienced and inexperienced participants' score of the factor satisfaction.

Technology Statements

Participants in videoconferences got seven additional questions about how they experienced the technology, how they felt about talking to the camera and whether they considered videoconference to be a useful tool in such meetings.

Clients and providers were significantly more positive than the providers from Frambu with regard to the technical aspects of the videoconferences. They gave higher score to the audio and video quality. Both clients and providers rated their comfort or discomfort in talking to camera almost equally. Nearly half of the clients and the providers did not feel any discomfort "talking to the camera". The providers from Frambu rated a higher degree of comfort in this statement (Table 14).

Technology Confidence	Clients		Providers		Providers Frambu		χ^2
	N (% agree)	N (disagree)	N (% agree)	N (disagree)	N (% agree)	N (disagree)	
I could clearly see the faces of the professionals from Frambu (visually clear)	22 (92%)	2 (8)	64 (88)	3 (4)	7 (47)	6 (40)	0,001
I could easily hear what was said (aurally clear)	24 (100)	0 (0)	66 (92)	1 (1)	10 (67)	5 (33)	<0,005
I did not like talking to the camera/screen	5 (22)	12 (52)	17 (24)	31 (44)	3 (20)	10 (67)	0,377
I would have preferred a conference where Frambu's professionals had come to us (face-to-face)	15 (65)	2 (9)	16 (22)	34 (47)	1 (7)	13 (87)	<0,005
Videoconferences are well suited for such meetings	16 (83)	1 (4)	59 (82)	6 (8)	12 (80)	1 (7)	0,44
I think I will be comfortable with videoconferencing after more experiences			47 (65)	5 (7)	12 (92)	0 (0)	0,037
All together, the videoconference was a positive experience	23 (96)	1 (4)	62 (86)	1 (1)	14 (93)	1 (7)	0,39

Table 14: Statements related to technology confidence for the participants in videoconferences. The scale is reduced from five to three items by merging “strongly disagree” and “disagree” into one item and “strongly agree” and “agree” into one item to emphasize possible differences. The table shows the percent of the participants in the videoconferences that agreed or disagreed. The same visualization was chosen in a similar study (16). In this table, providers from Frambu rated the audio and the video quality significantly lower than the other participants.

Most of the clients would have preferred a face-to-face conference (65 %), while half of the local providers (47 %) and almost all the providers from Frambu (87 %) disagreed with that statement. All but one in each of the informant categories agreed that “the videoconference was a positive experience”.

Comments in Free Text

The last question was open, inviting the informants to give further comments. Some of the comments, reflecting variations in opinions and experiences, are found in appendix no. 6.

Discussion

The aim of this study was to compare the users' assessments of two different modalities of encountering, in the ambulatory consulting service of a resource centre for rare disorders. Face-to-face conferences, where providers from Frambu travel to the municipality to meet the client (including relatives), the local providers, and often providers from the specialized health service, have a long tradition at Frambu. Since 2007, Frambu has been capable of performing videoconferences as a modality for this service. The users are clients and providers.

Methods

I chose to perform a descriptive study based on questionnaires, partly in order to compare the results with prior studies from other settings. Some of the statements have been used in previous studies and will be discussed related to them later. There exist some questionnaires for telemedicine that are validated, but they are made for measuring satisfaction in more traditional doctor-patient relations (45-47). They did not fit into the context of the ambulatory consulting services, and it was therefore necessary to create a questionnaire tailored to this specific study. This might be a weakness of the study, since the questionnaire has not been validated before. In former studies that were comparable to this one, the researchers also had to develop their own questionnaires (14, 16, 19).

The sample size caused some limitations for this study. The number of videoconferences was small, and though Frambu had an increased focus on and support to the use of videoconferences in the autumn of 2009, the final number of videoconferences that was included in the study was 19. This resulted in 122 informants divided on 27 clients and 95 providers that had participated in such conferences.

Informants

The initial estimate of the ambulatory consulting services that could be included in the study was: 27 videoconferences and 210 co-located conferences. In each conference, the typical number of participants would be two clients and ten providers.

It was more demanding than expected to gather the desired level of informants. It was especially the group of clients participating in videoconferences that was problematic. After searching for informants among participants in the ambulatory consultation service during 2008 and 2009, there were fewer informants than expected, and the collection period was extended with three months until the end of March 2010.

I started the search for informants in August 2009. Therefore, finding the informants for this study required both searching in Frambu's client records and a follow-up of Frambu's ambulatory consulting service during the autumn of 2009 and from January to March 2010.

To get in contact with possible informants was more demanding than expected. Frambu had registered the names of the clients and their relatives, but when it came to the local professionals that had participated in the conferences, they were only counted and names had not been recorded. Tracing them depended on three steps: first, identifying who was the local contact person, and second, getting in touch with him or her. The third and most demanding step was reconstructing the list of participants, finding their mail-addresses, and sending them to Frambu. If Frambu wants to do further research in this context, I recommend registering all participants immediately.

Response Rate

The response rate for the clients was lower than desirable. One reason might be that for many of the participants, the consultation they were asked to assess was nearly two years back in time. After such a long time, one might feel uncertain about the

details. Clients were only contacted by mail, and only one written reminder was given. The response rate was considerably higher when the questionnaires were sent only a week after the conference, than for those conducted several months earlier. This probably explains why the response rate for clients in videoconferences is higher than in face-to-face conferences (63 % vs. 45 %), because half of the videoconferences were conducted in the autumn 2009.

In the autumn of 2009, Frambu increased the focus on conducting videoconferences, and therefore organized a support service to help the professionals both in the planning and the performance of the videoconferences. The support was well received, and might explain to a certain extent why the providers at Frambu were more comfortable talking to the camera than the local service providers.

Study Group and Control Group

The ideal design to test the effect of videoconferences vs. face-to-face conferences would have been to make two equal groups of the two modalities, and randomize which conferences should be held as face-to-face conferences or videoconferences. This was not possible within the frame of this master's study. The face-to-face conference is a well-known and highly demanded service, while videoconference is a new method provided by the resource centre. The manager of Frambu challenged the staff to increase the number of videoconferences.

When the client or the local providers requested a clinical conference, this request was discussed and considered by one of the three multidisciplinary teams at Frambu. These teams covered health, welfare, and educational professionals. They decided what kind of services was the most suitable for the request. Frambu has guidelines for co-located meetings, but not yet for videoconferences. The choice of modality was probably to some extent influenced by the different experiences and attitudes of the

three teams. One of the teams was more eager to choose videoconferences than co-located conferences compared to the others. Some people seem to have a clear opinion about when videoconference is suited. However, the results from this study show that when it comes to daily practice, the practical and resource arguments are given considerable weight.

