1032users

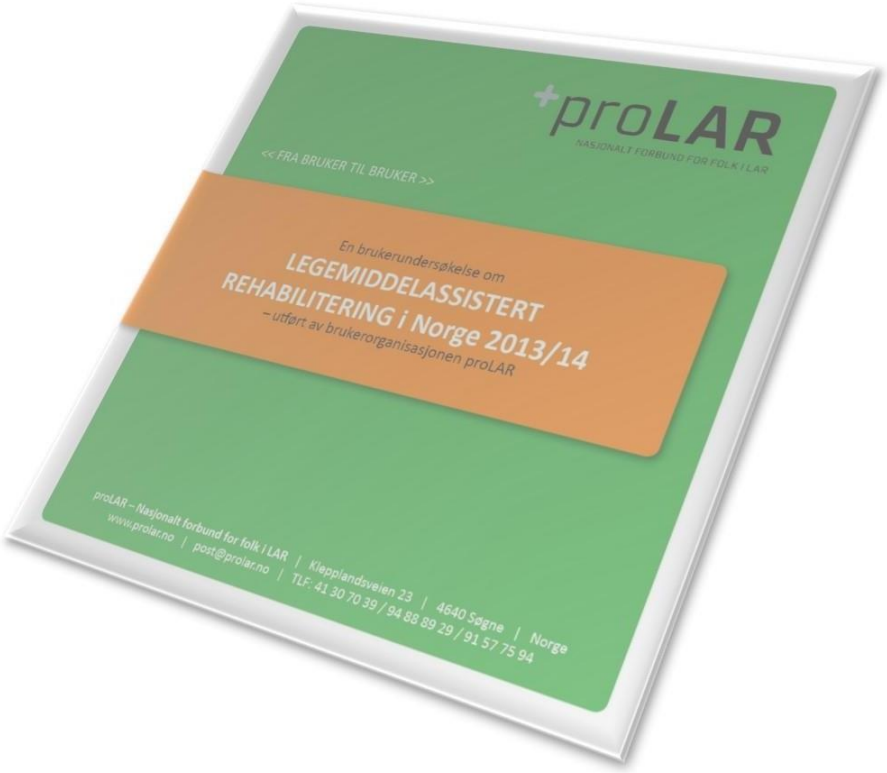
-About OMT in Norway

A "user to user" survey conducted

by

proLAR

NASJONALT FORBUND FOR FOLK I LAR



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Preface

This report presents results from proLAR's user survey
"From user to user" and was written in collaboration with the Norwegian Centre for Addiction Research - SERAF at the University of Oslo.

The goal of the user survey was to find out more about how people in OMT experience the OMT system on a daily basis, as well as gain a better insight into what we at proLAR should focus on going forward. Thank you to all the participants who took the time to respond to the survey, who provided thoughtful feedback and suggestions for improvements for OMT treatment in Norway, and who were willing to share personal information and experiences.

The user survey was inspired by, and based on, a Swedish user survey from 2012 under the auspices of the Swedish Drug Users Union. We thank you for contributing important experiences from your work into the design of our survey. The project group that developed the questionnaire further consisted of Ronny Bjørnestad, Tina M. Vestergaard, Geir Holum, Lena Marie Brun and Tone Øiern.
All proLAR employees have contributed input, acted as sounding boards and reviewed the data.

SERAF participated through contributions from Ashley Muller, Pål H. Lillevold and Thomas Clausen, with advice and input during the planning phase, practical assistance in connection with the data work and with analyses and report writing. A special thank you to Ashley Muller from SERAF who has made a great contribution to the analyses and report writing.

We thank all clinics, OMT departments, and hospitals who forwarded the questionnaires to their patients. A big thank you also to the Norwegian Directorate of Health for contributing financial support.

User quote:

"To be treated like ordinary people with the same respect, you should not feel ashamed to be an OMT patient."

Table of Contents

Summary

We at proLAR have received more than 1,000 responses in this first Norwegian user survey completed by people in opioid maintenance treatment (OMT). It is also the first user survey of its kind in the Nordic countries, with a national sample.

The sample is considered to reflect to a large extent the national patient population in OMT as described in the national OMT status report; the report is therefore considered to provide important complementary information about people in OMT and the experience of the treatment.

The main findings show that:

- As a main trend, people are satisfied with OMT overall, and see OMT as a positive influence in their lives. Most people report that the main reason they started OMT was the desire to improve their quality of life.
- The exception to a large degree of satisfaction with the treatment treatment organisation for OMT - is the follow-up from the Norwegian Labour and Welfare Administration (NAV), with which many people are dissatisfied.
- Many people struggle, with little social contact and sense of belonging and few or no leisure activities. Level of connectedness with the labour market, education, and social networks was somewhat low. 40% wanted to get a job or go to school/university, and often these were the same ones that started OMT with work/education as motivation. School/university is especially relevant for women.
- Satisfaction with OMT is not synonymous with the experience of user participation. Many people want to be heard to a greater extent than at present. For most people, the OMT system is perceived as being too flexible, and many people feel that they are not being treated on an equal footing with other patients in the health care system. Concerns about access to pain management if needed and/or lack of respect during urine sampling are often cited as examples where user participation is perceived to be too low.
- Contrary to the concerns that some people in OMT have in relation to Subuxone, Subuxone users do not report multiple side effects and are relatively satisfied with the OMT system and have the same user participation as others.
- A vulnerable group was identified and the characteristics of the group can be summarised as - those who are middle-aged have been in OMT for a long time and are most often men with insufficient social activities. This group gets on the least well in OMT, they have the least user participation and they report more risky behaviour. Medium-term participation in OMT can therefore be seen as a vulnerable phase, which should receive extra attention from the treatment organisation.

Based on this report, we have identified some vulnerable groups; including those who are least happy with OMT, and therefore need more follow-up and attention.
The importance in gaining a benefit from OMT treatment, and of improving OMT to make it a more optimum and individually tailored intervention for the majority of people, but especially those who are struggling the most. This is possible only when the users are heard, seen, and listened to. This type of representative, user-driven research is therefore a very important supplement to other knowledge about OMT.

1032 users to users: A national survey of opioid maintenance treatment

English summary: In the first Norwegian user survey of people in opioid maintenance treatment (OMT), and the first survey among Nordic countries with a national sample, Norway's user-led advocacy group *proLAR* has polled more than 1,000 individuals in OMT. The sample presented closely resembles the patient population as systematically reported in the national OMT Status Report, and therefore presents important complementary information about individuals in OMT and their treatment experiences.

Highlighted findings include:

- Respondents are overall highly satisfied with OMT, and OMT is seen as a positive influence in their lives. By far the most common reason to initiate OMT was to improve quality of life.
- Satisfaction with the entire treatment system was also high. An important exception was communication and cooperation with the Norwegian Labour and Welfare Administration, where more respondents were dissatisfied.
- Social contact and activities are a struggle for many, and reflected in low participation in the workplace and educational system and in weak social networks. Yet 40% still wish to work or study, and for many, this had been one of their original motivations for beginning OMT. Women, who reported lower educational attainment than men, were particularly interested in beginning to study.
- The high level of satisfaction with OMT does not correspond, however, to a sense of patient participation. The OMT system is often described as inflexible, and many do not feel they have a voice in their own treatment planning. Respondents say their OMT status induces differential treatment in the healthcare system than other patients receive, and this is felt acutely as a lack of respect during urine testing and in a common concern that appropriate pain medications could be withheld from them in emergencies, due to being in OMT.
- A positive finding is that those who take Subuxone do not report any more side effects than those who take Methadone or Buprenorphine. They are equally satisfied with treatment and report the same patient participation.
- One group emerging as particularly at-risk is made up of some – often men – who are middle-aged, neither the newest to OMT nor those who have been in treatment the longest, and appear to have the weakest social ties. They are most dissatisfied with OMT and report low levels of user participation, and they also report riskier substance use. This time phase in OMT, between the first several years of more acute case management and the stabilisation associated with many years' experience, may be a susceptible phase for them and warrant closer follow-up.

This user survey has helped to identify several vulnerable groups, including those who seem to be functioning poorly in OMT, and to whom the treatment system must pay particular attention. In order to optimize the benefits of OMT for the most, and to ensure that OMT can be extended and individualized to reach people with different needs, including those who need the most support, the voices and feedback of users themselves must be taken into account. This type of representative, user-driven survey is therefore an important supplement to existing knowledge of OMT and a treatment planning resource.

1. Content of the study

1.1 Background

People in OMT experience the treatment they receive very differently. Differences from region to region play a major role in the degree of satisfaction they experience and whether there is user participation.

In 2014, proLAR prepared a questionnaire with a total of 50 questions, which dealt with different aspects of what it means to be an OMT patient. We wanted answers on how users experienced their own treatment. We wanted to find out more about how they felt, what they thought, and what their experiences were. What their relationship with the support system was like, and what support they might have had from it.

To develop a questionnaire we set up a working group of employees and volunteers in our organisation. In addition, we brought in a professional who helped us to organise the form. We set up a reference group where we tested out the form and went through the questions to see if it was too demanding or took too long. This gave us an indication that the form was feasible and that it took no more than 10 - 12 minutes to complete.

1.2 Why the user perspective?

We had the belief that a user to user survey would give us honest and direct answers. The strength of such surveys is that, as a "user", you do not need not fear reprisals by telling the truth about your own situation. Previously, very few such studies have been performed. There are only a few small ones that can compare with our user survey. The REHAB pilot "The good life with OMT" was carried out in 2006 and had 227 responses. The user perspective, and what we as patients enrolled in the specialist health service (OMT) think about the treatment we receive, is the report's most important message. These are the users' own experiences, and exactly what we wanted to highlight with our user survey.

Every year, SERAF - the Norwegian Centre for Addiction Research publishes its own status report where they, using the OMT regions, obtain answers to their questions. This is done together with the users in person and/or via telephone interview. It can also be the case that health professionals complete the survey on behalf of patients. proLAR has previously pointed out that there is a problem with these status reports, as they are not always honest

Responses from users. This is of course a fear of reprisals that will affect their items such as collection/choice of medication etc.

As our report shows, many people feel that they have had the opportunity of a much better life with substitution treatment, and are quite happy with the scheme. Another point of view that is also very important is the degree to which someone is satisfied with the way the treatment is given or implemented. Here our report shows that there is an obvious division when it comes to this question. Even if you are satisfied with having OMT - you are not necessarily satisfied with the way you are treated or the way the treatment is given. User participation within OMT has for many years been a hindrance and something that has proved difficult to get to work well in practice. In many cases, the need for control has become so great that it has made the rehabilitation part more difficult than it should be. This is an issue that needs to be improved if one wants more people to succeed with their course of OMT.

Another important aspect of our user survey was to look more closely at reported side effects of medication use. Many people in OMT claim to have some side effects. We therefore used a lot of space for this particular question, and received an enormous amount of feedback on this.
As a user organisation for people in OMT, we are concerned about health, and we know from experience that the reporting of side effects is rarely recorded/reported by the OMT consultants.

1.3 Sample and methods

Our user survey was to be spread across the country, and we wanted a broad participation from the OMT users. We contacted the various regional health authorities and departments with responsibility for OMT. With the help of these we were able to send out our material which consisted of the questionnaire and a document explaining the survey and who we were. It was important for us to tell the users in OMT that we as a user organisation wanted to know more about their everyday lives. Only with the help of the users themselves can we gain knowledge in order to improve current practice.

