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Thesis, 2018

# **IMPROVING SERVICE USER INVOLVEMENT IN PRIMARY HEALTH CARE SERVICES**



## ABSTRACT

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57 p.

December 2018

Diaconia University of Applied Sciences

Master's degree in Social Services and Health Care

Master of Social Services

Master's Degree Programme in Community Development, Human Rights and Conflict Resolution

The Ministry of Social Affairs and Health Services started a Key Project in 2016 which aims to improve service user participation. This thesis focuses on to explore what kinds of service user involvement and expert by experience actions and models there are in Central Uusimaa; Järvenpää and Mäntsälä areas and in Helsinki and Uusimaa Hospital district hospitals by using their web pages and interviewing experts by experience and their coordinators.

The literature review was targeted at service user involvement actions and models in Finland and the UK where service user participation has been a part of national health care for more than two decades. The models from the UK and Finland have been evaluated well to get better understanding of service user involvement in public health care services.

This thesis includes a development project where expert by experience appointments started in Mustitijoen Perusturva. This organization produces primary health care services in Mäntsälä and Pornainen municipalities.

Keywords: service user involvement, expert by experience, equality, empowerment

## CONTENTS

1 INTRODUCTION .....	3
2 KEY CONCEPTS .....	4
2.1 Expert by experience .....	4
2.2 Patient, client or service user .....	6
2.3 Patient and public involvement (PPI) and service user involvement .....	6
2.4 Equality in health care services .....	7
2.5 Service user empowerment .....	8
3 BACKGROUND .....	9
3.1 Need for improvement in health care services.....	9
3.2 Suggestion for service improvement .....	13
3.3 Service user involvement.....	16
4 RESEARCH QUESTIONS.....	19
5 DATA AND METHOD .....	19
5.1 Collection of data.....	19
5.2 Literature review .....	20
5.3 Presentations, meetings and interviews .....	23
5.4 Participatory development process .....	24
5.5 Analysis of the data.....	25
5.6 Ethical considerations .....	25
6 FINDINGS .....	26
6.1 Service user involvement models in the UK .....	26
6.2 Service user involvement research in Finland .....	28
6.3 The beginning of the use of experts by experience in Finnish public health care .....	31
6.4 Service user involvement models in Central Uusimaa region .....	33
6.4.1 Customer panels .....	35
6.5 NGOs in Central Uusimaa region .....	35
6.5.1 Koulutetut Kokemusasiantuntijat .....	36
6.5.2 Kasvava .....	37
6.5.3 Werkko ry .....	37
6.6 Service users' thoughts of service user involvement.....	38
6.7 Conclusion of findings.....	40
7 PARTICIPATORY DEVELOPMENT PROCESS .....	41
7.1 Cooperation between Mustijoen Perusturva and Kasvava .....	42
7.2 Creating experts by experience appointments .....	43
7.3 Motivation for the future.....	44
8 DISCUSSION .....	45
8.1 Equality in Finnish primary health care.....	45
8.2 Researcher's self-experience of development process .....	46
9 CONCLUSION .....	49
REFERENCES.....	50

# 1 INTRODUCTION

The ideology of patient and public involvement comes from the United Kingdom where it has been part of public health care service development procedures over two decades. The interest to service user involvement has reached all over Europe in the last few years. The phenomena of service user participation and the use of experts by experience started in Finnish public health care services after the Ministry of Social Affairs and Health Services launched a Nationwide Key Project which aims at better service user participation (Ministry of Social Affairs and Health 2018). The field of public health care services has welcomed the new form of thinking by creating innovative ways to involve service users to their own treatment. This thesis focuses on studying existing methods and models in the UK and Finland, and ongoing projects in Central Uusimaa area (Mäntsälä, Vantaa and Järvenpää) and Helsinki and Uusimaa Hospital District, HUS.

The idea of using experts by experience is not new; non-governmental organizations have been helping people the very similar way for many decades. For example, Anonymous Alcoholics base their methods to peer support. It is not coincidence that the first experts by experience in public health care services started to work with people who have mental health care problems or addictions (Vantaa 2018; Järvenpääm2018a). Recently it is understood that experts by experience could be used to other fields of health care services, too.

Today, experts by experience are used in public health care services many ways; in customer panels, as a working pair with a nurse or as a person who shares experienced information to professionals. The development of service user participation has been fast, and it seems to become a standard in public health care services. However, it is hard to find research about service user involvement in Finland but even when there is only a little research data, the service user participation is seen as a great opportunity to improve health care services and increase and equality.

The aim of this thesis is to find how service users are taking part in public health care, how their experienced expertise is and could be used to improve health care services, and how these actions could improve equality in primary health care. A part of this thesis is to launch experts by experience appointments in Mustijoen Perusturva; an organization that produces primary health care services and social services in Mäntsälä and Pornainen municipalities. Mustijoen Perusturva cooperates with a NGO Kasvava (2018a) which has more than ten years of experience working as experts by experience.

## 2 KEY CONCEPTS

### 2.1 Expert by experience

An expert by experience can be defined as a person who has gone through an expert by experience training. An expert by experience action is somehow organized and the purpose of the action is to create and develop health care services. The point of using the experts by experience is not only for the individual good but for creating good for the whole community. Experts by experience have experience of getting sick, of a crisis, or other challenging experience in life. They can be in a role of a person with medical condition or as a relative/ close one to a person with medical condition. Experts by experience have valid information on what has helped them or their relatives to survive through the healing process. In addition, there is a desire to develop services or to help others through their experiences. (Väestöliitto 2016)

Koulutetut Kokemusasiantuntijat ry (KoKoA 2018b) defines an expert by experience as a person who has gone through training and who has personal experience of mental health problems and / or substance abuse problems, somatic illnesses or other problems in life. An expert by experience may have a role as a service user or as a relative who achieved expertise that way. Such an expert has experiences in illness, treatments and rehabilitation. The expert by experience knows what has helped him/her, what factors have

contributed the recovery of him/her or his/her relatives. Experts by experience have a desire to develop services and help others by using their own experiences.

Acting in primary health care as an expert by experience requires suitable training. KoKoA (2018a) has defined the guidelines of the training they require. Experts by experience need to be in that phase of their treatment and rehabilitation process that they have ability, skills and resources to help others. To become an expert by experience requires a lot of work and time. KoKoA (2018) wants to remind us that expert by experience training is not any degree. The training does not make expert by experience a professional in the field of social and health care services. The training should not be part of anyone's rehabilitation and participants should be mentally stable when they participate in the training. It is important that expert by experience could see his/her experiences not only subjective but objective way as well.

McLaughlin (2009) writes that the term expert by experience widens the area of people who are involved in the system of social and health care services. The professionals working with the expert by experience is suggestive of a relationship of equals whereby one expert's expertise has been accrued through their training and practice and the other through their experience. Experts by experience have unique knowledge and that helps with the inspection of social and health care services. McLaughlin (2009) reminds us that it is important to understand that experts by experience are not only those who are or have been service users, and those who needed services but were not offered, those who were offered inappropriate services and those who live with or caring for someone who uses services.

Kasvava CEO Katja Lemberg (2018b) mentions the problem with the term 'expert by experience'. The idea of using experts by experience should be to narrow the gap between the professionals and service users. By using a word expert, we may create a hierarchy between "normal" service users and experts by experience service users and that is against the ideology of experts by experience. However, the term is widely used and known in Finland and that is the reason why the term is used in this thesis.

## 2.2 Patient, client or service user

Previously, people who used health care services were called patients. A patient is someone who requires medical care for a somatic or mental health problem. The patient has symptoms and doctor's goal is to give a diagnosis or/ and relevant treatment. Patient's role is usually passive. Medical professionals make the decisions of the treatment and patient follow instructions. The problem of this term is the need for symptoms and diagnosis to receive services. It is also tied up to individuals; the service is given to a person with symptoms. (Valvira 2016.)

“Client is always right” shows the problem of using the word ‘client’ in health care services. The truth is that client is not always right and in the field of health care services this kind of thinking could be even lethal. A client is a person who uses money to get services in return. The word has a tone that all the services should be made for the client, but a client does not have to have any responsibility of herself/himself or the system. The truth is that very often the “diagnosis and treatment” the client wants is not a proper treatment. In these situations, the health care professionals must act according to their expertise and give the treatment people need and not what they want. (Paul 2018.)

Service user is the term that is widely used in the UK. This term includes the idea of an active participant. Such a person is using the services as a patient, but a service user also has a right and responsibility to be part of improving health care services. After all, the public services are funded by tax-payers money. Service users should be part of creating the system with the professionals for themselves. Service users can be all of these; a person with symptoms, their closest one or a person who does not get services. Health care services and the development of the services should be run by the management, professionals and service users all together. (NHS 2015.)

## 2.3 Patient and public involvement (PPI) and service user involvement

Patient and public involvement (PPI) is a term that is used in the UK to create cooperation between service users, professionals and public health care system. This term is used in this thesis when reviewing international literature. This term is not used in Finland. PPI includes patient participation and service user involvement. Patient participation focuses

on patient's right but also responsibility to be an active partner in his/her treatment. Patient participation aims at a feeling of empowerment, collaboration and possibility to influence the service. PPI concentrates on finding those people who would need health care, but they are not using the services for some reason, those who do not use the services and those who got inappropriate services. PPI does not narrow the participants in only people who are using the services, but it includes also their relatives/ close ones. PPI is used in research and the idea is to conduct the research with or by patients and members of the public and not solely on them. This way the role of the public extends beyond of being research subject and public become as research partners. (Dudley, Gamble, Preston & Buck 2015.)

Service user involvement is the term that is used in Finland and this thesis. Service user involvement focuses on influencing the health care culture and system. The main idea is that a service user should have a possibility to affect his/her treatment as well as the whole system. There is growing recognition that people who have direct experiences of using services have a unique insight into what works and that can be used to improve services. This is part of health promotion; the goal should be to try to keep people as healthy as possible, being responsible for their own health and create a better system for the next generation. Involvement can increase self-esteem and improve individual outcomes and that way increase people's satisfaction with services. The main point of service user involvement is that it can improve the quality of life, improve relationships between public health care employees and service users and improve outcomes for service users. (NHS 2015.)