Although Frambu had no guidelines for when to choose videoconference as modality for a clinical conference, the results of the study suggest that three topics were emphasized in assessment in the multidisciplinary teams:

1. Do the clients have a relation to Frambu?

According to the results of the study, we can assume that most of the professionals at Frambu thought that the first meeting with the clients should be face-to-face. As seen in

- 2.** Figure 12, 3 (N = 27) of the client informants from videoconferences had never met professionals from Frambu earlier, while the other 17 had either participated in a course or in a face-to-face conference earlier. The results also showed that most of the client informants from face-to-face conferences had met professionals from Frambu earlier, only 13 (N = 95) had not. Though the number is low, the results indicate that a previous relation in the form of a face-to-face meeting is not a premise for conducting a videoconference.

3. What are the topics for the conference?

The most often reported topic of the conferences was “information about the disease” (82 % VC and 83% FTF). The second most often discussed topic was “discussing an actual topic” (VC 52%, FTF 51%). There was no difference in the choice of modality related to these topics. Seemingly, face-to-face conference was used more often (14% vs. 7%) when the topic was a request for support in the kindergarten). Additionally, if there were problems or conflicts between the family and the local providers (often schools), face-to-face conference was used

most often (13% FTF and 4% VC). However, videoconference was the most used modality when the requests were related to challenges in the school (35% VC and 19% FTF), adolescent client (30%VC and 8% FTF), and the clients' Individual Plan (IP)(26% VC and 12% FTF), videoconferences was the most used modality. As the topic for the conference was emphasized as a limitation(12) for the use of videoconferences (12), these results are worth reflecting on.

4. Is there capacity to travel within an acceptable time frame?

The demand for outreach conferences was skewed, with more pressure on one of the multidisciplinary teams. This team conducted most of the videoconferences; 10 of a total of 19. The other teams conducted 4 and 5 videoconferences. An increased workload seemed to contribute to raising the motivation to decrease the number of travels and provide videoconferences as an alternative. Related to this topic, the results showed that 54 % of the videoconferences and 20 % of the face-to-face conferences were conducted in the North Health Region. In the South-East Health Region, it was quite the opposite; 8 % of the videoconferences and 40 % of the face-to-face conferences were conducted there.

Though the choice of videoconferences was made by the multidisciplinary teams based on their interpretation of the requests from the clients or the local service providers, practical and resource considerations had a considerable influence on the discussion. The descriptive data from both the videoconferences and the face-to-face conferences show that the previous relation to Frambu, the age of the informant and of the individual with the disorder, and the topics of the conference were quite similar in both modalities.

The Role of the Researcher

As employed at Frambu, I had both advantages and disadvantages with respect to conducting this study. The main advantages were knowledge about the centre and the field of rare disorders, and access to staff at Frambu. It has been possible for me to talk to everyone, and I have been regarded more as a colleague than a researcher. Therefore, I also got useful information about how they interpreted the two modalities. The disadvantage was that as an insider, I risked being too enthusiastic and thereby decreasing my critical view. I am conscious about this pitfall and have to the best of my ability emphasized all findings that could be of importance, whether they were in favour of videoconferences or face-to-face conferences.

Theoretical Framework (TAM)

The two determinants in TAM, perceived usefulness and perceived ease of use, were described by Fred Davis in 1989 (34). TAM has been the theoretical framework for a lot of studies, also in videoconferencing, and I found the theory useful as a theoretical framework of my study.

TAM has been discussed, developed and extended as described in the theoretical framework chapter (page 16). The core message of the theory is that people have to experience usefulness and ease of use to accept and make use of a system. Although usefulness is predominant for ease of use, the system will be rejected by the users if there are too many obstacles in the practical use of the system. This can also be postulated like this: the ease of use must be ensured before the users will mind the utility value. Usefulness can be associated with concepts such as satisfaction and benefit. In the context of, a resource centre, where the staff is well educated specialists, the aspired benefit consists in transferring knowledge to clients and local providers in order to achieve increased mastering and quality of life for the clients and their relatives. Hence, the value of satisfaction for clients and local providers will be

perceived as central to the professionals that are responsible for delivering the ambulatory consulting service at the centre.

As to user satisfaction in this context, one has to take into account that there are three categories of users whose perception of the modality might be dissimilar: the staff at Frambu who provides the new service, the local providers, and the clients. The clients often have other expectations to the conference than the providers; they often bring along more emotions to the conferences than the professionals (11). The providers are a heterogeneous group. But in a study of physicians, Liu et al. (14) found that although the patients were satisfied, the physicians were less satisfied; one of the causes was that they had to make changes in their working routines. The authors concluded that doctors are struggling with patient communication in videoconferences, and they “suggest new training programs for doctors to develop improved communication skills and the ability to express empathy in telemedicine consultations”(page 227)(14). In the design of the study, TAM in its original form inspired med. TAM explains very well the technology acceptance from an individual perspective. However, the unified model of TAM, UTAUT, seems to illustrate more of the complex connections in an organizational perspective. I also found it suitable to discuss how the four core determinants of intention and usage in UTAUT can be recognized in my results.

- **Performance expectancy** is the most crucial determinant, as it covers the notion “perceived usefulness” from the earlier model of Davis. In this study, the rating of satisfaction reflected the performance expectancy. The assessment of satisfaction included several statements that directly measured the outcome of the conference. The result of this study showed that the participants in videoconferences and participants in face-to-face conferences were equally satisfied. This can increase the performance expectancy at Frambu, and as said by Venkatesh et al, “..believe that using the system will help to attain gains in job performance” (page 447) (42).

- **Effort expectancy** is analogous to the “ease of use” determinant from Davis (34) . Taking new technology into daily use demands that the system, in this respect videoconference, is easy to use. The attitude of how easy or bothersome participants interpret videoconferences to be, is related to former experience. This is visualized by the relatively higher amount of videoconferences conducted in the northern part of Norway, where videoconferencing is a much more common tool than in the southern parts of the country. In this study, there were no significant differences in satisfaction rating of the conferences between participants with and without former experience with videoconferencing.
- **Social influence** is to what degree colleagues, friends or other role models expect you to use the system. Most people are influenced by their friends. That is why the influence of recommendations from friends has such a high value in advertising (52). In the multidisciplinary group that conducted the majority of the videoconferences in this study, social influence might have been prevailing. Introducing new working methods or new technology needs a “critical mass” of users to succeed. The results from this study might increase the social influence on the professionals that so far are skeptical to videoconferences.
- **Facilitating conditions** means to what degree organizational infrastructure supports the system, and that the system is robust and trustworthy. The organizations can educate their staff in videoconferencing so that they increase their communication skills for this medium. The response factor in the study showed lower values in videoconferencing than in face-to-face conferencing, so this is an important challenge. A technical support service is essential to let the professionals focus on their own task.