The user survey itself was anonymous and voluntary to answer. There was no way a respondent could be recognised or linked to their OMT centre. Along with the material was a pre-paid envelope, which they themselves could post to the return address at proLAR's head office in Søgne. In total, about 6,000 copies of our user survey were sent to the country's OMT patients. The regional health authorities provided addresses for

their patients in their region. They made it possible to send out the questionnaire to all OMT patients, who at that time had a fixed address. A few OMT regions could not help proLAR with sending out the material, as they had limited capacity or did not want to assist with the survey.
In addition to this sending out of material, proLAR visited some low-threshold locations in Oslo, and delivery locations elsewhere in the country. There, OMT patients had the opportunity to respond in person and hand the sealed envelope over directly to a proLAR employee. We did this to ensure that users there also had the opportunity to answer our survey. We wanted to reach a group that might not receive it by mail or that we were afraid would not respond. We could probably do this to a much greater extent, but we were unable to do this due to capacity.

The deadline for returning the questionnaire was set to 1 April 2014. But we also included some responses that were received during the month of May. In total, we received 1,042 response envelopes before we started our work to enter the responses electronically. In the end, data from 1,032 respondents could be used.

There is reason to believe that some OMT patients in Norway have not answered our user survey because they found it a bit too big and extensive. Another reason for low response may be the problem of having a permanent address, with a lot of moving and address changes. There are also grounds for thinking that many of those who have returned the questionnaire are OMT users who are quite well functioning.

Our ambitions with the report are that it can be used in several ways: As a tool to improve current practice, as a description of challenges between the support system and users, to identify the areas where patients in OMT themselves believe that there are everyday challenges, as well as pointing to good examples and opportunities for increased user participation.

1.3.1 Methodological reflections

The sample is considered to reflect, to a large extent, the national patient population as described in the national OMT status report, with regard to all demographic data, OMT medication and dosage, delivery location and health.

The representativeness of the sample used by proLAR		
	proLAR	**Status report**
Gender		
Women	34%	30%
Men	64%	70%
Age	40-50	43.7
OMT medication		
Methadone	41%	39%
Buprenorphine/Subutex	41%	36%
Subuxone	19%	22%
Benzodiazepines on prescription	26%	27%
Collection point:		
Pharmacy	59%	50%
OMT measures		10%
Urine samples: at least weekly	37%	51%
Individual Plan	53%	29%
Responsibility group meetings	62%[a]	54%[b]

[a] Over the course of the last 6 months; [b] Over 3 months

There were a few exceptions: A few more people in the user survey came from Eastern Norway and fewer from Southern Norway (50% and 11%), than in the status report (37% and 24%). Urine tests were less frequent among people in the user survey (37% were tested at least once a week) than nationally, according to the status report (51% were tested with the same frequency). More users in the user survey have an individual plan (53%) than the average in the status report (29%).

That is, we have no reason to assume that the participants in this user survey are not representative of the OMT population in general, even though this user survey represents only a portion of the users in OMT; 1,032 persons, about one-seventh of all persons in OMT. However, we should be aware that, as in all other patient outcome studies, including the National Status Survey, there will be a possibility that those responding are a "skewed sample"; or, to put it another way, a selection of patients that differs somewhat from those who do not answer the survey. It is customary to assume that at the group level, those who respond to surveys are slightly better off than those who do not respond to surveys. The fact that most of the respondents in the proLAR survey responded to a questionnaire they were sent, shows that they have a postal address, reply to letters, and therefore a reasonably good level of functioning.

Nevertheless, during the data collection, proLAR was careful to try to include not just people who were well functioning. Some forms were also collected through outreach activities aimed at low-threshold locations, including in Oslo.

The survey often asks questions with a time perspective, where the respondent reflects on how various aspects of their health and life have changed since they started OMT. Nevertheless, the information we have from the survey is gathered at a single point in time, (what is known as a cross-sectional survey). That is, we can describe well the different groups of participants and compare at the group level their different characteristics with regard to experience of OMT, and so on, while with this type of study you cannot say anything with any certainty about causal relationships. Future user surveys with follow-up over time, i.e. the repeated collection of data from a single sample, may provide additional knowledge about causal relationships.

This user survey is similar to previous user surveys from Denmark and Sweden, but stands out by being the most comprehensive in terms of number of participants, national prevalence and the thorough description of side effects, stated reasons for any leakage and abuse of OMT medicines, satisfaction with various aspects of the treatment, and the experience of user participation. The data therefore provides an opportunity to identify groups that are struggling more than others in OMT.

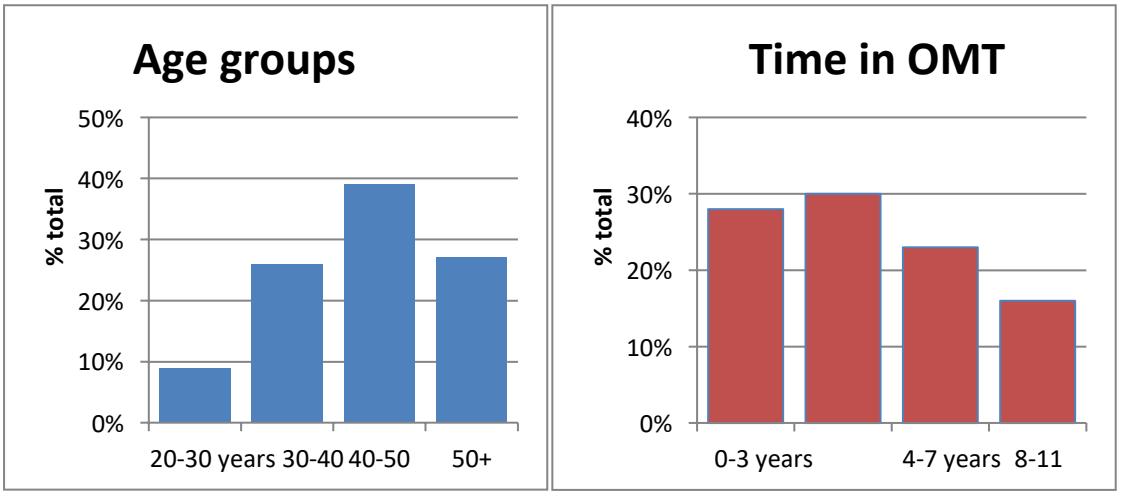
2. Feedback from people in OMT; results from the user survey

2.1 Group description

2.1.1 Gender, age, time in OMT, region

350 (34%) respondents were women and 658 (64%) men, (2% or 24 people did not indicate their gender in the response). The largest group (39%) was aged 40-50. The time they had been in OMT was almost equally divided between 0-3 years (28%), 4-7 years (31%), and 8-11 years (24%), while 17% had been in OMT for 12 years or more. Half (50%) came from Eastern Norway, one fifth from Western Norway (22%), and between 8-12% each from Southern Norway, Central Norway, and Northern Norway. The survey here is somewhat skewed towards Eastern Norway compared to the Status Report, where 37% of people in OMT are in Eastern Norway and 24% in Southern Norway. This may be because proLAR visited many low-threshold OMT initiatives in the Oslo area to ensure a more representative selection.

The time in OMT was equally divided between the regions, with one exception, the Western Norway. This region had a larger proportion of people who were "new" or had been in OMT for a shorter period of time (40% of people in Western Norway had been in OMT for less than 3 years) compared with about 25% in this category in the other regions. Eastern Norway and Northern Norway had the largest proportion of people over 50 years (approx. 30% each).



2.1.2 Health

More than half say that their physical health is better now in OMT than before they

started OMT and half say that their mental health is better in OMT than before OMT. More importantly is that the vast majority of those that self-reported "poor" physical health and "poor" mental health prior to OMT say that their health has improved (84% and 68%) since they started OMT.

Nevertheless, there are some people who report poorer health now than before they started OMT (28% with poorer physical health and 21% with poorer mental health). The trend amongthese people was that most reported "medium" physical health before starting OMT and then later experienced a deterioration. For mental health, the distribution was more evenly distributed between good, medium, and poor mental health before the OMT for those who experienced reduced mental health after starting OMT. This means that the physical health of those who started with poor health largely developed positively, but those who described their health as okay when starting OMT experienced mainly negative development. People appear to be more prone to experience reduced mental health during OMT than physical health.

Health assessments are linked to age and time in OMT, but in a way that points to higher age being associated with more stability and thus "better health": the youngest age groups, and some of those with the shortest experience of being in OMT, more often report poorer health before they started, but improved health now. Older people and those who have been in OMT for a long time more often report stable health. We must remember that it is normal to have an increasing number of physical ailments and reduced physical health when getting older, as is the case in the general population. It will probably be the case that people in OMT who are older and have been in OMT for a long time will experience reduced health that is due solely to the ageing process. However, we should be aware that those who describe negative health development may also experience this as part of an adverse reaction to the OMT medicines. It is also established knowledge that many people in OMT have one or more additional illnesses of a somatic nature.

A common somatic illness among people in OMT is Hepatitis C, and in the user survey, 55% state that they have Hepatitis C. Hepatitis C is most common among older people: almost 60% of those over 50 years of age, compared to 44% of those under 30 years of age (7% do not know if they have Hepatitis C). Just over half of those with Hepatitis C say they would receive treatment if possible, while a third were unsure. The majority were aware of the information about Hepatitis C and treatment; 65% say they have been informed about the disease and possible treatment options. In the 2-3 years after the user survey was conducted, there is reason to believe that the awareness and knowledge of Hepatitis C has increased both for people in OMT and among

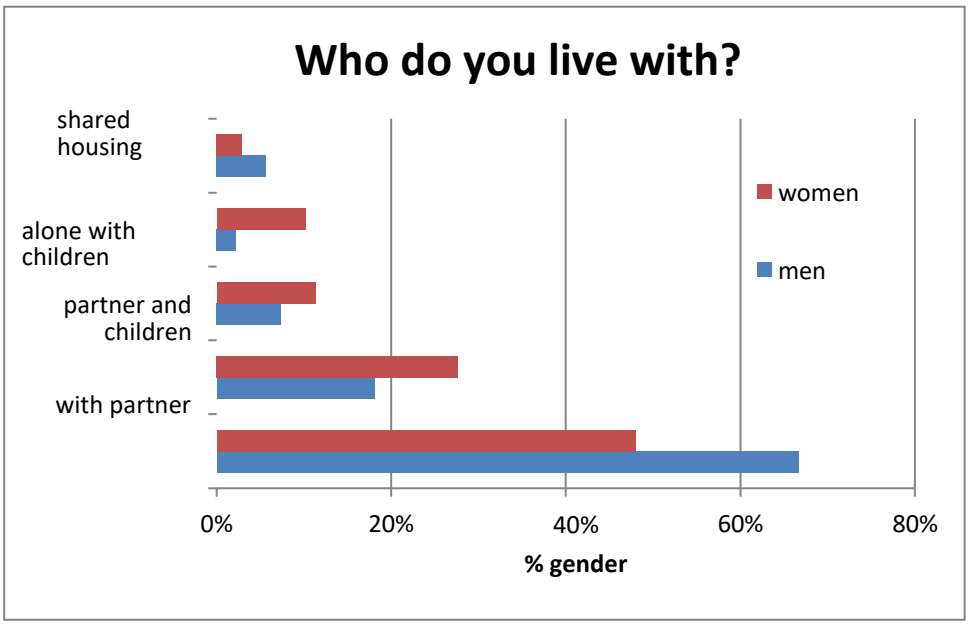
professionals in the field. There is now increasing access to modern Hepatitis C treatment with good treatment results and few side effects.
84% of people in OMT report that they have received dental treatment, and most of them (62%) are satisfied with the treatment. The longer you have been in OMT, the more likely you are to have had dental treatment, regardless of age.