## 2.4 Equality in health care services

There can be three types of equality; equal opportunities, equal results or equal everything; sameness. Nordic ideology bases on equal opportunities and an equal outcome. In this thesis, equality is understood as it is used to in Nordic countries. Everyone should have an opportunity to get primary health care services if needed and wanted. These services are not and are not supposed to be similar everywhere in Finland because of geographical, cultural and even genetic reasons but everyone's needs should be answered similar way. Not everyone wants services and these people should have an equal right not to be part of the primary health care system. However, the system should provide more



opportunities for people to become service users in primary health care. Now, the primary health care services work only during the office hours in health care centers. This does not guarantee equal opportunity for every service user to achieve proper services. (Kvist, Frizell, Hvinden & Kangas 2011.)

Equality includes term dignity which is a complex and multi-faceted concept, but it has an important influence on patients' healthcare experiences. Human dignity applies to all people equally. Healthcare workers should understand that dignity, diversity and equality interrelate. This is important to understand to preserve the dignity of everyone. Every service user should be treated person-centered and their family should feel valued. Organization should support the provision of equality and respect for diversity and dignity. (Baillie & Matiti 2012.)

## 2.5 Service user empowerment

Service user empowerment is gaining greater importance in healthcare. The western medicine is moving slowly away from paternalism towards an ethic of empowering patients to make informed decisions (Barr et al. 2015). Service user empowerment should occur at all levels; individual, service and system. Individuals should be involved in decision-making which considers their own care to achieve personalized care. Services should be able to give choices of how and where services are delivered. The system should be involved in strategic decision-making. (LGA 2018.)

In this thesis service user empowerment includes the ideology of service users' right and possibility to be seen as an individual with individual needs. The service users should be encouraged to take part of decision-making to achieve a feeling of being heard and understood as individuals.

### 3 BACKGROUND

NGOs have used peer support as a helping mechanism for decades. Their actions base on equality, everyone has or has had similar challenges. The NGO workers are usually volunteers. They do not base their action to the latest studies but their knowledge bases on self-experienced expertise. The idea of bringing service user involvement and experts by experience as part of public health care services is new in Finland. The Ministry of Social Affairs and Health started 37 million euros (between 2016–2018) Key Project “Services responsive to client needs”. This project has made health promotion and patient participation more visible and important in public health care services than before. The aim of the key project is:

- improve clients’ access to services supporting functional capacity
- the self-management of health
- make health and social services easier to find (Ministry of Social affairs and Health 2018.)

Primary health care centers, hospitals and NGOs seem to be inspired of this new innovative way of thinking and they are all creating something new. Many primary health care centers and hospitals are creating their own methods and many of them are cooperating with local NGOs.

#### 3.1 Need for improvement in health care services

The National Institute for Health and Welfare (THL 2016a) researched people who are using their right to change their primary health care center to another health care center and what were the reasons for the change. This possibility to choose the place of primary health care has been possible in Finland since the beginning of 2014. The number of the people who have made the change is not very big. However, most of the people who have made the change are suffering of one or more chronic illnesses. Because of their condition, they are frequently using the services. The research shows that the biggest reasons for the change are: doctor’s expertise in medicine and doctor’s social skills. These people

were less satisfied with the services in the new primary health care center, too, than an average service user.

Nyman & Jäppinen (2015) have been written a research of people who use primary health care services the most. The research was done in Helsinki primary health care centers in 2011. The researchers interviewed nurses and doctors. Their results were that almost 20 % of all the appointments were unnecessary according to nurses and doctors; the reason for the appointment was not something that primary health care services could have been able to help the service user. The article does not summarize better reasons for nurses and doctors' opinions.

Nyman and Jäppinen (2015) continue to list that the most common ICD10 (the international statistical classification of diseases and related health problems 10<sup>th</sup> revision) codes with these people who are using the services most were; diabetes type two, heart and vascular diseases, anxiety and depression. Very often social problems were in question, too. The research did not identify whether the service users had both; physical and mental problems. The research did not give any clear answer what were the needs of the service users other than those people who are using services often usually have these all; social, mental and somatic problems.

However, according to these research people who need the services the most are not satisfied the primary health care services. In addition, primary health care center employees experience that their services cannot answer these people's needs.

Roughly these needs could be put in three groups; people with one or more chronic illness (THL 2016a), young people (THL 2018a) and their problems and people who do not get or need a diagnosis, but they would need services e.g. life crisis. The law requires (Ministry of Social Affairs and Health 2009) that all the municipalities should have their crisis plan. Life crises usually do not need any organizational actions but according to service user feedback some other type of help is needed. Table 1 is created for this thesis to clarify the need of the services in following groups of people.

## People's needs in primary health care services

People with one or more chronic illnesses; mental, somatic and social problems. Every professional takes care only their own field of health care; no one has a clear, human or individual understanding of the situation

- Diabetes, chronic pain, rheumatic etc
- Care givers (e.g. dementia patients). The whole family would need support; mental, physical and social.

Young people

- Risk of exclusion from society (social, mental reasons)
- Medical conditions e.g. IBD and other intestinal problems; the need for the whole family support (Ashorn, Iltanen & Kolho, 2009)

People without diagnosis

- Crisis in life (death in family, divorce, unemployment, burn out)
- People who aren't using services but would need services

Table 1. People's needs in primary health care services

A primary health care center should be the place where service users are met as individuals. Their needs should be heard and taken into consideration better. Many people have severe health issues and they may need help in their everyday life. The primary health care center employees should be trained to see the service users' world in a wider perspective; medication can be expensive, and it can lead to money problems, relationships may fail because there is not enough support and help available, and many somatic illnesses contribute to mental health, too. People often resort to primary health care services, hospital services and social services. These departments and units do not cooperate well, and service users need to collect all the information they need by themselves from many places. This may confuse people and lower their quality of life. This can increase inequality; those people who know and can find the information may achieve better services. (Lääkäriliitto 2018.)

The other group who need better services is young people. According to THL (2018a) there are 14,000 to 100,000 young people in a risk of exclusion in Finland. The range is wide because exclusion and risk to exclusion are hard to define. However, the number is too big. Education is the key to prevent exclusion but only that is not effective enough to prevent exclusion. Many of these young adults have medical problems and better support in primary health care services could be in a big part of preventing the risk of exclusion. The reasons for exclusion may be problems with life-management, lack of education or health problems. Young people have good services for mental health problems but e.g. the number of young people with irritable bowel syndrome is growing (Ashorn, Iltanen & Koho 2009) and they do not get enough support. Some of these people are afraid to leave their home because their need to use the toilet may be urgent and it may be embarrassing if a toilet is not available and some accidents happen.

Third problem is found in the existing health care system. More attention should be put on to find out who are and who are not using the services. It would be important to do that e.g. if the survey shows that men in their early 20's are not using the services this could be one reason for their exclusion and finding the reason for that could be an opportunity to prevent exclusion. NHS uses resources to find these people to guarantee equal services for everyone (Dudley et al. 2015). The information would be valid when improving the services and equality. THL statistic report (2018b) collects information of the number of the visits in primary health care but statistic does not show anything else e.g. the age, sex.

One of the existing system's challenges is bureaucracy. The system bases on the idea that to get proper help a service user needs a diagnosis. In many cases the diagnosis is needed to help a person but not always. For instance, people who go through life crisis may need help if a family member dies. Very often these service users use primary health care services to get sick leave to recover the mental pain. The doctor tries to find out this person's needs in 20 minutes without knowing the whole story. The patient gets the sick leave paper, maybe some sedatives which can even stop the grieving process and leaves the room. Service user would have needed other kind of supportive and empowering help.

In many cases, the diagnoses are needed, and they are an important part of health care services. However, it would be good to remember that diagnoses do not need treatment

but the individuals behind the diagnosis is the one who should be treated. Human beings are psychosocial creatures; regardless of the reason for the need of health care services people should be met as individuals. There are, for instance, more and more morbidly overweight people in Finland. They go through the health care system with their symptoms; they have high BMI and because of that they have multiple chronic illnesses, metabolic syndrome (Duodecim 2017). They go through weight loss courses and see nutritional therapists until the decision is made; they get weight loss surgery. This leads to a situation where they can no longer eat the way they used to eat, and they lose enormous amounts of weight, but they still have the same psychological problems as they used to have before the surgery. Medical care in these cases solves only the somatic problem but they hardly ever get that kind of mental help they would have needed. These surgeries are only a way to treat symptoms and not the problem itself. (Madura & DiBaise 2012.)

### 3.2 Suggestion for service improvement

“We need to meet people as individuals and give them the services they need the best way we can. The quality of service is determined by a person’s own experience. Only when we listen to people’s experience, can we understand their needs.” (Kasvava documents, 2018b).

Quantum physics gives philosophical and theoretical perspective for the structure of the change. The existing health care model’s principles are; hierarchical structures, focus on control, top-down decision- making and process driven actions. The service user involvement and need for improvement will need a change eventually; the need is already visible. New healthcare, where everything is connected to everything, will be required to participate in a quantum unitary reality to sustain humanity. If the dominant leadership is the model where everything is based on a part versus a unitary human caring paradigm, it can lead to a totalizing and objectifying humanity. (Watson, Porter-O’Grady, Horton-Deutsch & Malloch 2018.)

Even if the ideology of quantum leadership in social and health services is still more philosophical than scientific, it will give a theory of the need for the change in health care services. Watson et al. (2018) have created quantum healthcare leadership principles.

Nonlinear structures

- Focus on connections-relatedness
- Value-driven actions
- Complexity-based models of design
- Multifocal processes
- Multisystem within systems
- Everything is connected

These unitary, quantum-converging themes are found in quantum leadership science, in contrast to non-unitary paradigm approaches. The second revolution of quantum physics has just begun but it can explain the need for the change scientifically. The actions are already moving towards unitary and service user involvement. It has been understood that everything has an effect on everything and that is why individual's health care should not be thought as a linear route. (Watson et al. 2018.)