UTAUT also has the key moderators age, gender, experience, and voluntariness of use. Two of them, age and experience, were hypothesized as being variables that would influence the satisfaction scores in this study.

The Hypotheses

The aim of this study was to compare clinical conferences held as videoconferences and face-to-face conferences by comparing the different participants' assessment of satisfaction. Four hypotheses were proposed in this study. As previously described, the first hypothesis was supported by the results while the three others were not supported.

The factor analysis contributed to reduce the set of variables from the questionnaire from 12 to two components that explained 51.7 % of the total variance. The largest component, a sumscore of ten variables, was seen as a variable that could be used to measure "satisfaction" in this study. The satisfaction component included variables for measuring the professional content, the ability to solve problems, and the cooperation between the participants in the conferences. The other component was called "response", since it consisted of two variables that measured how the participants had made comments or asked questions during the conference.

When the questionnaire was developed, the intention was to assess satisfaction as a combination of whether the professional content was as expected and, how the collaboration and communication between the participants were. The results from the factor analysis led to a clarification of the term "satisfaction" used in this study.

H1: Professionals and clients participating in videoconferences are as satisfied as those who participate in co-located clinical conferences.

The overall satisfaction rating for both clients and providers and for videoconferences and face-to-face conferences was high. The ambulatory clinical conferences are a service in demand, and both clients and providers are most often satisfied when they participate in such a service. Whether the modality is face-to-face or videoconference seems to be of less importance. This coincides with findings in a Cochrane review (13). Clients seem to focus more on the content than the technological context. Related to the Technology Acceptance Model (TAM), where perceived usefulness is the main determinant, these findings largely agree with the TAM. Perceived usefulness is a crucial determinant for a telemedicine application to succeed (26).

This seems to confirm results from the Norwegian Directorate of Health (12). Though the study from the Norwegian Health Directorate is rather small, their findings seem to follow the same pattern as this study; 90 % (N = 19) of their informants agreed with the statements “the conference was well structured” and “the professional content was well communicated” (12).

There were not found significant differences in clients’ and providers’ assessment of videoconferences vs. face-to-face conferences, and hypothesis 1 is considered as confirmed.

H2: The clients and their next of kin are more satisfied than the professionals with clinical conferences conducted as videoconferences

The results of the variance analysis (one-way ANOVA) of possible effects on the informant category and service modality (VC vs. FTF) do not show significant differences in how clients and providers assess the satisfaction statements in the questionnaire.

Several prior studies have found that clients are more satisfied than providers. What is essential to the clients, are increased accessibility to specialists, less travelling and reduced waiting time (16, 18). The providers who never have conducted a videoconference do not master this medium as well as they master traditional patient consultations (14).

In this study, the providers from Frambu got the benefit of saving time, while the clients met at the same venue whether the conference was face-to-face or as videoconference. In other studies, saving time has been important in the patients' assessment, but not in this study. This might explain why the clients are as satisfied as the providers, and hypothesis 2 must be rejected.

H3: Younger participants are more satisfied than older participants with clinical conferences conducted as videoconferences

An analysis with Pearson's correlation was done to explore whether age was a variable that influenced the satisfaction ratings. No significant association between age and satisfaction rating was found.

This hypothesis was based on the assumption that younger people are more familiar with communication with web cameras and the use of social media. This was thought to be something that could make them more confident and motivated in using videoconferences. A prior study with young parents was considered to support this hypothesis (16). In the present study, the age of the informants does not seem to influence how they assess the videoconferences, and hypothesis 3 must be rejected.

H4: Participants with former experience with videoconferences are more satisfied than first time participants

Videoconferencing has been available in Norway for many years, but it is still a new experience for most of the participants in this study. In total, 34 % of the participants in the study had former experience with videoconferences. The share was 61 % for the participants in videoconferences. When testing the satisfaction scores related to former experience with Student's T-test, no differences were found to be significant, and hypothesis 4 must be rejected.

Response

The variable called "response", showed significant differences between videoconferences and face-to-face conferences and between clients and providers. The variance analysis showed that the opportunity to make comments and response was seen as lower in videoconferences than in face-to-face conferences (mean value for VC was 3.72 and for FTF 4.16 (p-value = 0.001) (Table 7)). The informant categories were also tested on the response variable and showed that the clients were more active in the conferences than the providers (mean value for clients was 4.30 and 3.89 for providers (p-value = 0.001)(Table 8)).

One reason that the participants in videoconferences were less active in making questions and comments, might be they were unaccustomed with this way of communicating. Another possible reason might be that due to the technology, it is necessary to have a more clear structure in the dialog and one has to give a clear signal and wait for turn to talk. Some might experience this as more demanding than in a face-to-face conference where the body language is easier to interpret for the chair, and people might feel they can take turn more smoothly.

One reason that clients seem to be as active in videoconferences as in face-to-face conferences could be that they, independent of modality, are in the focus of the conference, and will always get questions that they want to answer. For the providers, the situation might be that they hesitate to make comments and ask questions because they do not feel confident about the videoconference.

Several factors can have influenced the providers' lower rating. However, other studies show that providers struggle with the communication because they are not trained or experienced with communication in videoconferences, and they are less positive than clients (14, 15, 27). Such differences are not seen in face-to-face conferences; thus it seems that they are related to the modality.

Technology Confidence

In the additional questions for the participants in the videoconferences, some clearer differences between the participants emerged. The clients and the providers were satisfied with the quality of the audio and video. "I could see and hear clearly", both groups agreed with the statements between 88 % and 100 %. Providers at Frambu were less satisfied, only 47 % were satisfied with the video and 67 % with the audio transmission.

In a study from the UK, the results of the same statements were that 100 % (clients) could see and hear clearly (16). In the Health Directorate study, 74% were satisfied with the audio and video (12). The rating of the technological items expressed by clients and providers is important, indicating proper quality of the equipment in the municipalities. The lower satisfaction rating from Frambu's providers could have several reasons. It could be due to poor quality of their videoconference equipment, but that is not likely since the equipment is in regular use and technical support is available. Another possible explanation is the lack of competence or experience in the local studios. When people are new or inexperienced with videoconferences, they are

not familiar with the equipment. For instance, they do not move or zoom the camera to the active persons. Another common lack of technical skills is to extend the range of the microphone. This might cause the lower satisfaction rating from the studio at Frambu.



Figure 16: This picture illustrates how the providers at Frambu see the local studio. In this example there were about 15 participants and it is easy to understand the importance of using the camera's ability to zoom closer to the active person. In the upper right corner of the screen (circle) is the picture Frambu is transferring; a close picture of the physician who is seen sitting with the table (in the right edge of the image).