2.1.3 Housing

The housing situation appears to be stable for most people: in total 83% rents or owns, about the same as 77% in the Status Report (almost equally divided between those who rent privately, rent from the municipality or own). 7% live with their parents and the rest (10%) in staffed housing, rehabilitation centres/care homes, or other types of temporary housing. Gender differences can be seen among those living with parents (9% of men, versus 2% of women), while 27% of men and 36% of women rent housing in the private market.

Nearly half (44%) have not used Norwegian State Housing Bank schemes while in OMT (this also applies to the half living in housing that they own themselves), while housing benefit has been used by 46% and housing subsidies by less than 1%. 8% have received a Start Loan through the Norwegian State Housing Bank in collaboration with the municipality, while 23% state that they have discussed the possibilities of applying for a Start Loan.

When asked who they live with, most men respond "alone" (61%). Women more often live with family members. The biggest difference in "who you live with" is in the category; grandmother (10%) versus grandfather (2%).



The proportion who say they are satisfied with their housing situation is only - 56%. Those living with partners and/or children are more satisfied (about two-thirds) than those living alone or in shared housing (50% each). When we look at housing types, almost 90% of those that are home owners are satisfied, while only half of those who rent are satisfied, and the majority of those living with parents or in temporary housing are more dissatisfied with the housing situation. It is important to be aware of the challenges associated with being socially isolated or experiencing loneliness among people in OMT. Loneliness and social isolation can increase the risk of psychiatric problems and perhaps relapse. The system should especially follow up with regard to this among those living alone. Efforts should be made to ensure that people living in temporary housing and who want more stable housing receive assistance.

Living situations and satisfaction			
	N	**% total**	**% satisfied**
Municipal rental housing	315	31 %	47%
Rented housing in the private market	304	30 %	52%
Own, owned housing	228	22 %	87%
Rehabilitation centre/sheltered accommodation, housing with staff, hospice, other temporary housing	106	10 %	39%
With parents	67	7 %	39%

2.1.4 Work and activities

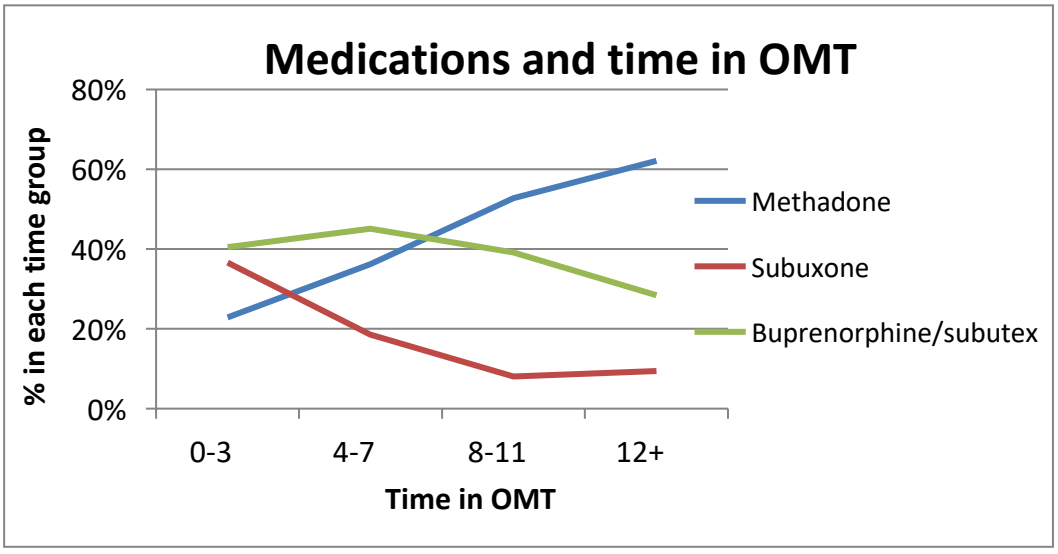
People in OMT were relatively less active in work and social activities. 13% have jobs (mostly in the 30-50 age group), while 43% are disabled (mostly in the 40+ age group). When asked if they wanted to get work experience/a job or start school, the response varied based on activity level. Among those without disability benefit or a job, 43% wanted to start
"regular work", 39% to get "work experience or adapted work via NAV", 21% wanted a place at school/university (almost twice as many women as men), and 20% wanted a "100 percent position". Educational ambitions are important to support, given that people in OMT have a lower level of education than the rest of the Norwegian population, and that education increases the chances of future employment. The subject of daily activity and employment/education had been discussed in the responsibility groups by the majority; (71%) of those who want a job or education.

Only 18% answered "yes" to the question, "do you have leisure activities or social events in the evening?". 32% say they have "not many", while 30% state "none" when it comes to leisure activities, i.e. over half have not many or no such activities. The rest (20%) respond "they have no leisure activities, but are happy with that". When people who live alone are compared with those living with a partner and/or children, more people living alone have no leisure/social activities (33%) than those living with others (26%). This shows that family life for many may serve as a substitute for other leisure activities.

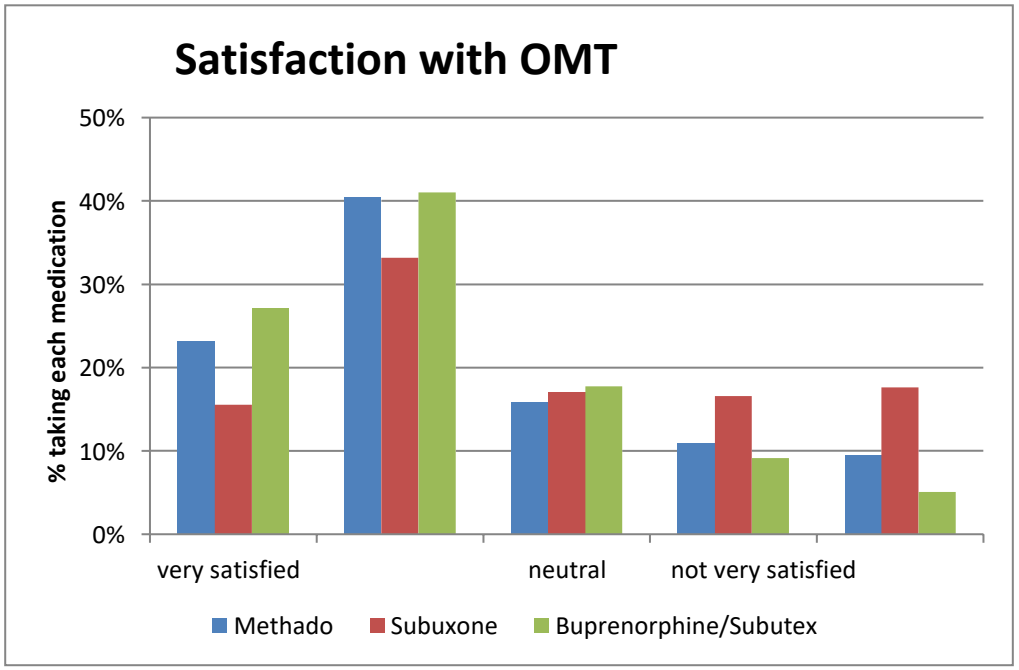
2.2 The medical part of OMT

2.2.1 Medications

41% of people took Methadone, 41% Buprenorphine/Subutex, and 19% Subuxone. The type of medicine correlates with time in OMT; the longer you have been in OMT, the more common methadone is (more than half of people in OMT for more than 8 years take methadone). Three quarters of the people new to OMT take Subuxone or Buprenorphine/Subutex. Medications used therefore partly reflect what was/are available drug choices when starting OMT, and that there has recently been a recommendation in the National OMT Guidelines that Subuxone should be the first choice when starting OMT.



Most (63%) were "satisfied" or "very satisfied" with their medications, while users of Subuxone had a slightly larger share with less satisfaction.



2.2.2 Side effects of OMT medications

83% (860) of people in OMT report at least one side effect from their OMT medication, and they report on average 4 different side effects from a list of 12. Of the reported side effects, approximately 80% of people are affected by them long-term (more than half a year). Reduced sexual desire was the most common side effect - 52% struggled with it. Severe sweating, poor sleep, nausea/constipation, and reduced sexual ability affected about 40%, and one-third is affected by fatigue, weight gain, and water retention/swelling. Nearly 30% struggle with wheezing and altered mood, and one fifth with itching/skin rashes and headaches/dizziness. Side effects are a subject that only 22% talk about with the OMT doctor.

On the whole, Methadone users were exposed to slightly more side effects than users of Subuxone or Buprenorphine/Subutex. Subuxone users did not report more side effects than Buprenorphine/Subutex users. ("Itching/skin rash" and "headache and dizziness" were reported slightly more frequently by Subuxone users, but the differences were not significant enough to have statistical significance).

Side effects seem to correlate somewhat with age and time in OMT. Those who have been in OMT for 3 years or less experienced on average less side effects than those who have been in OMT for longer. Fatigue was more common for people who had been in OMT the longest, regardless of age. Nausea/constipation and itching/skin rash was experienced more among younger people, regardless of time in OMT. Headache was the only side effect that was evenly distributed among all

age groups and OMT time groups. The rest of the side effects were more common the older you were and the longer you had been in OMT. More women than men reported nausea/constipation, weight gain, decreased sexual desire and fatigue.