Digital services are an effective way to improve equality in health care services; services could be available anywhere and anytime. The Ministry of Social Affairs and Health started ODA- project (2016b) which aims at better digital services and easier access to health care services. The project should become part of health care services in 2018. Some other digital reforms are under development too, e.g. Apotti (2018), which aims to reduce the time health care professionals spend in documenting; time for people, as their slogan says.

Service users should have an easy access to information and treatment. This is one of the main themes in upcoming social and health care service reform SOTE (2018). They should also have better opportunities to contact primary health care centers. There are some digital services available, but improvement is needed:

- Contacts should be available 24/7 (chats, calls)
- Better possibilities to have appointments online
- Better instructions online; self-help and instructions (Terveyskylä 2018)
- More possibilities to check and affect one's own health (THL ODA- hanke 2016)

- Primary health care services should be focused on one place; some people are using primary health care services, private services and hospital services to treat the same illness/ symptoms

The services should not be located only one place; the primary health care center. There should be better possibility to have doctor or nurse's appointment at home because there may be long distance to primary health care center and public transportation connections are poor and there are not enough taxis. Sometimes it would be important for the service user to have service at home for the professionals to visualize the living conditions. (SOTE 2018.)

The service users should have better opportunities to choose the professionals who take care of them (SOTE 2018) but also another way around; professionals should have somewhat opportunity to choose their patients. When a doctor and a nurse create a professional relationship with service user that bases on understanding and equality it would create better service user experiences. The professionals should have an opportunity to meet a service user, hear their story and show understanding to their situation to build trust between the service users. Both professionals and service user should have an opportunity to use an expert by experience services.

Cooperation between different health care units should be improved as well as possibility to use services between different units. Kokko, Peltonen and Honkanen (2009) write that health care employees are satisfied of the cooperation in places where primary health care services and hospital services are placed in one and same building. However, better understanding and cooperation is still needed. Ambulances do their own job and their only opportunities are to take a person to emergency room or leave the person at home. Sometimes the service user would not need transportation to hospital, but he/she may need some other assistance; instant home visits by nurses or other help. It is almost impossible to organize that other help because the resources are tight or there are none. There are cases in Finland when resources were used unintentionally, e.g. when a person had been transported with an ambulance 186 times during his/her last year of life (Heliste 2012).

Heliste (2012) continues that only 13% of the people over 70 years old were allowed to die without transporting, sometimes even uselessly, from one place to another.



Professionals in ambulances, home care, primary health care centers and hospitals should cooperate better with services users to avoid this kind of torture. Service user's voice should be heard, and his/her will should be respected. Death should not be any penalty where a person is tortured until the last breath.

Monitoring the services would be one of the most important things when improving the services. THL (2018b) published their record of service use but more monitoring would be needed. It is important to have experts by experience with different experiences (McLaughlin 2009);

- People who are using the services and the service is good
- People who are using the services and the service is poor
- The closest ones of a person who is using services and service is good
- The closest ones of a person who is using services and service is bad
- Those who are trying to get services, but fail
- Those who aren't using the services even if needed

### 3.3 Service user involvement

There are many ways to improve service user involvement and empower people. Kasvava documents (2018b) has created a very simple formula; the circle of these four; inspiration, space, time and support. Kasvava uses the method in their own organization. It was developed during several years with a help of academic research and clinical work. The method could fit to public health care services, too.

Inspiration gives the service users a new direction they can choose for themselves. A human being is a gregarious animal. It always tries to find something to identify with. From the beginning of time people have created and loved stories. Everyone has their own unique story. People who go through life crises are looking for someone to identify with; to feel understood and empower. Primary health care should be interested in service users' life stories to be able to treat people as individuals. This should be made by doctors and nurses, too, but would fit experts by experience the best. When paying attention to an individual it would be helpful when creating trust between a service user and

professionals. It would help professionals to see why people act the way they do and that could improve the quality and equality of services. (Kasvava documents, 2018b.)

Kasvava (2018b) continues that it is important to be understood. It could help service users to understand their own situation, their own resources and possibilities to take a control of themselves and their own treatment better. It is important that service users are not any objects that professionals could pinpoint and show the things that need to be fixed (Rissanen 2015). Rissanen (2015) shares experience with Kasvava (2018b); patients are not being heard during their treatment. If we educate doctors and nurses to take care of patients, so, why could not we “educate” experts with experienced expertise to be equal partners to nurses and doctors? By this far the professionals are telling what and when experts by experience should and could tell other service users (Kasvava 2018b). This does not serve the system the best possible way. There is more potential left to help service users in multi focal way where everything relates to everything.

People have different personalities and the health care service system should serve everyone. Not everyone wants to tell their own stories; some does not even want to use the services. People should have their own space where they feel safe and where they fit a person; both physically and mentally. That is why services should serve people as many ways as possible. Alongside space people need time for the change and processing. The amount of time cannot be dictated from the outside. Kasvava (2018b) values a right for individuality and equality. People need support and information to understand their treatment and care. Every instance and organization have the same goal; to help individuals and their families who need help. It would be an important mission to bring together hospitals, primary health care and NGOs to create a network where people could easily find the service they need and fit their situation.

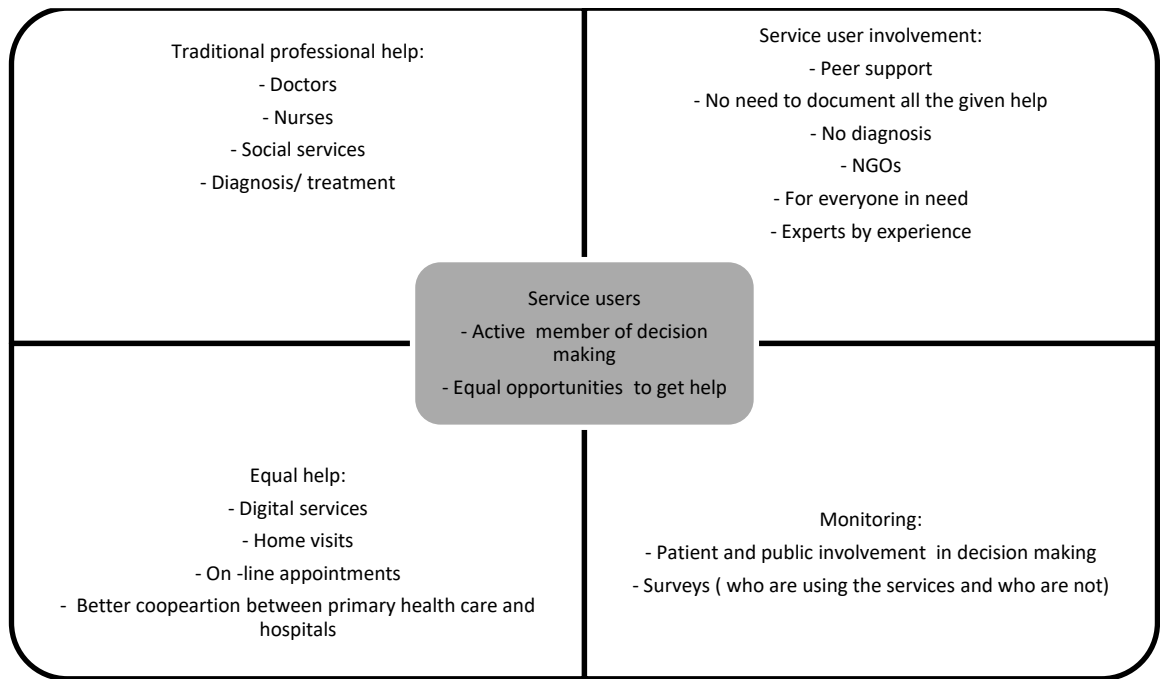


Figure 1. More equal services and service user involvement

After all, the need for the development need is shown in Figure 1 where service user is in the center of the figure with opportunity and responsibility to be an active member of decision making and different instances that could help the service user are placed around the service user. This figure is created for this thesis to visualize the suggestion what service user involvement should and could be.

## 4 RESEARCH QUESTIONS

The aim of this thesis is twofold: on the one hand, to introduce the concept of service user involvement and on the other hand, to find out how the concept is used in health services in Finland and the UK. The number of different models and forms of services is high in the UK, where the concept of service user involvement has been part of national health care much longer than in Finland. As far as Finland is concerned, the thesis focuses on the projects in Central Uusimaa area, but some case studies related to other parts of Finland are also included. The aim of the empirical part of my thesis is to answer the following two research questions:

1. What kind of models of service user involvement or experts by experience services are employed in the UK and Finland?
2. How could service user involvement be used and improved in Finnish primary health care services?

Question 1 calls for a description of the situation today in both countries. Question 2 is linked with the values of social and health services in the future.

## 5 DATA AND METHOD

### 5.1 Collection of data

Since the concept of service user involvement is relatively new in Finnish public health care, there is variation in its implementation in health organizations. In other words, the organizations may lay stress on their own viewpoints in the implementation of the concept. Therefore, it was important to collect the data of the various models used. In this study, the data was drawn from three sources: a literary review, interviews, and a participatory development process in Mustijoen Perusturva.

The data consists of existing models and experiences of the health care professionals in various organizations in Finland, mainly from Central Uusimaa region. The Finnish data consists of documents, projects and interviews. The international literature of relevant models and experiences comes from the UK.

In this type of study, the researcher's role was threefold. She was simultaneously a researcher, a primary health care service employee and a service user. This triple role complicated the research process, but it made it more challenging and more rewarding. In this kind of study, the researcher had to be prepared to change her approach and working methods as a nurse during the process in order to achieve an understanding about the idea of service user involvement.

## 5.2 Literature review

This research part is mapping literature review (JAMK. Opinnäytetyön ohjaajan käsikirja n.d); the aim of the literature review is to find information of service user involvement and patient and public involvement phenomena from the UK and Finland. The literature review aims to find information of different models of service user involvement. This content will be analyzed.