How to communicate "through a screen" is an often emphasized challenge when videoconference is used in dialogues between clients and providers. Only 22 % of the clients "felt uncomfortable talking to the camera", while 52 % disagreed with this statement. The providers' ratings were very similar, 24 % agreed and 44 % disagreed. Frambu's providers seem to be more experienced, as 67 % answered that they felt comfortable. An equal statement for clients in a British study gave 21 % uncomfortable and 79 % comfortable (the neutral answers were excluded) (16).

As the result showed, 65 % of the clients would prefer to meet face-to-face, if that were an option. The providers were more divided, as 22 % would prefer face-to-face, and 47 % would not prefer a face-to-face conference. Compared with the British study, their result showed a more positive attitude to preferring videoconferences to face-to-face consultations, 58 % (16). In the Health Directorate study, 69 % preferred to meet face-to-face, if that were an option, but 79 % also agreed with "I mean that videoconferencing is well suited for clinical conferences" (12).

Videoconferencing is a "New" Service

As an arena for performing clinical conferences between providers from a resource centre, local providers, and the client or his/her relatives the choice of modality depends on several factors. Videoconferences and face-to-face conferences have different strengths and weaknesses, and knowing the characteristics of the modality is of benefit when choosing the service best suitable for the actual case.

Although telemedicine has been available through several decades, only a few applications have been sustainable and implemented on a large scale(31, 32). In the context of Frambu's ambulatory consultant services, there has been a resistance among the providers caused by insufficient knowledge about "the usefulness", too much practical bother, and lack of own experience. That is probably why the number of videoconferences conducted is lower than expected, compared to the strategy of the centre.

The most important conditions for increasing the motivation and feasibility seem to be "perceived usability" and "perceived ease of use", which brings us back to the Technology Acceptance Model in its original version. To be more concrete, the best motivation for providers is when they know that this new modality increases their job

performance, and they know that the clients are as satisfied as if the conference was conducted face-to-face. It is necessary to learn how to conduct videoconferencing, as it is a new modality with its own characteristics. This study indicates that videoconferences and face-to-face conferences to a certain degree have been chosen unequally related to the topics discussed at the conference. The study seems to be useful to initiate a discussion about which circumstances are suitable for videoconferences (18) and when face-to-face conferences should be preferred. Learning videoconferencing also has to focus on communication skills (14, 18) and the human factor (26, 27), such as being aware of people's different levels of education and expectations. It is a challenge to bridge "the gap" between the participants to achieve synchronous communication. Education and training are probably the most important parts of an action program to increase Frambu's use of videoconferences and the level of the variable, response, by the local service providers.

Communicating in a videoconference involves depending on a technology that seems to make providers less confident. Having available support to take care of the equipment ought to be an obvious factor to succeed.

Conclusions

The ambulatory consulting service is a corner-stone in the services of a resource centre for rare disorders. This service is tailored to each client, and a typical clinical conference is organized as a meeting in the client's municipality. One or two professionals from Frambu travel to encounter the client and his or her relatives, together with several local service providers and often professionals from the specialized health service. Such meetings often gather 10-20 participants. Videoconferencing is considered an alternative way of meeting, to decrease costs and time spent on travelling and to increase the number of professionals from Frambu participating at the conference. Additionally, it may lead to a broader multidisciplinary scope.

Through questionnaires, 375 participants at videoconferences and face-to-face conferences assessed to what degree they were satisfied. Videoconferences were compared with face-to-face conferences. The results contributed to define two items that seem to be the most important in satisfaction studies like this: satisfaction and response. The main result was that both clients and providers were equally satisfied with the services whether they were delivered at a videoconference or a face-to-face meeting. There were no significant differences in satisfaction, considering the age of the participants and former experience with videoconferencing.

For the aspect of interaction, there was a significantly lower rating by the service providers in videoconferences than in face-to-face conferences, but this was not the case with the clients.

Based on these results, there is no reason not to increase the use of videoconferences in the ambulatory consulting services. The results address some challenges to work on: First, the need for education and support of the service providers participating in videoconferences to so that they can learn the interaction characteristics of the

modality. Second, the need for the providers at Frambu to choose videoconferences more actively to make this modality just as ordinary as face-to-face conferences.

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Appendix

1. Questionnaire and information letter for clients (7 pages)
2. Questionnaire and information letter for providers (6 pages)
3. Regional Committee for Medical and Health Research Ethics (1 page)
4. Norwegian Social Science Data Service (NSD) (2 pages)
5. Research protocol (3 pages)
6. Comments in free text given in the questionnaire (3 pages)



Forespørsel om deltakelse i forskningsprosjektet

”Erfaringer og holdninger til Frambus veiledningstjenester” (utreiser/informasjonsmøter i brukers hjemkommune)

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie om Frambus veiledningstjenester. Frambus veiledningstjenester er i denne studien informasjons- og veiledningsmøter som arrangeres i kommunen du bor eller som videokonferanse med Frambu. Veiledningsmøtene kalles ofte utreiser eller informasjonsmøter.

Vi vil undersøke hvilke erfaringer og holdninger de ulike deltakerne har til bruk av videokonferanse i møtene mellom Frambu og deg som bruker eller pårørende sammen med fagpersoner fra kommunen. Vi vil sammenligne svarene fra de som har deltatt på videokonferanse med de som har deltatt i et ”vanlig” møte, hvor Frambus fagpersoner har reist til kommunen din. Frambu har lang erfaring med å reise til møter i kommunene, men i løpet de siste tre årene er det gjennomført en del videokonferanser som et alternativ til reisene. Det er flere grunner til at Frambu vurderer å øke tilbudet om videokonferanse, men man har behov for mer kunnskap om hvordan deltakerne opplever og vurderer denne møteformen.

Alle som har deltatt i et informasjons-/veiledningsmøte med Frambu i perioden januar 2008 til april 2010 får denne forespørselen.

Studien gjennomføres av informasjonsrådgiver Kari Hagen som hennes prosjekt for mastergrad til telemedisin og e-helse ved Universitet i Tromsø. Professor Rolf Wynn ved Institutt for klinisk medisin ved Universitet i Tromsø er veileder.

Frambu senter for sjeldne funksjonshemninger har godkjent forskningsprosjektet. Det er Frambu som sender ut denne forespørselen og vi (Hagen og Wynn) vil ikke kjenne din identitet før du har takket ja til å delta

Hva innebærer studien?