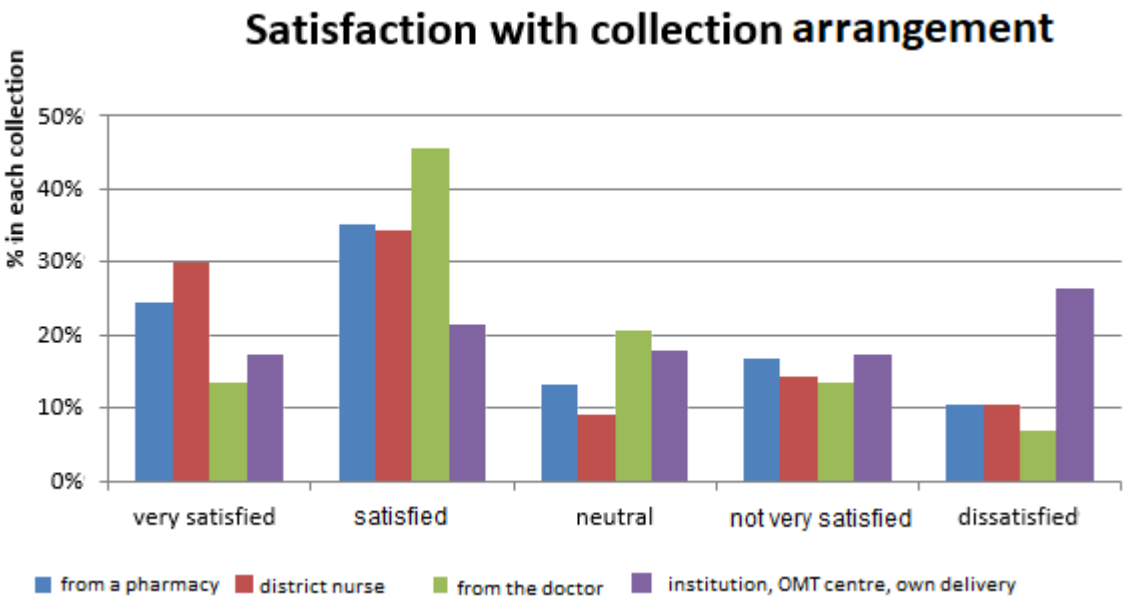
Side effects of OMT medications				
	Metha-done	**Subux-one**	**Buprenorphine / Subutex**	**Who is struggling the most?**
Reduced sexual desire	60 %	43 %	50 %	Women, older, over 4 years in OMT
Excessive sweating	54 %	33 %	40 %	Over 4 years in OMT
Bad sleep	49 %	37 %	43 %	Over 4 years in OMT
Weight gain	44 %	24 %	27 %	Women, middle-aged
Fatigue	43 %	24 %	28 %	Women, longest in OMT
Nausea/constipation	43 %	36 %	39 %	Women, younger
Reduced sexual ability	42 %	31 %	35 %	Elderly
Water retention and swelling	37 %	21 %	26 %	Elderly
Wheezing	35 %	25 %	22 %	Older, over 4 years in OMT
Changed mood	31 %	27 %	29 %	Over 4 years in OMT
Itching/skin rash	18 %	25 %	17 %	Younger
Headaches and dizziness	15 %	25 %	22 %	Evenly distributed

Overall, a significant number of side effects are reported, although it is not possible to distinguish these from e.g. "normal" ageing phenomenon, or from being symptoms of the additional illnesses that the persons in this study may have. Regardless of the cause of the symptoms, very few people discuss this with their OMT doctor, and this along with side effects should probably have been discussed and investigated to a greater extent as part of the OMT treatment.

2.2.3 Collection arrangement

The most common arrangement is to collect the OMT medication from the pharmacy (59% of people), followed by delivery by the district nurse (12%). Between 4-9% get the OMT medication from the OMT centre, at an institution, from their own delivery centre, from the doctor, or elsewhere.

More than half are satisfied with the collection arrangement (56%), while 14% are neutral and about 30% are dissatisfied or not very satisfied. The level of satisfaction is about the same, irrespective of the type of OMT medication. The trend is that the longer you have been in OMT and the older you are, the more satisfied you are with your collection arrangement. Somewhat more dissatisfaction is reported among the few who collect it from an institution or OMT centre, which probably reflects that these individuals are in a more acute treatment phase or have a more demanding substance abuse situation.



2.2.4 Ingestion, dosage, wastage

As a general rule, the majority take the OMT medications as prescribed (82%). However, 11% report that they inject the OMT medication (8% "usually", 3% "occasionally"), while 7% take a lower dose than agreed.

Those who take lower doses mainly do it in order to taper off the medication (77%). Among the few who injected their OMT medication, as shown in the table below, the reasons varied with the medication: about half of the Methadone and Buprenorphine/Subutex users who injected did so in order to have a "better effect", while half also responded that they "are unable to stop themselves". The number in the data material is low, so it is difficult to draw clear conclusions. It seems that people who receive Suboxone as an OMT medicine inject or abuse their medicine to a much

lesser extent than those who receive the other two medications. In this survey, 27% of people in OMT report that they talk to their OMT doctors about medication and/or dose changes.

Among those that inject the OMT medication, reasons for why they do not take the OMT medication as prescribed						
	Methadone (n=31)		Subuxone (n=14)		Buprenorphine / Subutex (n=65)	
	n	%	n	%	n	%
It works better when injected	17	**55%**	4	29%	27	**42%**
Unable to stop themselves	14	**45%**	4	29%	34	**52%**
Struggles with an additional form of substance abuse	9	29%	7	**50%**	11	17%
It's just the way I do it	10	32%	6	43%	24	37%
Wanting to taper off	5	16%	1	7%	9	14%

Some groups were more likely to inject than others. A larger share of Buprenorphine/Subutex users injected (17% of all those receiving these medications had experience of injecting their OMT medication), compared to Methadone and Subuxone users (7% each). More young people injected than older people (almost 20% of all those under 40 have experience of injecting OMT medication, compared with 7% of those over 40). The groups that inject OMT medicine are also more dissatisfied with various aspects of OMT, such as the collection arrangement, responsibility groups, and the knowledge of and interest in OMT among general practitioners.

28% of all people in OMT state that they have at some point sold or given away the OMT medicine. Leakage is most frequent among those aged 30-40 and those who have been in OMT for a long time (4-7 years) compared to the other age groups and the "time in OMT groups". Fewer Methadone users (23% of them) reported leakage than Buprenorphine/Subutex or Subuxone users (approx. 31% each). Leakage is closely related to bad substance abuse in general, see section 2.2.7, and is also more likely to occur among people who injected their OMT medication either regularly or occasionally.

Among those who have sold or given away their medication, the most common reasons are: "in order to help" (79%), followed by "due to poor finances" (18%). "Pressure from others" only applies to 6%, and "other reasons" 5%.

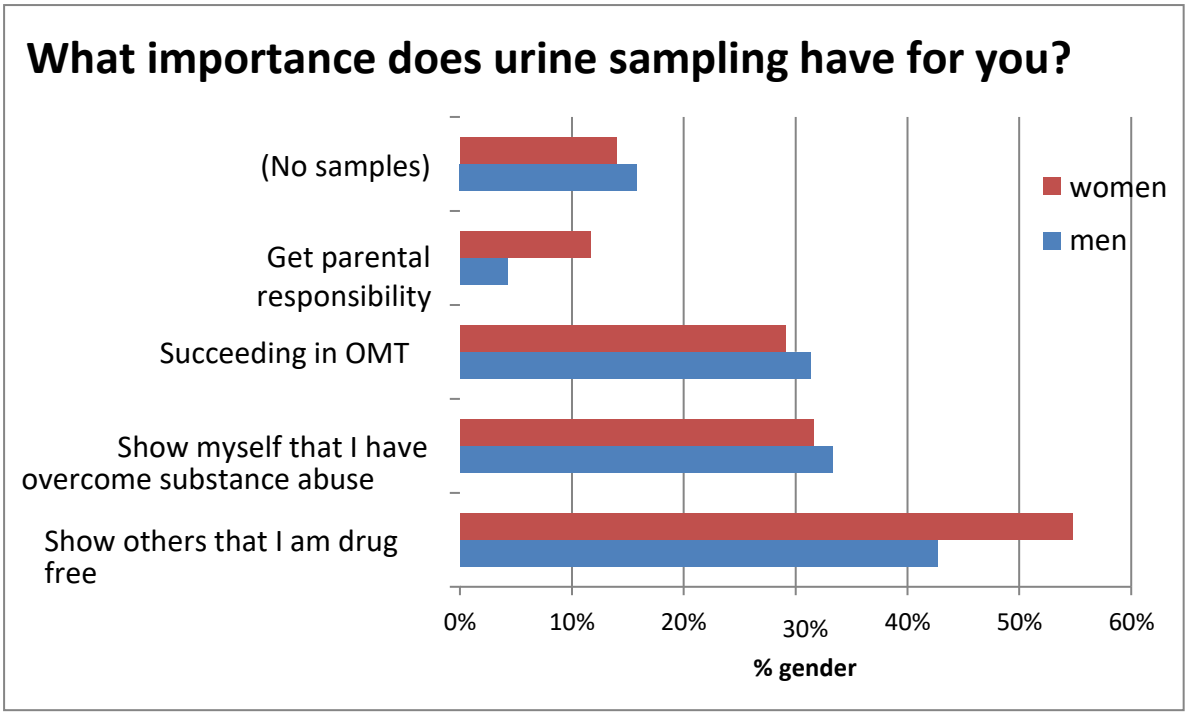
The housing situation appears to be related to the leakage of OMT medication. Although few report pressure from others to sell or give away the medicine, 50% (8 of these 16) live in temporary housing (institutions, staffed homes, or with parents). 60% of those reporting OMT medicine leakage due to poor finances live in temporary housing or municipal housing.

2.2.5 Urine samples

A little over 1/3 give urine samples weekly or twice a week (37%). 41% give urine samples between every other week and 4-5 times a year, and 7% less often. 15% do not give a urine sample, and these are more often older and have been in OMT for more than 12 years. Reporting of infrequent delivery of urine samples is associated with less self-reported problems with heroin, amphetamines, and benzodiazepines; presented in the section (insert numbers).

Regardless of how often samples are taken, 62% state that sufficient discretion and dignity was exercised when urine samples were taken (33% disagreed and 5% did not know). 1/3 of people in OMT have negative experiences related to urine test, which is a significant proportion of the OMT population. To a greater extent than at present, sufficient consideration should be given to the fact that the urine test situation does not cause more distress to people in OMT than absolutely necessary ,and the taking of samples should be limited to situations that have a clinical use and relevance.

When it comes to perceiving the reason and rationale for giving urine samples, 55% of women and 43% of men stated that the purpose of taking urine samples was to show others that they are drug-free. Self-efficacy and succeeding in OMT is important to one-third of both genders. Three times as many women (12%) than men (4%) view tests as a way to gain/retain parental responsibility.



2.2.6 Benzodiazepines and use of other medicines

People in OMT reported being prescribed significantly less painkillers, benzodiazepines, and ADHD medications now than before they started OMT. 57% of people report not having any of these medications on prescription at present, while 31% state that they are receiving the same medications on prescription as in the period before starting OMT. The proportion of people receiving benzodiazepines on prescription (26%) is almost identical to the Status Report (27%), and the majority of these (20%) have had a prescription since before starting OMT. 6% received benzodiazepines on prescription after starting OMT. 2% reported prescriptions for pain relief, 2% for ADHD medication, and 8% for other medications for sleep/mental health problems.

Medication on prescription			
	Before OMT	**Now**	**Both before and now**
Benzodiazepines for anxiety/sleep problems	52 %	26 %	20%
Pain relief from bodily pain	33 %	6 %	5%
Other medication for sleep/mental health problems	26 %	19 %	11%
ADHD medication	5 %	3 %	1%
(No prescription medication)	32 %	57 %	--

Receiving a prescription for addictive medications largely correlates with age and/or

time in OMT. Experience with pain relieving medications from the time before OMT is more common among the oldest groups (73% of those who were previously prescribed such medications are now over 40), while several young people report previous prescriptions for ADHD medications (10% of those under 30) and other medications for sleep or mental health problems (37% of those under 30).

The current prescription of benzodiazepines in OMT has more to do with how long you have been in OMT than with age. Between 30-33% of people who have been in OMT for more than 8 years have been prescribed benzodiazepines in OMT, compared to 22-24% of newer people. Therefore, it is not surprising that people with a benzodiazepine prescription also more likely to have methadone (50%) as their OMT medication (Buprenorphine/Subutex (37%), Subuxone (13%)). OMT providers appear to have reduced access to benzodiazepine prescriptions to some extent in recent years compared to previous years. Understandably, there also appears to be a link between the acceptance of benzodiazepines in OMT by OMT consultants and the prescribing of benzodiazepines in OMT. Among those who receive benzodiazepines on prescription in OMT, such use is accepted by the OMT consultant, or accepted to some degree; (a total of 84% of OMT consultants). Similarly, the majority of people without a prescription say that their OMT consultant has low acceptance for the concurrent prescribing of benzodiazepines in OMT (73%).