The literature review was based on four different databases. Three of them (PubMed, Cinahl EBSCO and Academic Search Premier) were international, and one (Terveysportti; Lääkärilehti and Duodecim-lehti) domestic. The manual search of one dissertation (Rissanen, Päivi. 2015. Toivoton tapaus. Autoetnografia sairastumisesta ja kuntoutumisesta) and one domestic study by THL (Kaste-project) were also included (Figure 2). These databases were chosen in order to get a comprehensive picture of service user involvement and experts by experience. The articles included were published between 2013 and 2018. The keywords used in the searches of the databases were as follows: the expert by experience, health care, patient and public involvement, primary health care; and in the Finnish database, kokemusasiantuntija, vertaistuki, and terveydenhuo\*. The total number of matches was 1679. After exclusion based on the criteria, see Figure 2 below, 111 abstracts were read. In the final phase, 9 articles were chosen for a closer examination. The data give a perspective of what information is found about

service user involvement, what kind of models are found in the UK and Finland, and what are the aspects that would need improvement.

The scarcity of academic research on service user involvement actions in Finnish primary health care was compensated by examining the webpages of Central Uusimaa primary health care centers (three) and NGOs (three) they cooperated with. In addition, the Helsinki and Uusimaa Hospital district web pages were examined, too. Through these pages it was possible to find information on ongoing service user involvement and experts by experience projects, models and actions.

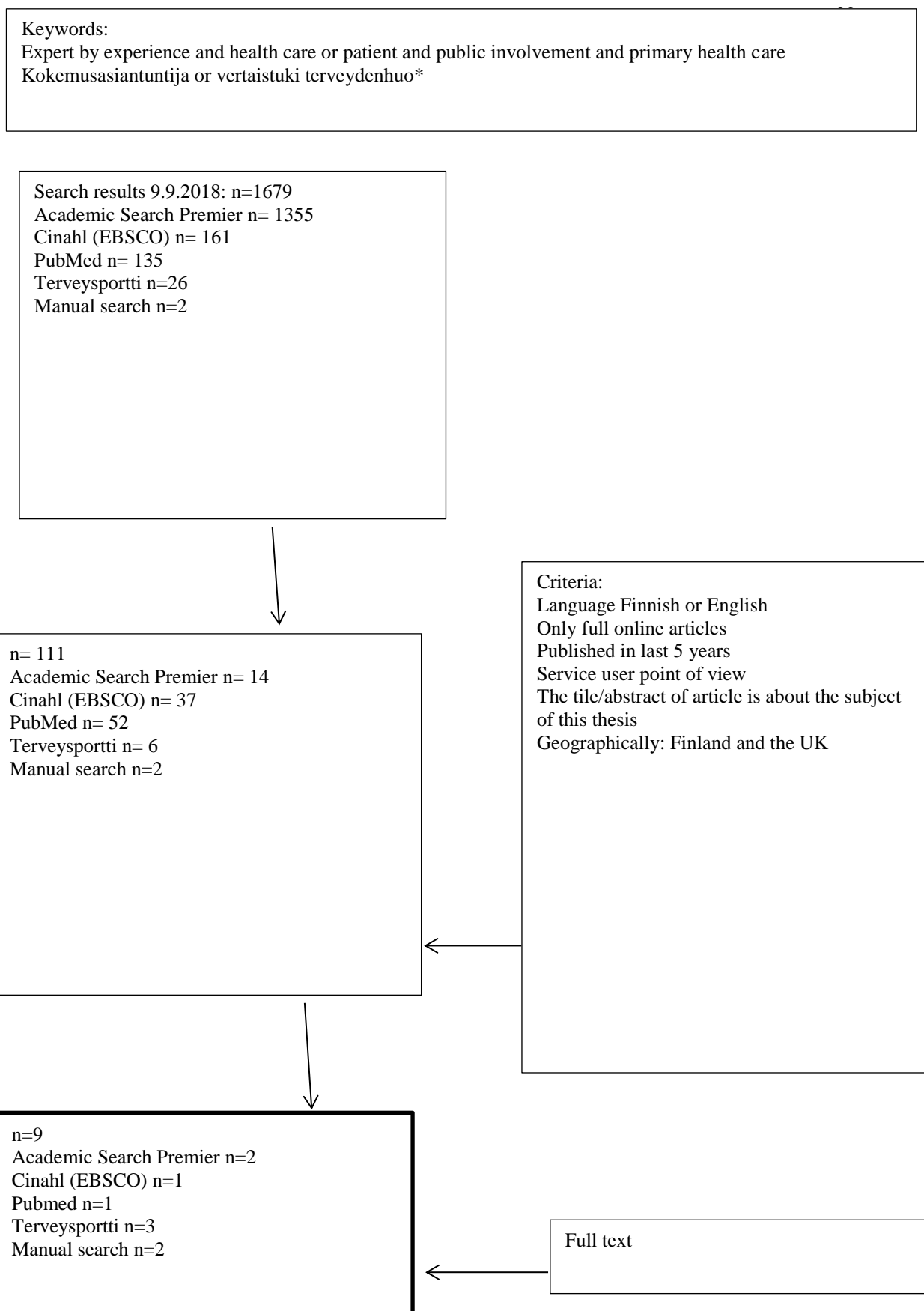


Figure 2. Literature review

### 5.3 Presentations, meetings and interviews

The data also comprised four presentations to the employees and service users of health care services, meetings in such units and interviews, where the employees and service users answered my open-ended questions. The first of the four presentations and group interviews took place in Mustijoen Perusturva in Mäntsälä on March 15<sup>th</sup>, 2018. The participants (n=18) were employees, doctors and nurses, of Mustijoen Perusturva. The aim of the meeting was to present the idea of the experts by experience appointments in Mustijoen Perusturva primary health care center. After the presentation the audience had time and a chance to share their ideas and suggestions.

One of the interviews was a phone interview on August 31<sup>st</sup>, 2018, with HUS gastroenterology unit's expert by experience coordinator. The interview focused on the model in the gastroenterology unit of HUS Meilahti. The main topics were the following; (i) What criteria was used in choosing the experts by experience? (ii) How was their education organized with Laurea University of Applied Sciences? (iii) How did the experts by experience experience their work and (iv) How did the employees of the HUS gastroenterology unit experience these experts by experience. In addition, the interview also included a question of cooperation between the HUS units and with the primary health care centers.

Two of the interviews were open group interviews without specific structure of questions. Research and some results were presented to the interviewees and their experiences were heard. One group interview took place in Mustijoen Perusturva on April 24<sup>th</sup>, 2018, in a customer panel meeting. Four Mustijoen Perusturva employees and 8 customer panel service user members participated in the meeting. Another customer panel meeting took place in HUS Meilahti Hospital on October 17<sup>th</sup>, 2018, where the gastroenterology unit's expert by experience coordinator and three experts by experience were present. The main topics in these meetings were presentation of the findings of this thesis, and the collection of the feedback from the service users about the development process. I also tried to find out how the experts by experience saw their role in health care services.

One NGO, Kasvava, was visited twice; in April 20<sup>th</sup>-21<sup>th</sup>, 2018 and July 7<sup>th</sup>- 8<sup>th</sup> 2018. The CEO of Kasvava, Katja Lemberg, was interviewed both times. During the first meeting three other Kasvava members were interviewed in a group, too. The main questions of



the interviews were the following: (i) What kind of experiences Kasvava members had of being a service user in Finnish health care services? (ii) What did they consider important when improving service user involvement in primary health care services? and (iii) What kind of experiences did they have as working as experts by experience?

In addition, one Werkko ry (NGO which operates in Central Uusimaa region) annual meeting was participated to achieve better understanding about the expert by experience actions in Järvenpää primary health care center.

The aim of the data collected was to serve grass roots level in Finnish primary health care services, and to find out how existing information could be used to improve primary health care services by using service user involvement. The interviews were used to achieve deeper understanding about service user involvement phenomena in Finnish public health care services.

#### 5.4 Participatory development process

The working life partner of this thesis, Mustijoen Perusturva, produces primary health care services for Mäntsälä and Pornainen municipalities. The aim of the development process is to create an expert by experience appointment service to Mustijoen Perusturva. The process includes creating cooperation between Kasvava and Mustijoen Perusturva. The need for the development was understood in Mustijoen Perusturva but they had not found an organization to cooperate with. The development process started in February 2018 and has since then had the full support of the management.

The appointments are scheduled to start in December 2018. However, the future may change the plans because Mustijoen Perusturva will be close down at the beginning of 2019. After the turn of the year, the primary health care services in the region are provided by Kuuma Kunnat (the municipalities of Järvenpää, Mäntsälä, Pornainen, Tuusula, Nurmijärvi and Hyvinkää).

## 5.5 Analysis of the data

I collected the data by making notes on the interaction in the group interviews and meetings, in which the service users and health care employees and service users could express their viewpoints freely. I completed the notes immediately after the meetings or the interviews so that they were in line with the actual contents of the discussions. This procedure was important in order to improve the validity of the study. The videoing of the meetings would have been a good choice, but it could not be organized.

I regarded the notes as texts, which could be analyzed by using inductive content analysis (Silverman 2002, 128). The qualitative content analysis is a method which can be used to analyze documents systematically and to some extent objectively (Tuomi & Sarajärvi 2018, 93–114). The objective of the analysis is a concise description which describes in a general form a phenomenon to be examined. In this study, the analysis made it possible to understand how the health care professionals and service users described their experiences of the services. The viewpoints of both types of informants make it possible to plan the future services and make them more user-driven than today.

## 5.6 Ethical considerations

Ethical considerations are an important part of data collection and the writing process of a thesis in general (Kuula & Tiitinen 2010, 446–459). In my study, the focus was especially on the following two principles presented by American Psychological Association (APA 2018): (i) Follow informed-consent rules, and (ii) Respect confidentiality and privacy.

In collecting the data for the study, one has to follow informed-consent rules. The informed consent consists of the following principles (Silverman 2002, 201):

- Giving information about the research which is relevant to subjects' decisions about whether to participate
- Making sure that subjects understand that information (e.g. by providing information sheets written in subjects' language)
- Ensuring that participation is voluntary (e.g. by requiring written consent)

- Where subjects are not competent to agree (e.g. small children) obtaining consent by proxy (e.g. from their parents)

## 6 FINDINGS

### 6.1 Service user involvement models in the UK

In the UK all the National Health Service (NHS) organizations have a duty to involve patients and the public in decision-making around service planning, operation and proposals for changes. There is a growing international interest in community participation in public sector services. The revolution of social and health care services has started. The results of using experts by experience or PPI (patient and public involvement) have been good. However, there is widespread debate about what their representation is or what it should be. (O'Shea, Chambers & Boaz 2016.)