Dersom du vil delta i studien, må du fylle ut spørreskjemaet som ligger i konvolutt. Du skal svare uten å oppgi navnet ditt, men vi må ha skriftlig dokumentasjon på at du vil delta. Derfor må du underskrive samtykkeskjemaet og legge dette i den lille konvolutt som du limer igjen. Samtykkeskjemaet blir oppbevart for seg, og det vil ikke være mulig å koble navn med spørreskjema etterpå. Dersom vi ikke hører noe fra deg i løpet av to uker etter at du har mottatt spørreskjemaet, vil du bli kontaktet av en ansatt ved Frambu per telefon. Ønsker du ikke å delta i studien, kan du også gi Frambu beskjed ved å kryss av i rubrikken for ”nei” på samtykkeskjemaet og legge det i den ferdig frankerte returkonvolutt. Du kan også sende en epost til gunn.pedersen@frambu.no eller gi beskjed til Frambu på tlf 64856000 (spør etter Gunn Pedersen).

Kriterier for deltakelse

Det er enten bruker selv eller hans/hennes foreldre/foresatte som kan fylle ut spørreskjemaet

- hvis bruker er 18 år og har samtykkekompetanse, er det han/hun som deltar i studien
- hvis bruker er mellom 16 og 18 år, kan foreldre/foresatte gi bruker selv anledning til å delta

Dersom bruker ikke er til stede eller ikke har samtykkekompetanse, er det foreldre/foresatte som kan delta.

Dersom begge foreldrene har vært til stede på møtet eller videokonferansen, er det ønskelig at de besvarer hvert sitt spørreskjema

Mulige fordeler og ulemper

Deltakelse i studien medfører ingen fordeler eller ulemper på kort sikt. På lengre sikt vil resultatet kunne bidra til at Frambu kan forbedre sine tjenester.

Alle som deltar i studien vil få tilsendt to flakslodd som kompensasjon for tidsbruken.

Hva skjer med informasjonen om deg - personvern

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste.

Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Informasjonen knyttet til deg vil bli slettet når studien er ferdig og resultatene publisert, senest i løpet av 2012. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Universitetet i Tromsø er databehandlingsansvarlig.

Rett til innsyn og sletting av opplysninger om deg og sletting av opplysninger

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Informasjon om utfallet av studien

Alle deltakere har rett til å få se resultatet av studien. Når masteroppgaven er sluttført, vil studien være tilgjengelig fra Universitetet i Tromsø og fra Frambu. Dersom det publiseres resultater fra studien i vitenskapelige tidsskrift, vil disse være tilgjengelige for eksempel ved fagbibliotek.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte Kari Hagen på tlf 90749021 eller epost: kari.hagen@frambu.no

- Tidsskjema – hva skjer og når skjer det?
 - Spørreskjemaer sendes ut høsten 2009
 - Resultatene publiseres i masteroppgave våren 2010
 - Resultatene kan kanskje publiseres i en vitenskapelig artikkel 2011-2012
 - Koblinger mellom navn og data slettes 2012, alle data er da anonymisert

Samtykkeerklæring følger på neste side

Hilsen fra Frambu

Tove Wangensten, direktør

Dette samtykkeskjemaet fylles ut og legges i den lille konvolutten

Samtykke til deltakelse i studien

”Erfaringer og holdninger til Frambus veiledningstjenester”

Dersom det var flere til stede på møtet/videokonferansen på vegne av brukeren (foreldre, foresatte eller andre nærstående), er det ønskelig at alle deltar i studien og fyller ut eget spørreskjema. Alle som sender inn spørreskjema, må signere på dette samtykkeskjemaet.

Jeg er villig til å delta i studien

(gjelder foreldre/foresatt eller bruker med samtykkekompetanse)

(dato og signatur)

(dato og signatur)

Dersom bruker selv skal delta i studien, men ikke har samtykkekompetanse, signeres her av nærstående. Det gjelder barn over 16 år.

(Signert av nærstående, dato)

Dersom du ikke ønsker å delta i studien, kan du sette et kryss her _____ og returnere skjemaet i den ferdig frankerte svarkonvolutten.

Skjemanummer

Frambus veiledningstjenester



En studie for å sammenligne videokonferanser og samlokaliserte møter i Frambus veiledningstjenester

I denne studien spør vi deg om dine erfaringer fra ett bestemt **møte** med Frambu. Møtet kan ha vært i form av *utreise, videokonferanse, informasjonsmøte eller hjemmebesøk*. Dette defineres som *veiledningstjenester* fra Frambu.

Vi spør om **ett** gjennomført møte. Dersom du har deltatt på flere i løpet av 2008 og 2009, skal du velge det siste. Dersom begge foreldre/foresatte var til stede på møtet, ønsker vi at dere svarer på hvert deres spørreskjema.

Spørreskjema for brukere og foreldre/foresatte

1) Når ble dette møtet (veiledningstjenesten) gjennomført?

Måned _____ År: _____

2) Hvor ble møtet gjennomført?

Fylke: _____

3) Din rolle

- Mor (evt foresatt)
 Far (evt foresatt)
 Bruker (det er jeg som har diagnosen)
 Annet, spesifiser _____

4) Din alder _____ år

5) Hvilken diagnose har personen møtet handlet om?

Dersom personen har flere diagnoser, skriv den diagnosen som er årsak til møtet med Frambu

6) Alder på personen møtet handlet om? _____ år

Alder er ved møtetidspunkt.

7) Har du hatt kontakt med Frambu tidligere?

- Ja Nei (gå videre til spørsmål 8)

8) På hvilken måte har du hatt kontakt med Frambu?

(Flere svar er mulig)

- Deltatt på kurs på Frambu Videokonferanse med Frambu tidligere
 Deltatt på helseleir på Frambu Snakket med fagperson(er) på telefon
 KIK (kort individuelt kurs) på Frambu Lest på Frambus nettsider
 Frambu har vært på utreise hos oss tidligere
 Annet, vennligst spesifiser: _____

Skjema-
nummer

9) På hvilken måte ble møtet med Frambu gjennomført ?

(Kun ett svar)

- Møte hvor Frambus fagpersoner reiste til din kommune
- Videokonferanse
- Kombinasjon: Videokonferanse og fagperson(er) fra Frambu reiste til din kommune
- Annet, vennligst spesifiser: _____

10) Hvorfor ble dette møtet arrangert? (Hva var de viktigste temaene)

(Inntil tre svar er mulig)

- Informasjon om diagnosen
- Veiledning i forhold til en aktuell problemstilling dere sto oppe i
- Veiledning i forhold til utarbeiding av individuell plan
- Informasjon/veiledning ved oppstart i barnehage
- Overgang fra barnehage til skole eller til ny skole
- Utfordring i forhold til ungdomstid
- Flytting til eget hjem eller utfordringer/informasjon til de som yter tjenester i hjemmet
- Endring eller forverring i den medisinske tilstanden
- Uenighet om tiltak/løsninger om hva som skal gjøres
- Annet, vennligst spesifiser: _____

11) Hvor mange fagpersoner deltok fra Frambu?