When asked whether the doctor has provided them with good information on the effects of benzodiazepines in combination with the OMT medication, a fairly large distribution of responses is seen: equal shares (around 25%) answer either "totally agree", "neutral", or "totally disagree". At the same time, 70% "totally agree" that greater demands are made on OMT patients to refrain from using benzodiazepines for anxiety and insomnia than for other people. 18% of people say that benzodiazepines are a subject they talk about with the OMT doctor.

People were also asked if they were anxious about being hospitalised for surgery/injuries because they feared they would not receive good enough pain treatment, and this was the case with the vast majority (71%). Concern was more evident among those struggling most with pain, represented by having pain medication on a prescription in OMT. 10% of women report currently having a prescription for pain medication, while only 4% of men do the same.

2.2.7 Substance abuse problems

The user survey asked "What substances are difficult to stay away from" while in OMT.

Benzodiazepines and cannabis are the most difficult substances to stay away from for the largest proportion of people (43% and 42% of people). Heroin (27%) and amphetamines (22%) are also difficult for large numbers of people. Fewer people struggle with alcohol (13%) and cocaine (4%), while a fifth (18%) say that it is not difficult to stay away from any substance.

There are some patterns in reported substance abuse problems. Men struggle with cannabis, heroin, amphetamines, and alcohol more than women. Younger people and those new to OMT reported heroin and amphetamines more often than older groups and those who had been in OMT the longest. The middle age group (30-40 years) reported difficulties with benzodiazepines more than other age groups.

Hardest to keep away from:			
	N	**% total**	**Who reports it the most?**
Benzodiazepines	445	43 %	30-40 years
Cannabis	431	42 %	men
Heroin	275	27 %	men, younger, new in OMT
Amphetamines	230	22 %	men, younger, new to OMT, Buprenorphine/Subutex users
Alcohol	134	13 %	men, Subuxone users
Cocaine	45	4 %	no pattern
(Nothing)	184	18 %	women, older

2.3 Other aspects of and activities in OMT

2.3.1 Responsibility group meetings

The majority say their responsibility groups have met over the past six months (62%, which is similar to 54% in the Status Report in the last 3 months), but meetings are more common among young people and those who have started OMT relatively recently. Between 66-75% of the age groups under 40 and people who have been in OMT for less than 8 years have had one meeting in the responsibility group during the last six months, compared with approximately half of the older groups and those who have been in OMT for 8 years or more.

Those who have had responsibility group meetings are significantly more satisfied with various aspects of their responsibility groups than those who have not had meetings.

Assessments of various aspects of responsibility groups		
	At least one meeting in the last six months	**No meetings**
The way the members collaborate with each other?		
satisfied, very satisfied	**52 %**	22 %
neutral	24 %	33 %
slightly satisfied, dissatisfied	23 %	**45 %**
Tools to reach my own goals?		
totally/partially agree	**64 %**	33 %
neutral	20 %	31 %
totally/partially disagree	16 %	**36 %**
Satisfied with follow-up?		
satisfied, very satisfied	**55 %**	24 %
neutral	23 %	29 %
slightly satisfied, dissatisfied	22 %	**47 %**

2.3.2 Individual plan

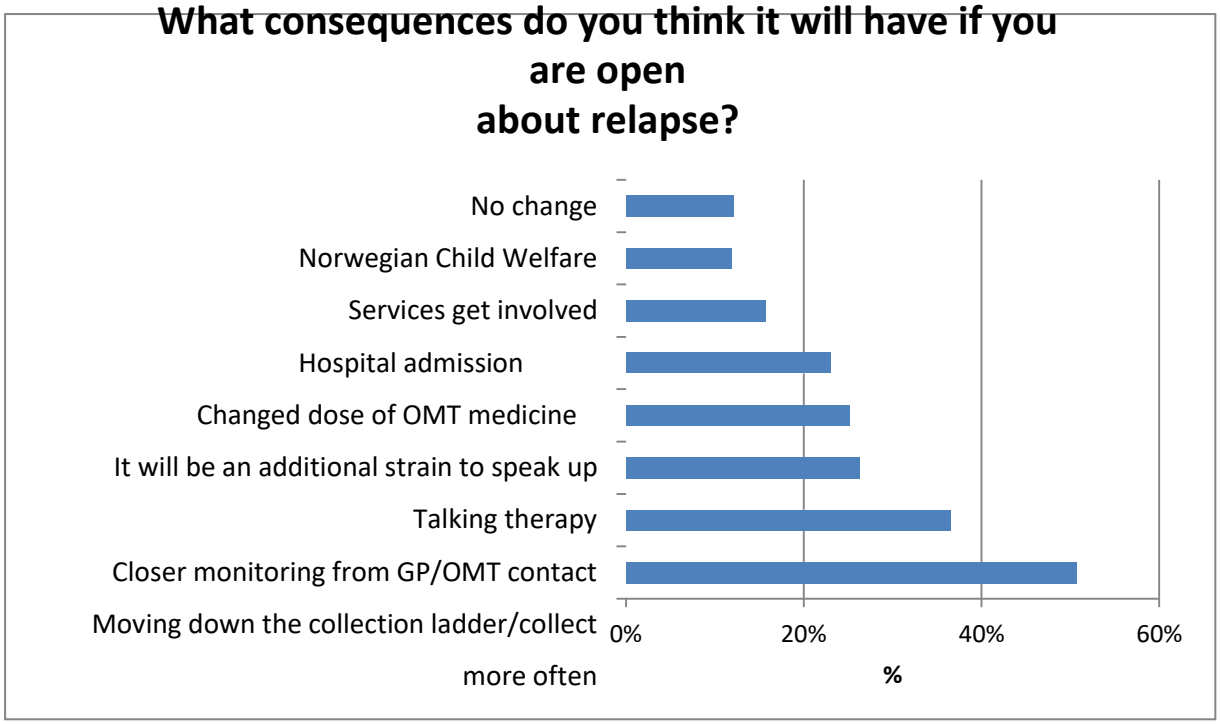
Half (53%) state that they have an individual plan, more than what is reported in the Status Report (37%, but the proportion of unknown in the Status Report is 10%). Subuxone users are more likely to have an individual plan (62% of them) than users of other medicines (50-54%); which indicates that it is easier to get individual plans in place for newer people, than for those already in OMT.

2.3.3 Relapse

When asked, "what consequences do you think it will have if you are open about relapse?", a more stringent collection arrangement is the most commonly envisioned consequence (51%).

Women are more likely to envisage a stricter collection arrangement (58% of women versus 47% of men) and closer monitoring (42% versus 34%) as a result of reporting relapse. At the same time, the likelihood is that men will not be worried about any consequences (14% versus 9% of women). Younger age groups are more concerned about stricter collection arrangements and hospital admission.

The involvement of child welfare in the event of relapse is not among the most common concerns (12%), but it is most relevant for women, younger patients, and those new to OMT.

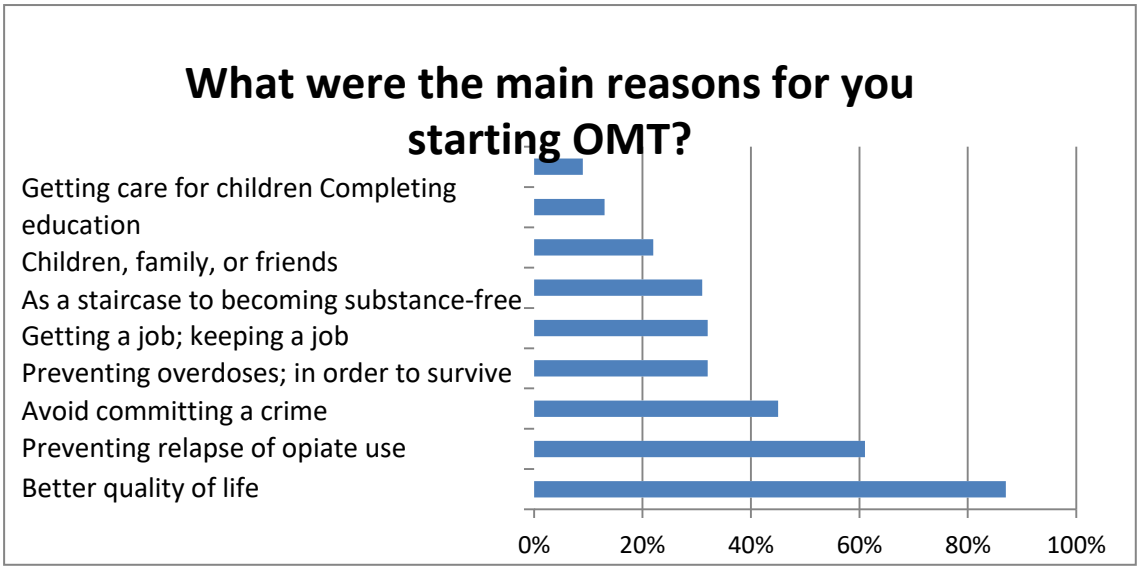


2.4 Motivation for OMT

The reason for starting OMT was most often to get a better quality of life (87%). Staying away from opiates specifically (61%) was more common than the motivation to become generally substance-free (31%), but these two motivations were not related to current substance abuse problems. Half want to avoid committing a crime. Getting or keeping a job was the reason for a third of people, of which 21% of these currently have a job, compared to just 9% of those who did not point to work as a motivation.

Contact with or better relationships with family, children or friends was a motivation for one fifth. 10% were motivated by caring for children, and one third of them currently live with children (alone or with a partner), compared to 12% of those who had other reasons for starting OMT.

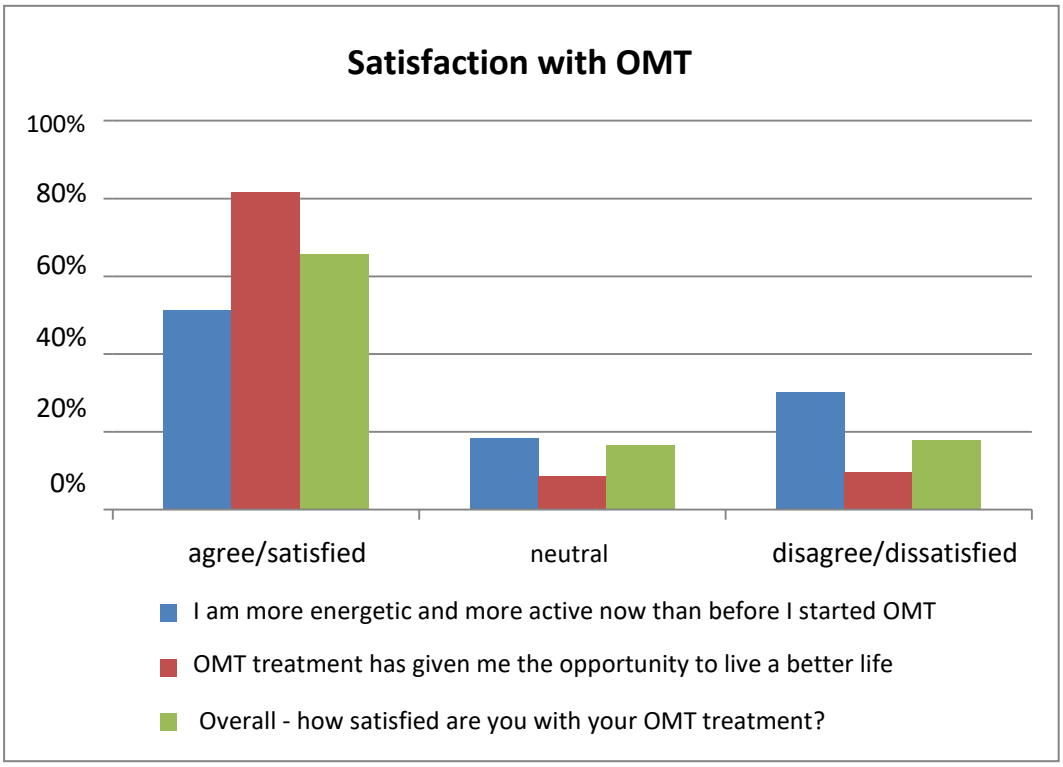
About 10% said they started in OMT in order to complete education, and almost half (43%) say they still want to start school or university, compared to 8% of those who did not choose education as a motivation.