The idea of PPI is to bring service users as part of decision making. In many studies the professionals were suspicious of PPI but O'Shea et al. (2016) got an interesting result where service users were insecure of their ability of being part of developing the health care system. The experts by experience were thinking whether they can or cannot represent the whole community. Everyone has his/her own subjective experiences of services and understanding what good service is. This was one of the first researches where it was an expert by experience who was concerned about her/his abilities. Previously, professionals have had concerns about experts by experience' ability and skills. The truth is that not everyone or all kind of people are interested in developing services. It is a certain type of people who are interested in actions of this kind. This raises the question: "Can they represent everyone?" PPI is a good start but that is not enough to create equal services for everyone. What would be the next step? How can we find the voice of the people who are not that active community members? More research needs to be done to answer these questions.

Not everyone wants to be part of decision-making or be an active part in their own medical treatment. A survey was made in the UK and Sweden (Fredriksson, Eriksson & Tritter 2017). In England 1625 and in Sweden, 1500 over 15-year-olds were interviewed. The results of this study supported previous findings suggesting that many patients (66% of the English and 70% of the Swedish respondents) preferred the physician to make health care and medical decisions and that few wanted to take a fully active role. However, even if patients did not want to play an active role in treatment decision-making, most wanted physicians to take their preferences into account and to inform them of options. The Swedes were more positive towards being involved in local decision making on the organization and provision of health and social care services; 55% of the Swedish respondents wanted to be involved compared with 33% among the English.

The research of the savings is not easy to do. While evidence indicates that PPI can improve health-care decision making, it also consumes monetary and non-monetary resources. It is important to think about the costs and benefits of PPI and how to evaluate it.

“There is only limited debate about where resources should be invested and whether this investment provides an immediate or sustainable return. Public and patient involvement is difficult to value in economic terms for a number of reasons. The variety of approaches, differences in objectives, and distinctions between individual and collective perspectives on its benefits all present practical difficulties. One problem from a financial and economic perspective is that the process of engagement by patients and the public is seen as equally important as the outcomes” (Pizzo, Doyle, Matthews & Barlow 2015).

A systematic review of PPI impact on health and social care research (Brett, Staniszewska, Mockford, Herron-Marx, Hughes, Tysall & Suleman 2014) collected the existing information into one paper. The idea of the research was to identify the impact of PPI in research on health and social care area. The main points of the review were as follows:

- Interest in involvement has expanded internationally with many countries now actively involving users in research
- Incorporating user views into the research agenda may lead to divergence from scientific methods and cause ethical dilemmas during the protocol design.

- There is also evidence of researchers' tokenistic attitude towards PPI, for example, researchers involving users to comply with policy or because they do not really understand the contribution what PPI could bring to the research.
- The practical aspects of planning, collaborating with users and managing user involvement in the research can be timely and costly.
- Much of the evidence base concerning impact remains weak and needs significant enhancement in the next decade.

## 6.2 Service user involvement research in Finland

Finland has a long history of using peer support and experts by experience in the field of mental health and e. g Alcoholics Anonymous' work bases on peer support. NGOs do not base their actions to the latest research, but they base their knowledge on the assets they have and common sense. It could be said that this kind of action has not been organized well or professionally and that is why the experts by experience's expertise have not been respected the way it should have been. The concept of an expert by experience is not very clear. It is something between volunteering and working. However, wherever these experts by experience have been used, their actions have been found relevant and good. Today they should be considered more as employees than volunteers. Experts by experience have widened the professionals' perspective of the overall treatment of the patients. (Hietala & Rissanen 2015.)

By this far only one good and relevant domestic research of service user involvement is done by THL (2014). They started Kaste- project in 2011 and one of their goals was to gather the information of experts by experience and how their expertise is and could be used in public health care services. THL conducted a web survey where they collected the data of the resources, needs and possible areas of development.

The survey (THL 2014) information was collected in the autumn of 2013. 104 people answered the survey from all over Finland and 30 of them presented a municipality or a hospital. Only 9 answered that their expert by experience field was the social services and health care. The survey indicated that there is expert by experience action in the field of

mental health and addictions. NGOs have provided services in different illnesses, but that information is not documented well.

The study (THL 2014) revealed that most of the experts by experience had had expert by experience training or at least they were going to the training in the future. However, there was nowhere to be found what valid training is even when most of the participants answered that training was required before a person can work as an expert by experience. People who had answered this survey had positive experiences about experts by experience. Their comments of the benefits:

- They are a good way to share valid information to other community members
- They can improve understanding about certain subjects and affect people's attitudes
- They share realistic experiences
- They are practical, the information is easier to understand
- They help professionals to widen their perspective to work
- They help people to empower and rehabilitate themselves

Most of the comments were positive but some of the negative comments were found, too:

- The professionals had prejudice against experts by experience
- Their actions/ appointments are not coordinated well. Experts by experience don't have legal employee rights and services
- The experiences of the experts by experience aren't universal. Their training varies and there's no clear definition of the concept of expert by experience
- Experts by experience are not volunteers but they don't have collective bargain either

Some development suggestions were mentioned as well:

- A nationally coordinated organization for experts by experience is needed to plead experts by experience rights
- Organized training and training methods are needed
- Experts by experience should be considered as plenipotentiary employee: occupational health care and other services
- Experts by experience are not volunteers and they should be considered as part of sustainable health care development

The survey was conducted in 2013 when there were not too many experts by experience in primary health care. However, pros and cons are found well. It would be challenging if experienced service users should be considered as equal partners. However, this kind of change is needed. The health care workers should be informed about the need of these experts and the experts actions should be organized better. (THL 2014.)

Many changes have been made since THL (2014) survey. Nationwide Key Project is encouraging hospitals and primary health care centers to educating experts by experience to achieve a better quality of treatment. Service users and professionals have understood the need of these services. Many case reports have been written by people who are both professionals and patients. In *Lääkärinlehti*, Ahlblad (2018) writes a story about a Canadian woman who got extra sensitive to everything; perfumes, chemicals and even electricity. This woman, Annie Hopper, tried to find medical help from different doctors but got no treatment until she discovered that her limbic system was too active and that was causing symptoms. Nowadays, there are all the time more extra sensitive people and many of them have a feeling that our health care system treats them as mental health patients and that is the reason why experts by experience' expertise is very important for these people. Ahlblad (2018) interviewed Työterveyslaitos senior doctor Markku Sainio who comments that experts by experience got better results in helping extra sensitive patients than educated doctors did. The DNRS system does not include any medication but more like mental practicing what a patient can do by him/herself. This method has helped people with fibromyalgia and chronic fatigue syndrome. Both syndromes are hard to treat with the help of traditional western medicine.

Linnanmäki (2017) argues about a problem in Finnish health care services; the services are not integrated, and the service users are suffering of the situation. The hospital and primary health care do not cooperate well enough for service users' good and that leads to even life-threatening situations. Those are luckily quite uncommon, but it happens. Sometimes the reason for the treatment and the question what the service user should do are problematic. The service user is forced to choose a procedure the professionals say because he/she does not have a clear picture or control of his/her own medical condition. This causes fear and distrust to services and professionals.

Linnanmäki (2017) continues that our health care system should concentrate on service user's participation; taking service users to be an active partner in his/her own treatment. This will be the biggest challenge in the future; to achieve better services means that the existing hierarchy between professionals and service users should be broken down. A service user should be interested in to be an active member in his/her own treatment and the professionals should hear their opinions when considering treatments. It has been easier to start with patient and public involvement to improve the system and infrastructure than to make the change to the professional - service user relationship.

The first steps have already been taken e.g. in Keski-Suomi central hospital where the experts by experience were following the actions in emergency room for several weeks. Seppänen (2018) writes about their findings. The experts by experience gave feedback and the results surprised Johanna Tuukkanen, the senior physician of the emergency room; the patients were feeling insecure and lonely. The service users did not get enough information on what was happening, and nurses were hidden behind doors and the service users did not know where they were. This was totally different kind of information what the hospital management expected. The professionals and management did not see these things as problems. The hospital changed their methods and the infrastructure of the emergency room. Today the nurses are closer to patients and the service users are better informed to create a safe atmosphere in the acute emergency room. This kind of patient and public involvement seems to be useful when creating a new culture of health care. However, the effects of patient's participation are still unclear (Linnanmäki 2017).

### 6.3 The beginning of the use of experts by experience in Finnish public health care

Päivi Rissanen (2015) has written an autoethnographic dissertation about being a patient in the Finnish health care system. It is by this far the only Finnish dissertation of the subject. It can be considered as the influence that created wider interest to service user involvement in Finnish health care. She has a long history of being a patient in mental health units. After many years of being a patient she found her way of handling her own feelings, motions and situation and finally she made a dissertation of her experiences. This was one of the earliest research in Finnish that brought up the service user's point of



view. Her texts started a revolution in mental health care and now the change is happening in other fields of health care, too.

She started to use term the expert by experience and that is the word the Finnish health care system knows and uses. There are some problems with the term as analyzed earlier but this dissertation caused a positive reaction where everyone in the field of health services knows what experts by experience are.

Rissanen (2015) criticizes the Finnish health care system wanting to give diagnosis to everyone. Our health care system wants to diagnose people and then they could be called patients. This creates roles. The professionals are telling the patients what to do and how to feel. We tend to treat the diagnoses and not the people behind them. Individuals are forgotten when professionals assume that all the people with the same diagnosis are the same. As being a patient, it is easy to be passive and to surrender under the expectations and treatments of the system. The patient is no longer a human or individual with his/her own will. This has been and still is a big problem at least in mental health care. Of course, we need diagnoses and we need guidelines how to treat a person, but we should understand that it is only one part of the treatment. There are many more levels where our health care system should be able to meet people; not only those with diagnosis but the people around them. Not all the skills can be taught in schools but some need to be experienced by yourself to truly understand. People who are only book-smart cannot give help to people who need expertise from people who are experience-smart.