12) Hvilke fagpersoner deltok fra Frambu?

Sett kryss i ruten for de du kjenner yrket til. La stå åpent om du ikke vet.

- | | |
|---|-------------------------------------|
| <input type="checkbox"/> Ergoterapeut | <input type="checkbox"/> Pedagog |
| <input type="checkbox"/> Ernæringsfysiolog | <input type="checkbox"/> Psykolog |
| <input type="checkbox"/> Fysioterapeut | <input type="checkbox"/> Sosionom |
| <input type="checkbox"/> Lege | <input type="checkbox"/> Sykepleier |
| <input type="checkbox"/> Annet, vennligst spesifiser: _____ | |

13) Har du kommunisert med andre på skjerm/webkamera?

Jeg har deltatt på videokonferanse

Ja Nei Vet ikke

Jeg har brukt webkamera mens jeg snakket med andre på internett (eks Skype, chatteprogram som MSN mv)

Ja Nei Vet ikke

14) Hvordan opplevde du møtet?

Nedenfor finner du noen påstander.

I hvilken grad er du enig i påstandene?

Sett kryss i den aktuelle ruten

	Svært uenig	Delvis uenig	Verken enig eller uenig	Delvis enig	Svært enig
a) Det var en avslappet steming på møtet					
b) Jeg kunne snakke fritt med fagpersonene på møtet					
c) Jeg følte meg godt ivaretatt av fagpersonene på møtet					
d) Jeg følte at fagpersonene snakket "over hodet" på meg					
e) Jeg kommenterte og stilte spørsmål					
f) Jeg fikk spørsmål og/eller direkte henvendelser som jeg svarte på					
g) Frambus faglige bidrag svarte ikke til mine forventninger					
h) Det burde deltatt flere fagpersoner fra Frambu					
i) Frambus fagpersoner bidro til å løse de oppgavene vi ønsket					
j) Frambus rolle på møtet var uklar for meg					
k) Fagpersonene fra kommunen og fra Frambu samarbeidet bra på møtet					
l) Vi hadde en god dialog på møtet					
m) Jeg følte meg utilpass					
n) Pausen(e) bidro til nyttige samtaler					
o) Jeg er fornøyd med utbyttet av møtet					

--> Du som deltok på samlokalisert møte (dvs at Frambus fagpersoner var hos dere), svarer på spørsmål 15 og går deretter videre til spørsmål 17

--> Du som deltok på videokonferanse går direkte til spørsmål 16

15) For deg som deltok på et samlokalisert møte (Frambus fagpersoner var hos dere)

Nedenfor finner du noen påstander.

I hvilken grad er du enig i påstandene?

Sett kryss i den aktuelle ruten

	Svært uenig	Delvis uenig	Verken enig eller uenig	Delvis enig	Svært enig
a) Jeg ville foretrukket å møte Frambus fagpersoner på videokonferanse					
b) Det var viktig for møtet at Frambus fagperson(er) var fysisk til stede på					

16) For deg som deltok på videokonferanse

Nedenfor finner du noen påstander.

I hvilken grad er du enig i påstandene?

Sett kryss i den aktuelle ruten

	Svært uenig	Delvis uenig	Verken enig eller uenig	Delvis enig	Svært enig
a) Jeg så tydelig ansiktene på fagpersonene fra Frambu (godt bilde)					
b) Det var lett å høre hva som ble sagt (god lyd)					
c) Jeg likte ikke å snakke til kamera/skjerm					
d) Jeg ville foretrukket et møte hvor Frambus fagpersoner reiste til oss					
e) Videokonferanse er velegnet for slike møter					
f) Når jeg oppsummerer, videokonferansen var en positiv erfaring					

17) Hva kunne vært gjort for at møtet skulle vært bedre tilrettelagt og gjennomført?

Nedenfor finner du noen påstander.

I hvilken grad er du enig i påstandene?

Sett kryss i den aktuelle ruten

	Svært uenig	Delvis uenig	Verken enig eller uenig	Delvis enig	Svært enig
a) Det burde vært satt av mer tid til møtet					
b) Det burde vært mer tid til spørsmål og dialog					
c) Møtet burde vært bedre forberedt					
d) Frambus fagpersoner må bli faglig dyktigere					
e) Det trengs et oppfølgingsmøte					
f) Frambu bør legge mer press på andre instanser for at viktige fagpersoner skal delta					
g) Flere fagpersoner fra Frambu ville gitt bedre utbytte av møtet					

18) Har du spørsmål eller kommentarer?

(erfaringer som ikke dekkes av spørsmålene - noe du ønsker å utdype - synspunkter på hvordan Frambus veiledningstjenester kan bli bedre mv)

November 2009



Til fagpersoner

Forespørsel om å delta i forskningsprosjektet

”Erfaringer og holdninger til Frambus veiledningstjenester”

Veiledningstjenester er et felles begrep for informasjons- og veiledningsmøter som arrangeres i kommunen brukeren bor (”utreiser”), eller som videokonferanse med Frambu.

Bakgrunn og hensikt

Vi vil undersøke hvilke erfaringer og holdninger fagpersoner og brukere/pårørende har til bruk av videokonferanse i Frambus veiledningstjenester.

Vi vil sammenligne svarene fra de som har deltatt på videokonferanse med de som har deltatt i et samlokalisert møte, hvor Frambus fagpersoner har reist til brukerens kommune. Frambu har lang erfaring med å reise til møter i kommunene, men i løpet de siste tre årene er det gjennomført en del videokonferanser som et alternativ til reisene. Det er flere grunner til at Frambu vurderer å øke tilbudet om videokonferanse, men vi har behov for mer kunnskap om hvordan deltakerne opplever og vurderer denne møteformen.

Alle som har deltatt i et informasjons-/veiledningsmøte eller videokonferanse med Frambu i tiden januar 2008 til mars 2010 får denne forespørselen.

Studien gjennomføres av informasjonsrådgiver Kari Hagen som hennes prosjekt for mastergrad til telemedisin og e-helse ved Universitet i Tromsø. Professor Rolf Wynn ved Institutt for klinisk medisin ved Universitet i Tromsø er veileder.

Hva innebærer studien?

Dersom du vil delta i studien, må du svare på det elektroniske spørreskjemaet som du får tilsendt med e-post i løpet av uken (Questback).

Det tar 3 – 5 minutter å fylle ut skjemaet

Dersom du har deltatt på flere veiledningsmøter med Frambu, skal du svare i forhold til det møtet (dato) som står i e-posten.

Personvern – anonym studie

Studien er helt anonym. Vi garanterer at e-postadressen vi nå bruker, vil være skilt fra spørreskjemaet når vi mottar det. Vi vil derfor ikke kunne knytte svarene dine til deg.