Improved quality of life was therefore the most common and a definite motivational factor for people who started OMT. There is every reason to emphasise only factors that can contribute to a better perceived quality of life as part of the treatment offered. Establishing systems where people in OMT are regularly surveyed for perceived quality of life is important, such that they become a continuous theme and may guide the treatment.

2.5 Satisfaction with OMT

Most people agree that they are more energetic and more active now than before they started OMT, and that OMT treatment has given them the opportunity to live a better life, and that they are satisfied, all in all, with OMT treatment.



58% agree/disagree with most of these three questions, 28% are neutral, and 14% disagree/are dissatisfied. Satisfaction seems to be related to the health and perception of improvements during treatment. For example, current prescriptions of painkillers, benzodiazepines, or other medicines for sleep or mental health problems are not related to satisfaction, but those who think their physical and mental health have improved are most satisfied. Those who have contact with NAV and OMT consultants (compared to the few who do not have contact, described below) are also more often satisfied. Housing type has less to say - rented, owned, municipal, or institutional - but those who live with their families instead of alone are more often satisfied. The type of OMT medication, age, gender, and most substances do not explain satisfaction either. “Struggling to stay away from benzodiazepines, or cannabis,” is linked to lower levels of satisfaction.

2.5.1 Follow-up from treatment organisation

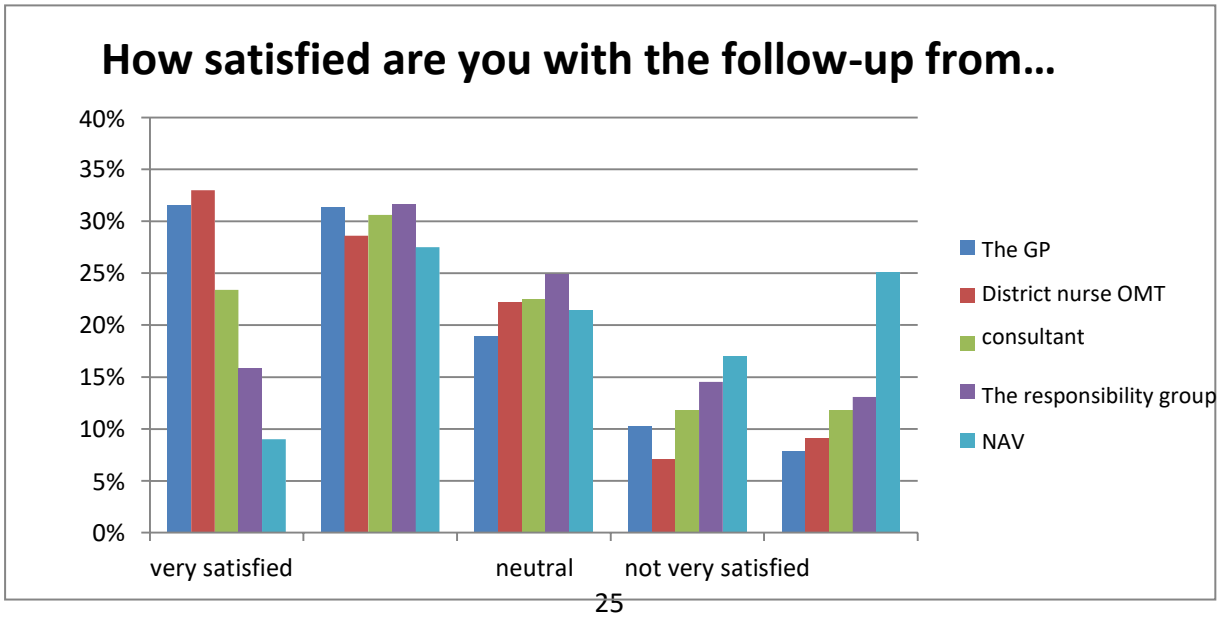
Contact with various services in the treatment organisation is common. Almost all (97%) have contact with their GP, 86% with OMT consultants (more common among those who have been in OMT less than 7 years), 84% with NAV (less common if they have been in OMT over 12 years), 83% with responsibility groups, and 58% with a

district nurse.

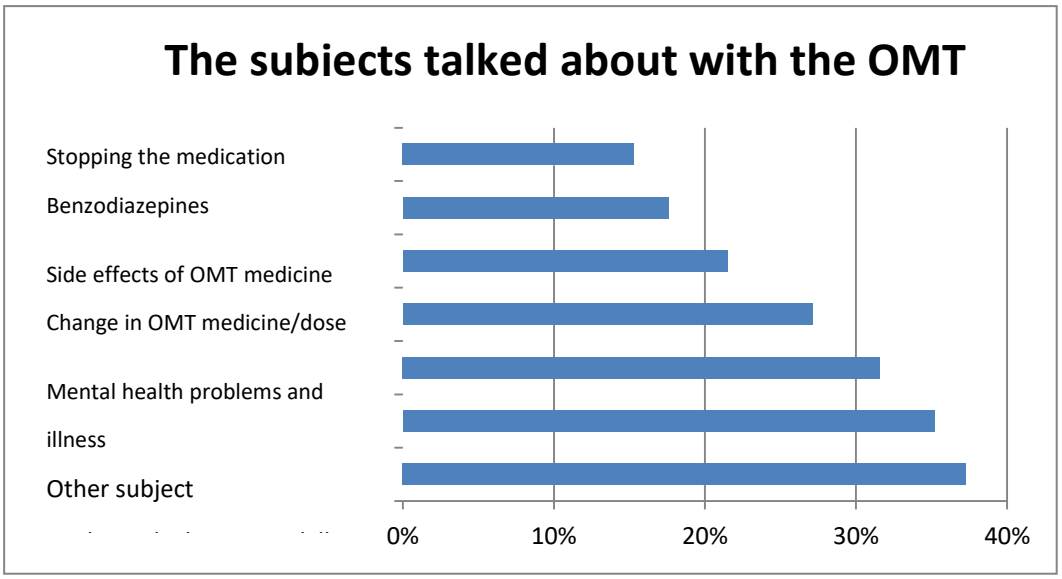
Most people are "satisfied" or "very satisfied" with follow-up from the OMT consultants, GPs and district nurses, among those who indicated that they have contact. Almost half (48%) say the same about the responsibility groups. Age has varying effects on satisfaction. Older people, and those who have been in OMT the longest, are more satisfied than young people and people new to OMT with GPs and district nurses, while those newest in OMT (0-3 years) stand out as the most satisfied with the OMT consultants. It may be that the youngest have the most contact with the OMT consultants, and that satisfaction corresponds to the amount of contact, or that monitoring is closer, which is more positive for younger people. Women are also more satisfied with their OMT consultants than men.

The exception to a high degree of satisfaction is in the follow-up from NAV, about which more people are negative (42% "dissatisfied" or "not very satisfied") than positive (37%
"satisfied" or "very satisfied"). Collaboration between the OMT consultants and the NAV should be strengthened, and efforts towards this user group in NAV should receive more attention. The survey has shown that people in OMT are not very active in the labour market or social areas in general, and closer follow-up to connect people to such measures is desired.

One more question that could be asked in the future comes from the Danish user survey; they not only ask about satisfaction with contact with the treatment organisation, but also if people want more contact with each service - more contact with psychologists and psychiatrists is especially desired among the Danes.



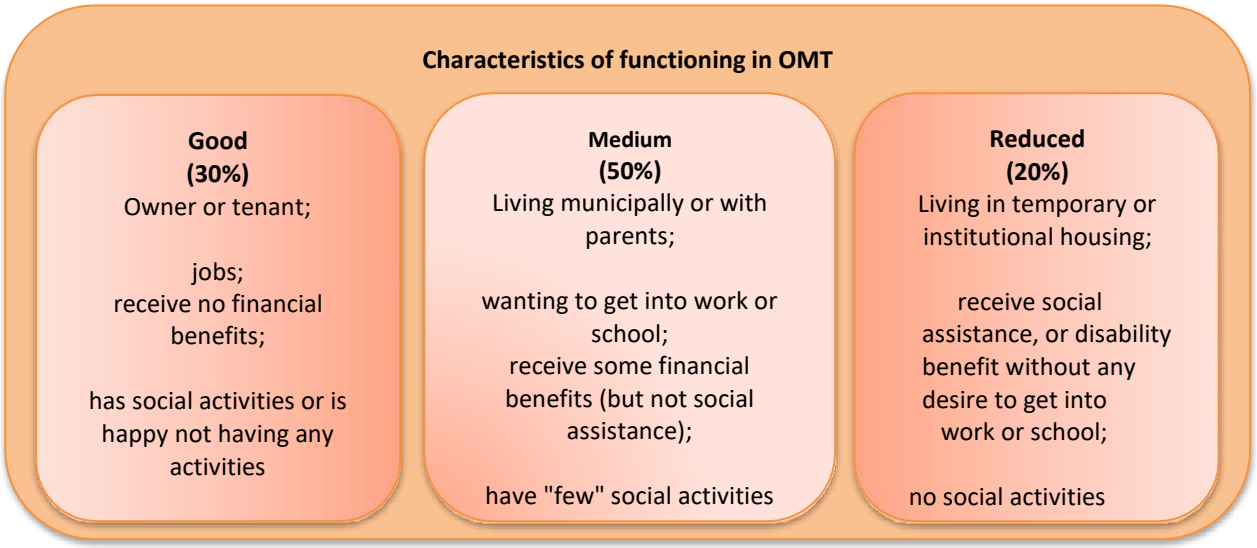
People talk most often with the OMT doctor about physical health (37%), mental health (32%), and OMT medication/dose changes (27%). Less than a quarter talk about side effects, benzodiazepines, or about stopping the OMT medication.



2.6 Functioning and user participation

In the following, we try to use several different indicators of "functioning in OMT" in order to investigate additional factors that appear to be related to functioning. We have divided those who participated in the user survey into 3 groups, based on belonging to different indicators: We have put together an indicator of variables for level of functioning as follows: housing situation, connection to the labour market, need for financial benefits, and participation in social activities.

Functional level is described as "good", "medium", or "reduced". They function well in a majority of the following categories: they own or rent housing, work, receive no financial benefits, and have social activities or state that they enjoy not having any activities. Medium-functioning are those who, on average, live municipally or with parents, receive some financial benefits but not social assistance, want to get into work or school, and have "few" social activities. Those with the lowest level of functioning live in temporary or institutional housing, receive social assistance, are disabled with no desire to get into work or school, and have few or no social activities.