The big problem is when the people start to see themselves as patients; they get used to routines and they are losing a touch of themselves. For some people this can happen even in days; they lose normal control of themselves. If we create a system where people could be heard and treated as humans, it would be beneficiary for the service users, professionals and the whole health care system. (Rissanen 2015.)

The most important and interesting part in Rissanen's (2015) dissertation is where she writes about her steps to get back to normal life. She writes about how important the peer support was; she finally and once again saw herself as a human and she noticed that she is not different. She is still a human. She had never really understood that she is not alone with her situation. Her story is a good reminder that mental and somatic illnesses walk

hand in hand. It should not matter why a person needs health services; the person should always be seen as an individual and she/he should allow to be who she/he is, and the treatment should be individual and paying attention to all person's needs.

#### 6.4 Service user involvement models in Central Uusimaa region

Many of the primary health care centers are offering peer support and expert by experience appointments (Järvenpää 2018a; Vantaa 2018). Primary health care centers have their own experts by experience and many are cooperating with local NGOs. The best situation is in Vantaa where an expert by experience has a vacancy in Vantaa primary health care center; this may be the future where an experienced expert is considered as equal a working partner (Vantaa 2018).

Järvenpää (2018a) primary health care center started expert by experience appointments in the autumn of 2017 with a cooperation of an NGO, Werkko ry. These appointments are mostly for people with social or mental problems or addictions, Experts by experience are trained and they work together as a team with a nurse and social worker. This service is available every weekday between 12.00-15.00 o'clock in Järvenpää primary health care center JUST.

One interesting concept for service user participation is Arkeen voimaa- project. These groups have meetings in several Finnish primary health care centers e.g. Mustijoen Perusturva in Mäntsälä. Arkeen Voimaa –peer support project bases on Chronic Disease Self-Management Program (CDSMP) invented in Stanford University in 1996 where the researchers made a study with over 1,000 people with some chronic illnesses; most of them had more than one chronic disease diagnosis. The process of the program is based on the experience of the researchers and others with self-efficacy experience. The assumption was that one could learn and master a new skill and affect one's own health. The results of the research were good: improvements in exercise, cognitive symptom management, communication with physicians, self-reported general health, health distress, fatigue, disability, and social/role activities limitations. They spent fewer days in the hospital and there was also a trend toward fewer outpatient visits and hospitalizations. The program is especially helpful for people with chronic illnesses, as it gives them the

skills to coordinate all the things needed to manage their health, as well as to help them keep active in their lives. (SMRC 2018.)

Arkeen Voimaa – peer support group is intended for people who have some chronic illnesses or some other challenges to survive everyday life. The group meets six times, once a week and 2.5 hours at a meeting. There are two leaders in this group; one registered nurse and an expert by experience. Both have gone through specific CDSMP training. Group activity helps participants to make and maintain positive changes in their lives. The results of these courses have been good in Finland, too: peer support helped people with surviving everyday life with chronic illnesses. (Arkeen voimaa 2018.)

Helsinki and Uusimaa district hospitals (HUS) have started their service user involvement and the use of experts by experience in 2017 (HUS 2018c). Their actions are more organized than in primary health care centers. They are educating their own experts by experience in cooperation with Laurea University of Applied Sciences. The education lasts six months and the students are both; ex-patients and hospital workers, mostly nurses. The teaching includes information of the organization, but it also helps experts by experience to cope with their own situation (HUS expert by experience interview 2018b). The third party of the expert by experience organization is a NGO, KoKoA (2018b), which is a national umbrella organization for experts by experience.

HUS, Meilahti hospital, Gastroenterology center started their experts by experience actions in the autumn of 2018. Their experts by experience have e.g. gone through organ transplantation. The aim in HUS is to develop and train the new methods of patient participation. The activities of experts by experience and customer panels are being modelled and established to become part of operations widely in HUS departments and hospital areas. Related to this, staff and customers are trained to become experts in shared expertise. (HUS expert by experience coordinator interview 2018b)

The experts by experience work together with HUS staff members, and they can participate in various work, steering, or management groups. Via shared expertise, the experts by experience discuss and participate in the development of HUS's operations and give their valuable customer viewpoint of the treatment process. They do not do any one to one work but are working more behalf of the organization. HUS does not cooperate with

primary health care centers (HUS 2018c; HUS expert by experience coordinator interview 2018b.)

#### 6.4.1 Customer panels

Service users have the possibility to participate in the development of health care services by becoming members of customer panels. Customer panels consist of customers or people who are familiar with the service, and professionals; both doctors and nurses. Service users are usually elected for these panels. The term usually lasts two years. These panels are an important channel between professionals and service users. (HUS 2018a.)

Panels usually have meetings two to four times a year. The purpose of these meetings is to create better services. The panel members find this method as an effective channel to build understanding between service users and health care professionals. The customer panel's service user members have a feeling that they have been heard and respected in the meetings. The health care professionals have a positive feeling of these meetings, too. (Mäntsälä 2018; HUS 2018a; Mustijoen Perusturva customer panel interview 2018a; HUS customer panel interview 2018d.)

#### 6.5 NGOs in Central Uusimaa region

There are many active NGOs in Uusimaa region. Many of these cooperate with local primary health care centers or hospitals (KoKoA 2018b; Werkko ry, 2018a). This cooperation is useful for service users to get more information and to find people with the same life situation. NGOs have valid information about what is not found in primary health care centers. It would not be meaningful to mention and present all the NGOs and that is why only three are presented; KoKoA because it is cooperating with public health care and Kasvava because they have long history of the use of experienced expertise. They have a unique and a little bit different perspective to service user participation. Werkko ry is an active NGO in Järvenpää and Hyvinkää municipalities.

Other active NGOs in Järvenpää is e.g. Setlementti Louhela which is partner in SOSKU-hanke. (Setlementti Louhela 2018) and Mäntsälän ja Pornaisten Muisti ry (2017) in Mäntsälä which runs the cafeteria in Mäntsälä primary health care center.

### 6.5.1 Koulutetut Kokemusasantuntijat

Koulutetut Kokemusasantuntijat ry, KoKoA (2018b) is a NGO that aims to bring together experts by experience nationwide. This NGO was founded recently, and it is needed. They cooperate e.g. with hospitals, like HUS, universities of applied science, like Laurea, and with Väestöliitto. KoKoA aims to be an umbrella organization for all the experts by experience in Finland.

KoKoA (2018a) is following Mielen avain – the guidelines of the project when defining what kind of education experts by experience should have. KoKoA offers an opportunity to get an expert by experience to tell about their experiences and that way anyone could become an expert by shared experienced expertise. KoKoA cooperates with hospitals but they also work for experts by experience benefit; KoKoA gives guidelines of how experts by experience should be treated and what kind of compensations they should get for their actions.

While writing this thesis KoKoA was contacted via email but they never answered via mail or a call. There are no phone numbers available on their web page. During the field research some members of KoKoA were met, but conversations did not include KoKoA itself but more the actions the experts by experience do. However, they seem to be very active organization. Their values are: individuality (a person should allow to be an individual as he/she is in society), all humans should be respected equally, equality, reciprocity and all the actions happen with confidence. (KoKoA 2018b.)

After hearing and studying about KoKoA it got clear that this organization's intention is good and in time it will be even bigger part of Finnish health services. Now, when everything is still very new, it will take some time to find the best ways to participate. This will need hard work, feedback of their actions and most of all; cooperation with hospitals and primary health care.

### 6.5.2 Kasvava

Kasvava is a small NGO placed in Pyhtää, Finland. The founder and CEO of Kasvava, Katja Lemberg, has a long history of being a patient in the health care system and as a worker in social services. Today there are several members in Kasvava and their methods and help are available for everyone in need. They have a sponsor that supports their actions in the area. With the help of a local businessman Reino Uusitalo, they have started interesting actions in two different locations in Pyhtää. (Kasvava 2018c)

Kasvava's working methods and tools have been developed in a long-term co-operation with service users since 2004. These methods have been used and studied in multi-professional client work in learning situations and in varying assistance situations among various social and healthcare providers including THL. The methodology is developed into overcome inequality and to minimize the waste of human capacity and resources. Kasvava is a structure in which everyone discovers their own skills and competencies. Kasvava takes a comprehensive and holistic approach to wellbeing. They are offering compassionate, people-centered approaches. (Kasvava 2018b; Kasvava 2018c.)

Kasvava members were contacted and visited in their house in Pyhtää twice. Their ideology and expertise are very useful when thinking about creating even better, equal person orientated health care where people's diversity is taken in question and everyone is met with dignity. Their goal is to treat people as individuals; everyone should get individual and equal care. Everyone should be allowed to be as they are. Their ambitious goals for creating better and equal society must be appreciated. Kasvava has a lot of valuable information and knowledge. This is a good opportunity to mix sociology, health care, practice and research. Their ideology could be brought to primary health care services (Kasvava 2018b; Kasvava interviews 2018c.)

### 6.5.3 Werkko ry

Werkko ry (2018a) produces peer support groups and experts by experience services for community members in Keski-Uusimaa; mostly in Järvenpää and Hyvinkää area. There are many active members in this NGO. During the background information search for this thesis their annual meeting was participated to hear their plans and interview the

members. This NGO has members who have suffered from mental health problems or addictions and social and health care professionals who want to get closer to these people with experienced expertise.

One of their most active members was interviewed (Werkko ry interview 2018b). He has a long history of alcohol and drug abuse. Today he is sober and uses his energy to help other people in need. He is one of the experts by experience who works in Järvenpää primary health care center, too. He finds that these services are needed by the service users and he wish that this kind of service is part of every primary health care service. He had a good experience of cooperating with the primary health care center.