Informasjon om utfallet av studien

Alle deltakere har rett til å få se resultatet av studien. Når masteroppgaven er slutført, vil studien være tilgjengelig fra Universitetet i Tromsø og fra Frambu. Dersom det publiseres resultater fra studien i vitenskapelige tidsskrift, vil disse være tilgjengelige for eksempel ved fagbibliotek.

Spørsmål – eller behov for mer informasjon?

Kontakt [Kari Hagen](#) tlf 907 49 021

Vennlig hilsen fra Frambu

Tove Wangensten, direktør



Veiledningstjenester som møte eller videokonferanse

Dette spørreskjemaet er en del av et forskningsprosjekt som tar sikte på å kartlegge erfaringer med og holdninger til bruk av videokonferanse i veiledningstjenester om sjeldne funksjonshemninger.

I prosjektet vil "vanlige" veiledningstjenester (som kan kalles samlokaliserte møter) bli sammenlignet med veiledningstjenester gjennomført på videokonferanse.

Både brukere/foreldre og fagpersoner som har deltatt på møtene vil få tilsendt spørreskjema.

I skjemaet brukes begrepet "veiledningstjeneste", som her betyr betyr både informasjons- diskusjons- og/eller veiledningsmøte mellom fagpersoner fra Frambu og fagpersoner fra kommunale tjenester og habiliteringstjenesten (der det er aktuelt). Dette kalles i Frambus dagligtale "utreise".

Hilisen fra Frambu
Ditt svar er anonymt
Les om anonymitet her...

Vi ønsker svar og meninger om én spesifikk sak, dersom du har deltatt på flere, kan du sende inn flere skjema.

1) Når ble denne spesifikke veiledningstjenesten gjennomført?

- Velg alternativ -

2) Hvilken diagnose har brukeren?

3) Alder på personen med diagnose:

4) I hvilket fylke jobber du?

- Velg alternativ -

5) Hva er din yrkesbakgrunn?

- Assistent
- Ergoterapeut
- Ernæringsfysiolog
- Fysioterapeut
- Lege
- Pedagog
- Psykolog
- Sosionom
- Sykepleier
- Vernepleier
- Annet, spesifiser her

6) Har du hatt kontakt med Frambu tidligere?

- Ja Nei



Denne informasjonen vises kun i forhåndsvisningen.
Følgende kriterier må være oppfylt for at spørsmålet skal vises for respondenten:
Har du hatt kontakt med Frambu tidligere? - Ja

Flere svar er mulig.

7) På hvilke(n) måte(r) har du hatt kontakt med Frambu?

- Jeg har deltatt på kurs på Frambu
- Fagpersoner fra Frambu har vært på møte (utreise) hos oss tidligere
- Jeg har vært med på KIK (kort individuelt kurs) på Frambu
- Jeg har deltatt på videokonferanse med Frambu tidligere
- Jeg har snakket med fagperson(er) fra Frambu på telefon
- Jeg har lest på Frambus nettsider
- Annet, spesifiser her



8) På hvilken måte ble møtet med Frambu gjennomført?

- Frambus fagpersoner reiste til kommunen
- Videokonferanse
- Kombinasjon (én fra Frambu reiste, de andre deltok på videokonferanse)
- Annet, spesifiser her

9) Var dette møtet oppfølging av et tidligere møte (holdt mindre enn 6 måneder før dette møtet)?

- Ja Nei Annet, spesifiser her

Annet, spesifiser her:


10) Hvorfor ble møtet arrangert? Hva var det viktigste temaet?

- Informasjon om diagnosen
- Veiledning i forhold til aktuell problemstilling dere står oppe i nå
- Veiledning i forhold til utarbeiding av individuell plan
- Skal begynne i barnehage
- Overgang fra barnehage til skole eller til ny skole
- Overgang fra barn til voksen
- Flytting til eget hjem eller utfordringer/informasjon til de som yter tjenester i hjemmet
- Endring eller forverring i den medisinske tilstanden
- Annet, spesifiser her

11) Hvor mange fagpersoner deltok fra Frambu?

- Velg alternativ -

12) Hvor mange fagpersoner deltok fra lokalmiljøet?

- Velg alternativ - 

Du bes om å vurdere flere utsagn og markere i hvilken grad du er enig eller uenig i påstanden. Skalaen er fra 1 til 5, hvor 1 er sterkt uenig og 5 er sterkt enig.

13) Hvor nyttig var møtet - i hvilken grad var du fornøyd var du med møtet?

	1	2	3	4	5
	sterkt uenig	delvis uenig	nøytral	delvis enig	sterkt enig
Jeg er fornøyd med utbyttet av møtet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Det var en avslappet stemning på møtet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg fikk svar på mine spørsmål	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg kommenterte og/eller stilte spørsmål	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg fikk spørsmål og/eller direkte henvendelser som jeg svarte på	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Frambus fagpersoner løste de oppgavene vi ønsket	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jeg opplevde at pausen(e) bidro til nyttige samtaler	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Det burde vært flere fagpersoner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

fra Frambu



Denne informasjonen vises kun i forhåndsvisningen.
Følgende kriterier må være oppfylt for at spørsmålet skal vises for respondenten:
 På hvilken måte ble møtet med Frambu gjennomført? - Frambus fagpersoner reiste til kommunen

14) Ved samlokalisert møte

1	2	3	4	5
sterkt uenig	delvis uenig	nøytral	delvis enig	sterkt enig

Jeg ville foretrukket å møte Frambus fagpersoner på videokonferanse



Denne informasjonen vises kun i forhåndsvisningen.
Følgende kriterier må være oppfylt for at spørsmålet skal vises for respondenten:
 På hvilken måte ble møtet med Frambu gjennomført? - Videokonferanse
 eller
 På hvilken måte ble møtet med Frambu gjennomført? - <#other#>Annet, spesifiser her
 eller
 På hvilken måte ble møtet med Frambu gjennomført? - Kombinasjon (én fra Frambu reiste, de andre deltok på videokonferanse)

15) Ved videokonferanse eller kombinasjonsformer

1	2	3	4	5
sterkt uenig	delvis uenig	nøytral	delvis enig	sterkt enig

Både lyd og bilde var bra



Jeg likte ikke å snakke til et kamera



Jeg ville foretrukket møte hvor Frambus reiste til kommunen



Videokonferanse var velegnet for dette møtet



Jeg tror jeg vil like denne møteformen når jeg får mer erfaring



Når jeg oppsummerer, videokonferansen var en positiv erfaring



Denne informasjonen vises kun i forhåndsvisningen.
Følgende kriterier må være oppfylt for at spørsmålet skal vises for respondenten:
 På hvilken måte ble møtet med Frambu gjennomført? - Videokonferanse
 eller
 På hvilken måte ble møtet med Frambu gjennomført? - <#other#>Annet, spesifiser her
 eller
 På hvilken måte ble møtet med Frambu gjennomført? - Kombinasjon (én fra Frambu reiste, de andre deltok på videokonferanse)

Dette er siste spørsmål.