Characteristics of functioning in OMT
Good
(30%)
Owner or tenant;
jobs;
receive no financial benefits;
has social activities or is happy not having any activities
Medium
(50%)
Living municipally or with parents;
wanting to get into work or school;
receive some financial benefits (but not social assistance);
have "few" social activities
Reduced
(20%)
Living in temporary or institutional housing;
receive social assistance, or disability benefit without any desire to get into work or school;
no social activities

With this division, half of the persons can be described as medium-functioning, 30% as well-functioning, and 20% with the lowest level of functioning. Those who were well-functioning were the youngest (40% of everyone under 40 were well functioning, compared to 30% of 40-50 year olds and 20% of 50+ year olds). Buprenorphine/Subutex users had a better level of functioning (39% were well functioning) than Subuxone (28% were well functioning) or Methadone (only 23%) users, something that is also related to age. Those who lived with a partner and/or children were well-functioning more often than those living alone (42% vs. 25%). In addition, more women (36%) than men (27%) were well-functioning.

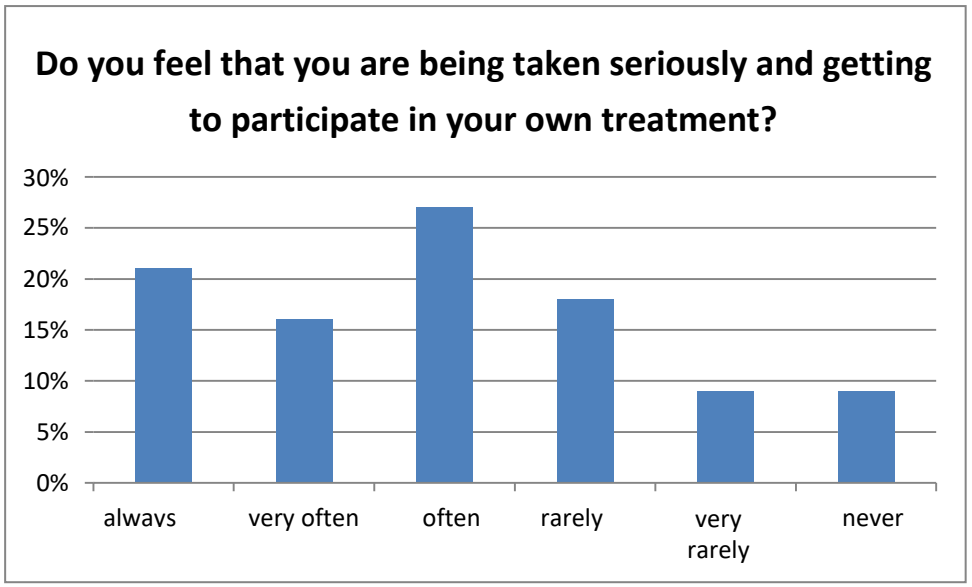
Those who were well-functioning had less difficulty with amphetamines, benzodiazepines, and cannabis. Health status was also important; 60% of well-functioning people say that their physical and mental health is better now than before OMT, and they also experienced less side effects than those that have a medium or poor level of functioning. It was largely those with a medium or poor level of functioning that experienced side effects, with a third saying that side effects were a potential reason for stopping OMT, compared to only a fifth of those with a good level of functioning.
Functioning is not related to how long you have been in OMT, but more people with a medium and poorer level of functioning (60%) consider OMT a lifelong treatment than well-functioning people (50%). Functioning was also not related to contact with the treatment organisation (for example, those with a poorer level of functioning had no less contact with the treatment organisation than those that were well-functioning), but the level of functioning was related to satisfaction with various follow-up services.

2.6.1 User participation and relationship with the OMT system

The Norwegian Directorate of Health confirms that:

> *"Users have the right to contribute, and services have a duty to involve the user. At the same time, user participation has an intrinsic value, a therapeutic value and is a means of improving and quality-assuring services. User participation means that the user is regarded as an equal partner in discussions and decisions concerning his or her problems."*

An important purpose of this study was to explore the extent to which people in OMT



feel that they are being heard and can influence their own treatment. Most (64%) say they are taken seriously and allowed to participate in their own treatment, either "always", "very often", or "often".

Nevertheless, two related questions were answered less positively: the largest proportion (36%) disagreed that the "OMT system adapts to my situation", 30% agreed in whole or in part, and 12% were neutral. 70% did not think they were being treated on an equal footing with other patients.

On average, 43% of people are positive about or agree with three user participation metrics, 15% are neutral or have mixed preferences, and 42% are negative or disagree. That is, a small proportion have no strong opinions about their level of user participation, while the rest are evenly divided between those who feel there is strong user participation and those who experience it as being too weak.

Experience the *most* user participation (43%)

Definition: Feels that they are being taken seriously and allowed to participate in their own treatment, that they are treated on an equal footing with other patients, and that the OMT system adapts to their situation

Who are they?

- More women
- Youngest and oldest
- Improved physical and mental health in OMT
- 54% are "well functioning": own or rent privately; work; have some social activities

How do they relate to the OMT system?

- Have IP and responsibility groups, and are satisfied with responsibility groups
- Satisfied with the collection arrangement
- Satisfied with the medication, but no pattern in the OMT medication
- Satisfied with follow-up from NAV, the OMT consultant, and GP, and with their GP's knowledge of OMT

What do they think of OMT?

- Cope better with OMT,
- Almost everyone sees OMT as an opportunity and is satisfied with OMT, all in all

Experience *least* user interaction (42%)

Definition: Not being taken seriously enough and not being allowed to participate in their own treatment, not experiencing being treated on a par with other patients, and the OMT system does not adapt to their situation.

Who are they?

- More men
- **Middle-aged, and a medium length of time in OMT**
- Struggles with bodily pain
- Has a long-standing prescription for benzodiazepines
- 54% have "reduced functioning": live municipally or in an institution; receive social assistance or disability benefits without any desire to get into work or school; lack social activities;

How do they relate to the OMT system?

- Less satisfied with medication
- Dissatisfied with the collection arrangement, which happens more often at an institution or OMT centre than at a pharmacy
- Dissatisfied with several aspects of OMT

What do they think of OMT?

- 50% say they are no longer clear about OMT
- 65% see OMT as an opportunity
- Distributed equally among those who are satisfied

User participation was also an important characteristic of functioning. We see relatively expected differences between levels of functioning, where, for example, there is better functioning - measured more objectively through association with the

job market and social activities along with younger age, less substance abuse difficulties, better health, and less side effects. User participation is associated less with these objective measurements and more with satisfaction with treatment, but more than half of those that are well-functioning also experience more user participation, and more than half of those with a reduced level of functioning

experience less. Something that was common to those with the best level of functioning and those who experienced the most user involvement was satisfaction with follow-up from the GPs, OMT consultants, NAV, and district nurses.

One group that stands out in the survey as getting on the least well with OMT are those who have been in OMT for a long time. Compared to those who have been in OMT for 3 years or less and 12 years or more, this middle group experienced less user involvement and felt that there was a greater requirement for OMT patients to abstain from benzodiazepines for anxiety and insomnia than others. In addition, those who are middle-aged (between 30-50 years) struggle with benzodiazepines more often than other age groups. This "medium length of time in OMT group" did not feel that they were able to cope more or are more active now than before they started OMT, and they reported more frequent "leakage" of the OMT medication. The reason for this group's dissatisfaction needs to be explored further, because it is difficult to see clear connections in this survey. They are no less satisfied with their medications or collection arrangements. One way to understand this is that the participants in the middle group were more satisfied with OMT in the early years, with many people focusing on working with substance abuse and other major life changes after a long period of severe substance abuse. It is conceivable that the focus and need for some will change over time in OMT and that, for example, after 3-5 years in OMT, people in the OMT treatment system will perceive it as having too little flexibility. For example, in the case of collection arrangements or trips abroad after several years in OMT, people with medium term experience in OMT feel that the system does not meet their needs - this can affect the perception of having influence on their own treatment. Dialogue with this group must be maintained in the OMT so that the OMT treatment is a continuum and individually adapted in order that people do not feel powerless in or "trapped" by the OMT system. Dialogue around, for example, ongoing rehabilitation programmes is needed to help people find meaningful roles, and have develop further in OMT.

2.7 Desires for OMT in the future?

About half (57%) see OMT as a lifelong treatment - more men than women (61% vs. 51%), and increasingly the older one is and the longer one has been in OMT. At the same time, the "medium" and "poor" functioning are more likely to see OMT as lifelong than those that are "well" functioning, suggesting that those that are well-functioning may see OMT as a tool/mechanism for functioning and also to a greater extent a life without

OMT medication. Nevertheless, 86% answered the question, “if you intend to discontinue treatment with OMT medication; what is the reason?". Among these "own wish" was selected the most (69%), a sign of a certain sense of accomplishment within the treatment; followed by
"dissatisfied with the OMT system" (36%) and "too many side effects" (29%). "Pressure from others" was only 6%.

2.8 Suggestions for proLAR from people in OMT

600 participants specified one or more subjects they wanted proLAR to take into account in the "open field" of the questionnaire. The most common subjects mentioned were access to additional medications, collection arrangements and control measures, and user participation. With such qualitative questions, it must be remembered that the subjects addressed are not necessarily representative of the concerns of the majority of people. For example, it may be that the most dissatisfied ones are more likely to raise a subject. After all, the quantitative part shows that most people are satisfied with OMT. It is most appropriate to use the more qualitative information below to highlight a deeper understanding of individuals' experiences of the OMT system, and to capture new ideas/experiences for future studies.

An underlying red thread among those who provided suggestions/comments was the desire to:

> “*Be treated like ordinary people with the same respect, you should not feel ashamed to be an OMT patient.*"

Equal treatment included having open conversations about access to benzodiazepines, painkillers, and ADHD medications, on a par with other patients. Not being able to get the desired medication was perceived by some as a lack of treatment, and they wrote about how they felt that the OMT framework limited access to the necessary help they needed. This group more often reported a deterioration in mental health after starting OMT. Several people also had experience with prescriptions for addictive medications before OMT, but now in OMT no longer had such prescriptions. This shows that it is important in clinical work to both offer alternative treatment, but also to have a good dialogue about the possible stopping of addictive medications in OMT. - It is an ideal that the patient also feels that they are being listened to when it comes to stopping benzodiazepines, so that patients do not perceive it as punishment. People who wanted increased access to medicines come more often from LAR-Midt (the central OMT region) than from other regions. In the Status Report, we also see that LAR-Midt is more restrictive when it comes to benzodiazepines (as the OMT guideline shows),

but in LAR-Midt they also have high ambitions and better results for the rehabilitation parts of OMT, such as housing and job initiatives.

Some also felt that the OMT system did not adequately adapt to their situation, the desire for personalised treatment was considerable. The desire to be seen and heard as individuals was part of a greater desire to influence the course of the treatment. For example, two very common desires were to be able to have more involvement in OMT drug selection and change in medication. Some also mentioned that relapse or side use should be taken into account in the individual rehabilitation programme, leading primarily to a conversation/help intervention: "*You must be able to be honest with OMT and get help, not punishment."* More flexibility in the collection arrangement and control measures was a subject for many respondents, and saliva samples instead of urine samples was something that appeared in the texts.