## 6.6 Service users' thoughts of service user involvement

During this thesis process the service users were asked about their thoughts of the existing system (Mustijoen Perusturva custom panel interview 2018a). Many of the people were using primary health care services and they knew how to act when they needed services. However, contact information to the primary health care center was hard to find and at least during the flu season there are problems to make a contact with the primary health care center or no one answered the call back. There are different numbers to urgent and non-urgent situations. The service users were confused what kinds of situations were urgent and what were not. This was one good example of a situation where health care center employees did not understand until the customer panel members mentioned about it.

The problem is not found only in Mustijoen Perusturva. Some of the appointments, mostly nurse's, can be booked online but to get a doctor's appointment a person must call or visit primary health care center during office hours. A primary health care center employee interviews (triage) the patient and books a doctor's appointment if needed. (Järvenpää, 2018; Mäntsälä 2018 & Tuusula. 2018).

Many primary health care centers advise that if the situation is urgent the call should be made between 8 and 9 o'clock and non-urgent issues after these hours. This model does not include life-threatening situations where the people need immediate help. (Järvenpää 2018b; Mustijoen Perusturva 2018b; Tuusula 2018.)

It is surprising that almost every primary health care center offers services only via phone calls or a person need to visit the primary health care center. Some of the primary health care centers do not even offer call services but people must leave a callback request, and someone calls back later (Helsinki 2018).

Call services bring inequality to our health care because if a person has problems with hearing or speaking, they must visit the primary health care center to make an appointment. Distances to the closest primary health care center may be long and public transport has poor connections. People who work office hours do not have always an opportunity to call a wait on line for long times. These are only some examples, there are many reasons why the existing system is not equal to all the service users.

If a person manages to book an urgent time, the doctor usually has 15 to 20 minutes time to do a diagnosis and start medical treatment and order laboratory tests if needed (Mustijoen Perusturva customer panel interview, 2018a). If a person needs an appointment for chronic symptoms they may need to wait for it many weeks and often only one symptom per appointment is allowed. This was surprising information for the researcher, too. However, most of the service users were satisfied with the service they got.

These existing experts by experience are a certain kind of people; they are using the services and are willing to contribute their help to improving the system. These experiences were asked from HUS Customer panel (2018d). The meeting was full of joy and people were open and wanted to share their feelings and information. They were asked whether they feel if they can represent all the service users. Some of them thought that they were doing their best the way they can and some of them did not seem to understand the question (Mustijoen Perusturva interview 2018a). However, this was a good conversation opening. All the experts by experience who were part of customer panels told that they were heard and that the professionals respected their opinions. Many of the experts by experience did not like to be called experts. They found the term problematic. One expert by experience said it well during a HUS customer panel meeting (2018d) when asked how they see their role in the health care system (translated from Finnish to English):



I'm not an expert of being a service user. Doctors were experts when they treated my cancer. They have had many years of medical training to take care of people and treat cancer. I'm not an expert of being patient. I don't know how all the patients are taken care of. I have only my experience of being a service user... I'm not an expert. I'm a human being with a story and if I can help someone else to survive the journey I had to do alone I would be very happy.

When asking about the future, the experts by experience answered that they hope that service users could be more involved when creating better services. The services should be built from service user perspective. The help, peer support and information should be easy to be found and it should be offered better. The service user often uses all the possible services; primary health care, hospital care, social services and pharmaceutical services. All the services should be built the way that these instances cooperate for service user's good. When people get the help, they feel understood and taken care of, it could help them recover faster and better. (HUS Customer panel 2018d; Mustijoen Perusturva customer panel meeting 2018a.)

## 6.7 Conclusion of findings

The service users can be involved to public health care many ways. According to literature search it is easy to see where Finland is getting the influence; they are following the methods from the UK. The NHS has put a lot of effort to create equal services. The models in the UK focus on service user involvement in creating better services for service users. There was no research found where a service user would work helping another service user which seems to be the model that is used widely in Finnish primary health care services. In the UK the service user involvement has been studied more and they are facing more problems; Can a service user present all the community members? or What should we do when not everyone wants to be an active member of his/her own treatment. The UK is using service users as researchers to find the most effective ways to create better services.

Monitoring has been considered an effective way to improve equality in services among the professionals in the UK. They use resources to find who are using the services and they pay attention especially to those who are not using the services. That kind of model is not found in the literature in Finland. The service user involvement is better organized

in the UK than in Finland. The network between NGOs and public health care services is developing and organizations learn of their experiences. That will promote the development process. It is good that the management in Finnish health care services is interested in service user involvement as well as those who are working in customer panels and as experts by experience. However, most of the health care employees and service users are not familiar with service user involvement and it takes time until the Finnish health care services are ready for this cultural change.

## 7 PARTICIPATORY DEVELOPMENT PROCESS

The development process started in February 2018 in Mustijoen Perusturva. Mustijoen Perusturva produces primary health care and social services in Mäntsälä and Pornainen municipalities. Pornainen health care center is a small satellite unit whereas most of the services are placed in Mäntsälä. The service user involvement is one of the biggest innovations in the field of primary health care services and Mustijoen Perusturva wanted to start their experts by experience actions, too. The head nurse and leading physician are focused on service user involvement and were interested in bringing new innovations to primary health care.

I have a triple role in this process; that of a researcher, a primary health care employee and a service user. I started working for Mustijoen Perusturva in the beginning of February 2018. My supervisor had just an idea of experts by experience appointments in Mustijoen Perusturva but not any specific plans. I got support of the management to create something new to the field of primary health care.

The development project started with an information lecture for Mustijoen Perusturva employees on their weekly meeting. The first presentation was on March 15<sup>th</sup>, 2018. The Kaste project (THL 2014) findings shows that one of the biggest problems with experts by experience in public health care services is that educated doctors and nurses do not understand the purpose and the potential and meaning of them. The point of this

information lecture was to inform professionals about the project and get feedback. They were interested in the project, but it was very clear that most of the people did not have any knowledge of experts by experience.

However, the audience got interested in the idea and shared their suggestions. They suggested that expert by experience appointments are needed in the fields of dementia, pain, heart diseases, and cancer as well as stomach problems. The caregivers were mentioned multiple times, too. They need more support than they get at the moment. This conversation and feedback modified the idea of experts by experience appointments in Mustijoen Perusturva; the service should fit and should be available to all the service users and not only for a specific group of service users. (Mustijoen Perusturva employee meeting, 2018c.)

### 7.1 Cooperation between Mustijoen Perusturva and Kasvava

The requirements for the NGO that could be suitable for cooperation was that they must have knowledge of being experts by experience. They must have skills to help people in difficult life situation and help should not depend on the reason of the life crisis. These experts by experience must be reliable and they need to be mentally and physically in that kind of phase that they can help others. The most important thing is that they should be able to be equal human beings with the service users and equal partners in Mustijoen Perusturva. Their goal should be to empower people.

Kasvava's ideology and actions fit the needs. Kasvava members have been working as experts by experience in the field of sociology as experts by experience more than a decade. Part of their ideology comes from the UK but most of it from self-experiences as being experts by experience; all their methods are based on humans and their needs.

Kasvava was introduced to Mustijoen Perusturva management and they agreed in cooperation during the summer 2018. The management was in contact with Kasvava to gather deeper information of their actions. The management agreed with the researcher of this thesis in that Kasvava's ideology fits the needs of Mustijoen Perusturva.

## 7.2 Creating experts by experience appointments

The experts by experience come from Kasvava and they are using Kasvava methods. Kasvava members are doing this voluntarily and they have a chance to abstain from doing the shift. In these cases, Kasvava will arrange someone to cover the shift. At this moment of the pilot there is no need to recruit or train other experts by experience. The aim of these appointments will be; meeting service users as equal individual human beings and service user involvement as a method for empowerment.

The appointments take place in Mäntsälä primary health care center. Mustijoen Perusturva offers the appointment room and Kasvava decorates it according to their ideology. Mustijoen Perusturva pays for these appointments directly to Kasvava. This was Kasvava members' wish. At the beginning of the pilot, the appointments happen once a week between 8 and 16. The first appointment lasts 2 x 45 minutes and if there are following appointments they are 45 minutes.

Mustijoen Perusturva employees are informed of what kind of service users could benefit from these appointments and they can share the information to service users. Some information could be found on the info screens of the primary health care center. Service users can find information also online. Kasvava experts by experience share their own stories and that is a way how people can identify with them. These stories could be found online and written in info leaflets. A person does not need a doctor's admission note or any visit to any health care professional to get an appointment time. A service user can book an appointment him/herself without any assistance.

Service users are informed that the meaning of these appointments is to empower them. This means that everything that happens in those appointments is voluntarily and is meant to help service user him/herself. They do not have to share anything out loud during those appointment sessions if they do not feel comfortable to. All the information and help are only for the service users if they choose to. These appointments are not documented and that will give the service user a freedom to speak and act the way they are without fear of any marks on their medical records. The very first experts by experience appointments in Mustijoen Perusturva are scheduled to start at the beginning of December 2018.

### 7.3 Motivation for the future

It is easy to get motivated of the idea of service user involvement. Everyone wants to add their contribution to this revolution of health care. The reality is not that easy. People are used to certain kind of services and it is hard to change old habits; even if the new method would be better. Some service users are interested in the participation, but some does not seem to understand why they should have any opinion when they visit primary health care; it is doctor's job to tell what to do. The employees would need a lot of training to understand what service user involvement means. This education should be part of the training in nursing and medical schools.

According to the conversations between management while writing this thesis, it seems to be that management is the most interested in these changes. They are more interested in than other employees or service users. It is important that the management is supportive; that is the way to make this as sustainable development. However, money is tight and primary health care centers should save money and not spend it on something that may not bring the money back to the system.

It is not enough that management, some service users and some employees find this service user involvement important. These experts by experience appointments are meant for those people who may not find these services; this new kind of thinking may feel scary or unreliable; how can a person without any degree be able to help? The primary health care employees are not trained to understand the benefit of experts by experience. It will need time and effort to make the change, but the change needs to start somewhere.

When it comes to the development project in Mustijoen Perusturva it is something that only time will show. There will be organizational change in the beginning of 2019; six municipalities are creating a coalition that produces primary health care services to all these 6 municipalities. This means that Mustijoen Perusturva will be part of this new health care service provider. This will give an opportunity to bring the expert by experience appointments in action in all these six municipalities or it can make the development process of this thesis useless.