Her presenteres noen utsagn som vi ber deg markere graden av enighet til.

16) Hva kunne gjøres for at du skulle få bedre faglig utbytte

**og/eller bli mer fornøyd med å delta på slike
veiledningsmøter på videokonferanse?**

	1	2	3	4	5
	svært uenig	delvis uenig	nøytral	delvis enig	svært enig
Møtet bør vare lenger	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Frambus fagpersoner hadde ikke forstått saken fullt ut på forhånd	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Det bør arrangeres et oppfølgingsmøte	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Det burde vært satt av mer tid til spørsmål og dialog	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Det kan være behov for å ta flere pauser for uformelle samtaler i løpet av et slikt møte	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lyd- og/eller bildekvaliteten bør bli bedre	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Det bør være noen som kan teknikken godt, så vi slipper å streve med den	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17) Har du andre kommentarer?

Fra: Regional komite for medisinsk og helsefaglig forskningsetikk REK Nord

Til:
Rolf Wynn
rolf.wynn@gmail.com

Dokumentreferanse: 2009/126-4
Dokumentdato: 01.07.2009

FRAMBUS VEILEDNINGSTJENESTER INFORMASJON OM VEDTAK

Prosjektet ble lagt fram for Regional komité for medisinsk forskningsetikk, Nord-Norge (REK NORD) i møte 18.6.2009. I referatet heter det:

Merknad : Komiteen vurderer det slik at i dette prosjektet er det formen på veiledningstjenesten som skal undersøkes, og at formålet ikke er å fremskaffe kunnskap om helse og sykdom

Vedtak : Av søknaden fremstår prosjektet ikke som et medisinsk eller helsefaglig forskningsprosjekt, og faller derfor utenfor komiteens mandat, jf. helseforskningslovens § 2. Prosjektet er ikke fremleggingspliktig, jf. helseforskningslovens § 10.

Vedtaket kan påklages av en part eller annen med rettslig klageinteresse i saken jf. fvl. §28. Klagefristen er tre uker fra det tidspunkt underretning om vedtaket er kommet fram til vedkommende part, jf. fvl. § 29. Klageinstans er Den nasjonale forskningsetiske komité for medisin og helsefag, men en eventuell klage skal rettes til Regional komité for medisinsk og helsefaglig forskningsetikk, Nord Norge.

Med hilsen

May Britt Rossvoll

sekretariatsleder



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www.nsd.uib.no
Org.nr. 985 321 884

Rolf Wynn
Avdeling for telemedisin
Institutt for klinisk medisin
Universitetet i Tromsø
9037 TROMSØ

Vår dato: 24.08.2009

Vår ref: 22154 / 2 / AMS

Deres dato:

Deres ref:

TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 12.06.2009. Meldingen gjelder prosjektet:

22154	<i>Erfaringer med og holdninger til bruk av videokonferanse i veiledningstjenester om sjeldne funksjonsbemminger</i>
<i>Behandlingsansvarlig</i>	<i>Universitetet i Tromsø, ved institusjonens overste leder</i>
<i>Daglig ansvarlig</i>	<i>Rolf Wynn</i>
<i>Student</i>	<i>Kari Hagen</i>

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

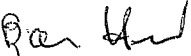
Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

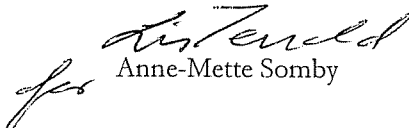
Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/forsk_stud/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://www.nsd.uib.no/personvern/prosjektoversikt.jsp>.

Personvernombudet vil ved prosjektets avslutning, 31.12.2012, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen


Bjørn Henrichsen


Anne-Mette Somby

Kontaktperson: Anne-Mette Somby tlf: 55 58 33 48
Vedlegg: Prosjektvurdering
Kopi: Kari Hagen, Hans Steinpukkers vei 4, 1273 OSLO



Prosjektet er forankret i Universitetet i Tromsø som behandlingsansvarlig i henhold til personopplysningsloven. Førstegangskontakten med brukerne skal opprettes av Frambu senter for sjeldne funksjonshemninger. Ombudet anbefaler at studenten som gjennomfører prosjektet skiller tydelig mellom sine roller som ansatt ved Frambu og student ved Universitetet i Tromsø. Purringer til brukerne bør derfor foretas av andre ansatte ved Frambu, slik at student og veileder kun får tilgang til navn på brukere som har takket ja til å delta.

Det skal gis skriftlig informasjon og innhentes skriftlig samtykke fra brukerne. Ombudet er i e-post mottatt 19.08.2009 informert om at forslagene til endringer i informasjonsskriv som ble gitt i vår e-post 17.08.2009 inkluderes. Vi finner derfor at informasjonsskrivet vil være tilfredsstillende utformet i henhold til vilkårene i personopplysningsloven.

Vi legger til grunn at alle deltakere får tilsvarende informasjon som brukerne, og at det derfor også utformes informasjonsskriv til den delen av utvalget som er fagpersoner. Informasjonsskrivene kan foreligge elektronisk for sistnevnte gruppe, og svar på forespørselen vil anses som aktivt samtykke.

I e-post mottatt 15.08.2009 opplyser veileder at det ikke skal inkluderes personer uten samtykkekompetanse i studien.

Ombudet vil bemerke at det i prosjektmeldingen ikke framgår at datamaterialet kan være indirekte personidentifiserende selv om deltakerne i studien har sjeldne funksjonshemninger. Vi gjør oppmerksom på at diagnose i kombinasjon med bakgrunnsopplysninger som alder, kjønn, fylke og når veiledningstjenesten ble gjennomført kan være indirekte personidentifiserende, og at datamaterialet ikke er anonymt selv om navnelisten/koplingsnøkkelen slettes. For at datamaterialet skal være anonymt må også bakgrunnsvariabler slettes eller kategoriseres. I prosjektperioden må materialet lagres sikkert. Rådata som ev. behandles av ekstern databehandler (Questback) må slettes når oppdraget er fullført.

Prosjektet skal avsluttes 31.12.2012 og datamaterialet skal anonymiseres senest ved prosjektslutt. Det innebærer at direkte og indirekte personidentifiserende opplysninger slettes eller skrives om. Koplingsnøkkelen skal slettes.

Prosjektet er vurdert av Regional komité for medisinsk og helsefaglig forskningsetikk, REK Nord, i vedtak 01.07.2009. Komiteen finner at prosjektet faller utenfor Helseforskningslovens §2.