Another important subject people in OMT were concerned about was ageing and older people in OMT. As the 2014 Status Report discusses, the cohort is getting older, and some people were worried about this:

> "*...Make a plan to ensure that the correct use of medicine and compliance with OMT guidelines and requirements are* "*rewarded*" *with respect and trust, so that, for example, after 10 or 12 - 15 years, you get a more normal collection arrangement and only one urine sample check per year.*"

> "*OMT patients and nursing homes/old people's homes. There are many people who will need nursing and care. I think it is important that this group has a good and adequate provision within welfare surfaces for the elderly.*"

This type of concern should be met with adequate systems for people who have been in OMT for a very long time and have a history of stability in OMT in order that they can experience customised user participation and control based on their level of functioning.

Some people also wanted proLAR as an organisation to communicate their right to equal status to society in general:

> "*Better information to society about what it really means to be an OMT user... social norms and those of the Norwegian health services must change.*"
> "*Promote good stories about people who have changed their lives [due to] OMT.*"

3. Conclusions

3.1 High level of satisfaction, but still somewhat low user participation

As a main trend, people are satisfied with OMT overall, and see OMT as a positive influence in their lives. But satisfaction is not the same as experiencing user participation, and the results from the qualitative section show that a lot of people want to be heard to a greater extent than is presently the case. People either end up in a group that experiences too little user participation or in one that experiences a lot and good involvement in their own treatment. For most people, the OMT system is perceived as being too flexible, and people feel that they are not being treated on an equal footing with other patients. Functioning is closely related to user participation; seen more objectively, those with a poor level of functioning are not only those who struggle more with side abuse and have poorer health, but also those who feel they are least heard.

3.2 Continued potential for improved quality of life

This study supports what has been found in several previous studies on people's motivation for OMT, namely that improved quality of life is the most important reason for starting OMT. If the quality of life is to be improved, we can see several areas that can be focused on:

a. People are much more satisfied with the housing situation if they live in their own, owned homes. Housing bank schemes could be of benefit to more people in OMT, and we suggest that it be a subject for OMT consultants and in responsibility groups more often.
b. The level of connectedness with the labour market, education, and social networks was somewhat low. 40% wanted to get a job or go to school/university, and often these were the same ones that started in OMT with work/education as motivation. School/university was especially relevant for women (twice as many women as men wanted to complete school/university education). Since an education can increase their financial independence and the chances of entering the job market, collaboration between OMT and NAV should be further strengthened in order to help with this. Measures to increase the connection to positive social networks, through, for example, recreational activities or therapeutic support to establish contact with family, must be prioritised and strengthened for most people. In practice this is a collaborative challenge.
   Almost everyone experiences side effects, and so much so that that it is a reason

for why one third can imagine quitting OMT. The pattern shown here is that older people on Methadone struggle the most, but it is difficult to distinguish age and associated health problems from side effects.

c. While satisfaction with OMT and follow-up from the treatment organisation was high, the interaction with NAV was the area that had the greatest potential for improvement.

3.3 Particularly vulnerable groups?

Contrary to the concerns that some people in OMT have associated with Subuxone, Subuxone users do not experience any side effects and are relatively satisfied with the OMT system and experience the same user participation as others - except that they are to a greater extent dissatisfied with the medication itself. This dissatisfaction should be investigated further. Subuxone represented a less risky medication with regard to injection and is less popular from a turnover perspective, but all in all it seems to contribute to satisfaction on a par with the other medications.

Instead, there is a vulnerable group of middle-aged people, that have been in OMT for a long time, and are usually men, without enough social activities, that stands out as being vulnerable. This group gets on the least well in OMT (in terms of satisfaction), they have the lowest level of user participation and report more risky behaviours, such as leakage and difficulties with benzodiazepines.

This report cannot pinpoint with certainty the causes of what makes this group most vulnerable. However, it does not appear to be associated with poorer mental health, physical health and side effects, general substance abuse (other than benzodiazepines), or other clinical factors. Instead, it can be speculated that this group receives less follow-up in OMT than those that are "new" to OMT, while at the same time not experiencing the stability that the
"oldest" in OMT have. Medium-term experience in OMT can be a vulnerable and gradual transition after a few years in OMT where impaired motivation and ambition in OMT may occur, while still being affected by the economic and social realities often represented by unemployment, loss of parental responsibility/right of care and general stigma as a substance abuser.

This can be seen as being a vulnerable phase, which should receive extra attention from the treatment organisation.

A stable group is older people who have been in OMT for the longest time and who

take Methadone. They reported less leakage and less side use. Compared to other groups, they are more satisfied with their GPs, who are their main contacts in their OMT treatment.

The basis for developments in the Norwegian OMT population is probably the fact that it was relatively highly motivated patients with a distinct "rehabilitation desire" that started early in OMT, i.e. more than 10 years ago. In recent years, and therefore among the younger people and those with shorter experience in OMT, there is also increasingly an element that has "damage reduction" as a goal for the treatment. This may be reflected in the level of functioning and also the satisfaction with the treatment, and it is perhaps the case that some of those who are accepted into damage reduction oriented OMT today would not have "entered" the treatment some years ago. Patients in OMT today are a heterogeneous group, and there will be a need for significant individual adaptation of the treatment.

It is important that today's OMT is arranged so that both groups, those with a clear rehabilitation desire and a good level of functioning, but also those with a poor level of functioning, receive adapted treatment, even beyond the first few years of an OMT treatment programme.

3.4 OMT in Norway in an international context

This user survey involves several methodological strengths that enable the contextualisation of Norwegian data in an international context. People in OMT have now been asked for subjective feedback, which means that the results can be compared with Danish and Swedish user surveys. Satisfaction with the treatment in general is about the same as in Denmark. Admittedly, in Denmark, those receiving Methadone were less satisfied with the treatment than those receiving Buprenorphine, and there were also significant differences between treatment centres (Rådet for Socialt Udsatte, 2015). We do not see such patterns in the sample here in Norway.

Norwegians report much fewer social or leisure activities than the Danes, and connected with the labour market to a lesser extent than in Sweden or Denmark (Svenska Brukarföreningen, 2012; Rådet for Socialt Udsatte, 2015). Employment status must not necessarily be viewed negatively, because disability insurance is an important financial security for an ageing population (Statusrapport 2015). Regardless of this, the Swedish user survey emphasises that the treatment system must not cause OMT to have a socially exclusionary effect on patients:

> *"In this context, a paradox of care means that medical treatment not only saves lives and relieves suffering, but aims to normalise a patient's life; but as soon as the rules and interventions in the treatment counteract normalisation, a paradox arises." (The Swedish Drug Users Union 2012, p. 24)*

Being able to obtain the benefits of OMT treatment, and improving OMT to being a more optimal and individually tailored intervention for the majority of people, and especially those who are struggling the most, is possible only when users are heard, seen, and listened to. This type of representative, user-driven research is therefore a very important supplement to other knowledge about OMT. As similar user surveys from Denmark and Sweden have shown, more users see OMT treatment as more than just medicine, but as a tool for a better life, including better quality of life, health, level of functioning and involvement in society. Through this user survey, people in OMT express their experiences and views on their own treatment. It is a natural right they have and it is important for people in OMT to be heard and respected, just like everyone else in society. The experiences shared by more than 1,000 people in OMT can contribute to a better understanding of how the OMT treatment and the OMT system are experienced by people in OMT, and the shared experiences can help improve the treatment provision for everyone currently in OMT as well as for future patients

4. Recommendations and important priorities for proLAR going forward

This report represents over 1,000 voices from people in OMT, and it is important that they are heard! It is also important that user involvement at all levels is included in the revision of the guidelines for OMT treatment - "**Nothing about us without us**". There is a need for new user surveys in the future.

Recommendations:

- Seek to improve collaboration and interaction between multidisciplinary specialist substance abuse treatment services and psychiatric and especially somatic departments in the specialist health service and the municipality.
- Focus on adapted and suitable housing. People in OMT will have more difficulty in utilising rehabilitation services, etc., if they have an unstable housing situation.
- A focus on good housing will promote good quality of life.
- Priority should be given to owning a home or renting good housing in neighbourhoods without substance abuse problems.
- Housing projects and "Housing First" are important measures; Starter Loans and House Bank Loans should be made more accessible to more people.
- Increased efforts with regard to meaningful daily activity. Many people in OMT have little or no meaningful daily activity. Opportunities should be sought for participation in civil society beyond the labour market, with introductions to and participation in, for example, association work, charity work and/or voluntary work, in order that the resources that people in OMT have can be better utilised. People in OMT represent an untapped resource and a potential that should and can be activated to a greater extent. It is important for people in OMT to have a role in society in addition to being an OMT patient, it can contribute to better lives, better quality of life and prevent psychological stress for the groups who are currently experiencing isolation and loneliness in OMT. Focus should be on collaboration between voluntary organisations, charities, sports teams, associations etc., multidisciplinary specialist substance abuse treatment services and the municipalities, in order to find locally adapted arenas where meaningful activities for the individual can be created and shaped.
- More than 80% report side effects, while only approx. 20% talk to the OMT doctor about the subject. It is a shared responsibility to address this, and the prescribing doctor should regularly raise the subject, if the patient does not address it themselves. (IMPORTANT!)
- An increased focus on detecting side effects and comorbid conditions, through regular health screening with a doctor, preferably annually. This may help to

detect if the ailments experienced are real side effects of the OMT drug or if there may be additional conditions that can/should be treated differently.

Specific points for investigation will be the screening of sex hormones and metabolism, cardiovascular status as well as hepatitis investigation. All of the aforementioned conditions can cause symptoms that overlap with commonly reported side effects, and clarification of such conditions will have therapeutic consequences. Examples of measures include testosterone supplementation, in male OMT patients with reduced levels of sex hormones.

- There will be a need for the individual adaptation of OMT medications and other treatment in order to optimise levels of functioning and satisfaction.
- Approx. 1/3 of people in OMT feel that the situation regarding urine testing is not taken into account sufficiently. A large proportion of OMT patients are affected by the urine sample system. Efforts should be made to ensure that the situation is as looked into, and that other forms of sample taking should also be considered, such as saliva samples for example.
- Many people in OMT are afraid that they may need emergency medical treatment that will include pain relief treatment. People in OMT do not think they will receive adequate treatment, and there is reason to assume that in many cases OMT patients have experienced receiving inadequate treatment for pain, during, for example, postoperative phases. Multidisciplinary specialist substance abuse treatment services should work with somatic departments at the hospital to provide good and satisfactory pain relief where required, so that OMT patients who also need somatic treatment receive this in a satisfactory manner. Because of the stigma experienced by the OMT group, it is important that people who undergo surgical treatment receive more than just normal follow-up at that stage , so that they can receive and be assured that they will receive adequate pain relief.
- Only 50% state that they have an IP; this is too low and an area with improvement potential, where the interaction between Multidisciplinary specialist substance abuse treatment services and the municipalities can be improved. It is important to get NAV involved in good rehabilitation programmes.
- It can be a challenge that many people have relatively little contact with the OMT doctor or GP if everything goes well, and that in many places there are not, for example, annual health check-ups and/or meetings with a doctor.
- Strengthen the provision to people who have been in OMT for a long time as well as the focus. It is a group that is over the "acute" stabilisation phase, but may still lack a good grounding in social activities and the housing market.

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