## 8 DISCUSSION

### 8.1 Equality in Finnish primary health care

Not everyone needs same services, but everyone should have an equal possibility to get the services. That is why public health care services should be developed to answer all people's needs. Everyone should have a right to be the individual they are, and everyone should get equal health care services. It is sad that the reality is not that. During this thesis process there were many real-life stories where people were not treated even as human beings. Kasvava CEO, Katja Lemberg (2018c) shared her story of being a patient in public mental health services. She remembers sitting in a room full of professionals; this was a treatment meeting where the professionals were there to help her, an individual human being. All the professionals did their best to help her to recover from depression; the professionals made a daily routine for her. She was supposed to wake up every morning and go to a walk in a forest for one hour. No one asked if she even liked walking or nature. She does not. She remembers that no one asked her opinion of the treatment. No one asked what she thought she would have needed at that time. She was not an individual. She was just an object. Other Kasvava members (2018d) and Päivi Rissanen (2015) share similar experiences.

The challenge for the primary health care is to create holistic treatment. It is the person who needs help; not the diagnosis. There is not and never will be a one-fits-for-all solution. People change and their needs change. However, the people are those who the services are supposed to be created for. The equality should mean that everyone could be able to get help. There should not be a situation where money could buy better primary health care services. There is already inequality in a situation where a service user needs expensive medications, and some have not money to buy those. However, the quality of services should be equal for every service user no matter how much money they have.

I understand that it is almost impossible to achieve equality in health care services but that should be the aim of actions. However, this aim creates multiple ethical problems. One example from recent years is when Kela decided to lower the coverage of diabetes type two medications in the beginning of 2017 (Terve 2018; Kela 2017). This caused a

lot of public discussion and created an ethical dilemma; what are people's responsibilities to take care of their own health if the medical situation is a consequence of bad life style decisions and what kind of medications should be covered by tax payers. On the other hand, if people do not take their diabetes type two medication it can lead to bad medical conditions and even hospitalization which tax payers pay, too. This thesis will not take any side in this ethical dilemma. However, this thesis aims that everyone should be able to get equal services. It is an individual's personal choice to decide what they are willing to do to improve their health. Primary health care services should be there helping the service user to achieve those goals, e.g. weight loss.

## 8.2 Researcher's self-experience of development process

Doing this research was an eye-opening experience for a researcher. I had a triple role in this process; a researcher, a primary health care employee and a service user. This made the process interesting and challenging, as well. As being a part of the development process led me in to a situation where I must evaluate my expertise as a nurse and my understanding of the whole existing health care service system. People are educated in nursing schools and medical schools to treat people and the quality of treatment is measured certain ways. Before this project I thought I was a good nurse; treating people equally and giving the best possible treatment. However, I have never liked to be a service user in health care services. I have always had a feeling that I am not considered as an equal person in treatment situation. Thereby, I do not use services almost at all. I never saw any contradiction in my actions before this project. I just tried to do my best while working as a nurse and avoid being a service user. When I got an opportunity to try Kasvava empowerment method I finally understood what was missing from my experiences in health care services; Kasvava met me as an individual human being and my needs were heard. The meeting was eye opening. I did not expect certain strong feeling.

This process changed my ideology of good quality of health care. It was also shocking to understand that the treatment I had been giving to people over the years was not that good as I have been thought. After a while I started to see the problems in the primary health care system. There were signs of inequality, bureaucracy and improper services. There were three groups of people who paid my attention; those who used the services a lot but

never seemed to be satisfied, those who would have needed help but there was no service to offer and those who were not using the services at all. It is frustrating to try to help people in their life situation with such limited possibilities. E.g. a person whose child had died previous night and she was in primary health care center to get a sick leave paper. She got the sick paper and some phone numbers where she could call, if she thought she needed some support. That was all the primary health care center had to offer.

I tried to talk about these with other colleagues, but they did not seem to understand my sayings. I could not blame them because I knew what their thoughts about good quality of services was. I had had same ideology only six months earlier. Some of the young doctors seemed to have better understanding of service user involvement than others. That was a positive surprise. They understood that service users should be active members in their own treatment. However, the service users did not understand if their opinion were asked. They gave feedback that doctor was not professional because she did not know what to do but she needed to ask service user's opinion. I got same kind of feedback after nurse's appointments; some of the service users were pleased, some confused and some even angry when I asked their opinion of their own health and treatment. The cultural change will need time to become new normal.

Every instance is creating new ways for service user involvement, including me with this development process. Their and mine actions are good, experts by experience are affecting the existing health care system. The action is happening in every level; NGOs, primary health care and hospitals. However, this existing method is not based on service users' needs. It is created by professionals in primary health care centers and hospitals, separately. I must say that this development process could have been done better if I had had all the information I have at the end of my thesis process. The development process is not following service user's treatment path. It would be about a time to see these actions from service user's perspective and develop the system from that point of view. As it has been written earlier, many people are using both services; primary health care and hospital services. The service user involvement actions should be available to service user during his/her whole treatment path; from the beginning in the primary health care center, to hospital care and back to rehabilitation in primary health care center.



It is understandable that the change takes time. It is not easy to change the ideology of health care in even years. It is hard to understand that there are knowledge and information that cannot be taught in medical schools. However, it would be needed if the aim is to create better services for service users. Service users should take part of the research as researchers and not only as an object. The service users are the experts of using the services and their expertise should take in consideration when creating new models of health care services.

The participatory process of this thesis is only one way to improve service user involvement and equality in primary health care services. Only the time will show what kind of benefits experts by experience and other service user involvement actions bring to public health care services. The figure 3 is created for this thesis to show what kind of possibilities experts by experience action could bring to primary health care services. It will need time and openminded decision makers; the health care professionals and service users need education. However, the experienced experts hold in so much potential that it would be stupid to not to use their expertise.

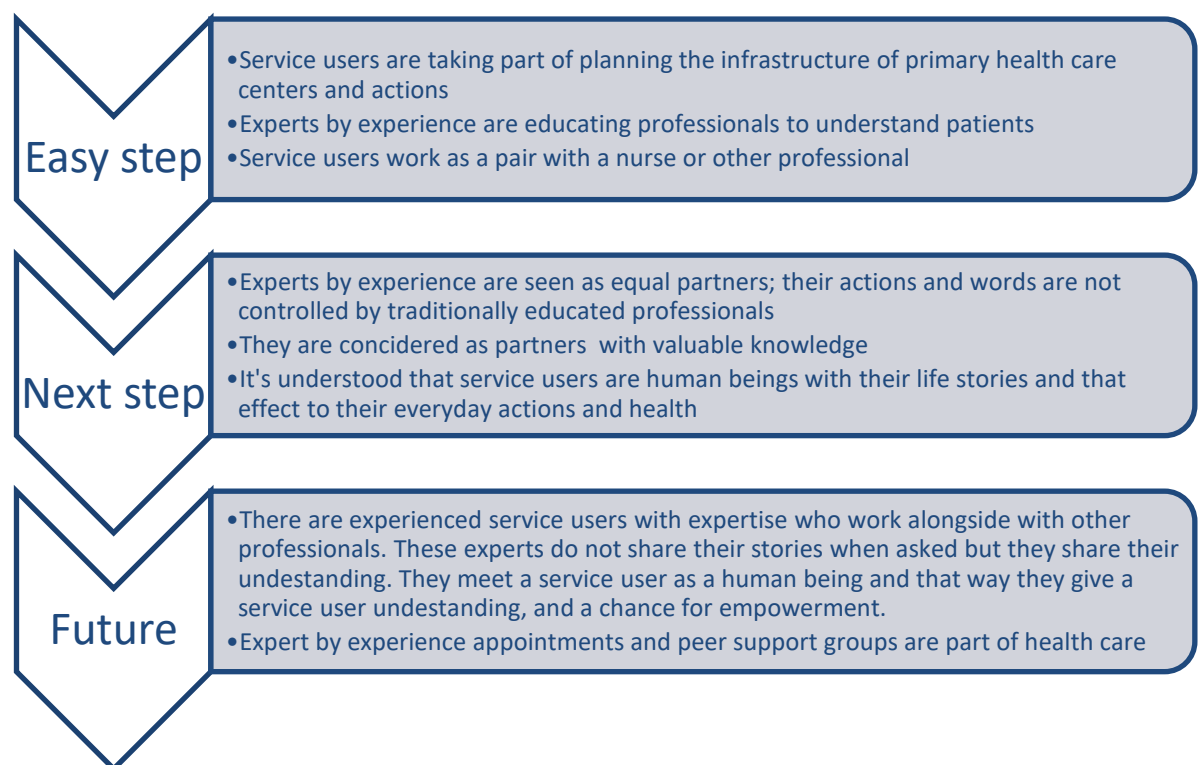


Figure 3. Experts by experience in the future

## 9 CONCLUSION

The field of health care is changing. The change is happening in grass root level and from top to down. The Ministry of Social Affairs and Health Services started a Key Project, THL is collecting data and giving advices of service user involvement and experts by experiences, and hospitals and primary health care centers are building their own expert by experience systems to improve equality and quality of services. The future brings more challenges when SOTE (health care service reform) is changing the field of health care services. The time will tell if they succeed creating more equal services (Sote 2018).

While writing this thesis it has been encouraging to see how much people are willing to do to achieve better services for all the users. People's intentions are good and if situation is seen from many perspectives the results are good, too. There is still a long way to achieve equality but the change for better is happening. The experts by experience are motivated and satisfied to their actions in public health care. Health care workers are getting more familiar with experienced experts and even service users are getting more familiar with being an active member in their own health care. More research is needed, and more development projects and processes are needed to create the best possible health care system to Finland.

Equality, empowerment and service user participation should be remembered in every decision and change what is made in the field of health care services. Cooperation is needed, and the system should be more organized; service user's perspective should be heard even better, and health care professionals should get more education of the meaning and need of this change. It will need only a little faith and intelligence to find the ways and act the most humane way.

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