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Implementation of user organizations in Swedish health care and social services for persons with substance use disorders

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ABSTRACT
Background: In Sweden, the National Guidelines for Substance Abuse Treatment includes new recommendations concerning integrating a user perspective.

From 2009 to 2014, the Swedish National Board of Health and Welfare supported and financed the development of organizations serving regional users. The programme was evaluated, and the results showed a development of user influence in substance use treatment services in 20 out of 21 regions by 2014. The implementation of user organizations’ influence was evaluated in 2018 for this follow-up study.

Aim: The aim of this four-year follow-up study was to evaluate whether user organizations continued existing once national support ended, and whether their influence in social services and health care, at both organizational and individual levels had been implemented.

Method: A questionnaire was dispatched to 20 regional user organizations. It included information and questions focused on their situation, and on participants’ experiences of the influence of user organizations in health care and social service.

Results: The results obtained from the questionnaire show that 14 out of 20 user organizations still existed and reported a developed influence in social services and health care at organizational and individual levels. National support was perceived as necessary for the ongoing development of user organizations and to continue increasing their influence.

Conclusions: Support at the national level initiated the development of user influence in Sweden, which has increased at both organizational and individual levels in the context of social services, as well as in health care for persons with substance use disorders.

Introduction

Questions about users’ influence and user empowerment are not new, and in Sweden they were influenced by ideological debate arising in the 1960s and 1970s (Börjesson and Karlsson 2011). During that time, questions raised internationally were inspired by, among other proposals, Arnstein’s ‘ladder of citizen participation’, a touchstone for policy makers and practitioners promoting user involvement in different areas of society (Arnstein 1969; Tritter and McCallum 2006). Factors such as patients’ living conditions in mental hospitals and how to promote patients’ rights were addressed during this time (Goffman 1963). Ever since these initial debates, service user involvement (SUI) has been emphasized in many strategies, plans and declarations (Laitila, Nikkonen, and Pietilä 2011), and has become a tool of recognized value in social work and health care. However, in practice, SUI is not
always achieved (Connor and Wilson 2006; Borg, Karlsson, and Kim 2009). In an exploration of current literature in the field of substance use disorders, Arnett (2016) revealed the importance of applying user-involvement models in treatment and care.

User involvement in social service and health care service is grounded in a shift from professional control towards a more active role for patients (Juhila et al. 2015). One active role for patients is when participating in ‘user organizations’, other types of user involvement could be patient participating in decisions concerning their own treatment and care (Tambuyzer and Van Audenhove 2011) or participating in the development of clinical guidelines (Harding et al. 2011). User involvement could also include work as a peer support specialist in health care service (Gillard et al. 2013) or participate in education for professionals (Happell et al. 2014).

In Sweden, the National Guidelines for Substance Abuse Treatment (Socialstyrelsen [The Swedish National Board of Health and Welfare] 2007) provided new recommendations for the integration of a user perspective within treatment (Socialstyrelsen [The Swedish National Board of Health and Welfare] 2007). Guidelines containing a user perspective, research results, and accounts of professionals’ experiences may be important tools for improving the delivery of evidence-based practice (Perron et al. 2010). The recommendations of the Swedish National Guidelines that focus on users’ involvement is part of the international movement towards ‘evidence-based practices’, which include patients’ wishes and needs, clinical practice knowledge, and empirical evidence from treatment results (Glasner-Edwards and Rawson 2010).

From 2009 to 2014, the Swedish National Board of Health and Welfare (SNBHW) supported and financed the development of regional user organizations. The SNBHW highlights that the traditional view of the patient/user as a ‘passive consumer’ of health care or social care must be replaced by activities that promote a collaborative attitude, thus defining the user as an active citizen (SKL – Sveriges kommuner och landsting [Swedish Association of Local Authorities and Regions] 2010). This support of the development of user organizations and their future influence was aimed at developing evidence-based practice in treatment and care in Sweden for persons with substance use disorders. Evidence-based practice in this particular context should ideally be combined with scientific knowledge related to successful treatment methods, and should consider users’ experiences and their treatment needs (Socialstyrelsen [The Swedish National Board of Health and Welfare] 2011).

SKL (Swedish Association of Local Authorities and Regions) opined that the traditional view of the patient/user as a ‘receiver’ of health or social care should be replaced by a more modern view, where the user is also considered as an active partner (SKL – Sveriges kommuner och landsting [Swedish Association of Local Authorities and Regions] 2010). To achieve long-term recovery from substance-related problems, individuals need support and assistance from others, both from staff and non-professional members of user organizations. The latter have often had similar experiences of substance use disorders and life conditions (Tracy and Wallace 2016).

The results of a Swedish research study about how political rhetoric regulates user influence, conducted at a psychiatric administration and a social services unit, showed that user influence is subject to considerable control and regulations; however, the users did have the opportunity to raise their issues on an individual level. The study also concluded that staff members were very supportive of the participation of user organizations at an organizational level (Eriksson 2015).

An in-depth case study examining user involvement in mental health care was carried out in 2008–2012. The results showed that users wanted to be involved in treatment development, and when staff actively supported them, user involvement occurred. However, the study also suggested that user involvement is sometimes unrepresentative and tokenistic (El Enany, Currie, and Lockett 2013).

Interest in treatment of substance use and in users’ influence in this area, increased in Swedish social services and health care when support from the Swedish government was initiated (SKL – Sveriges kommuner och landsting [Swedish Association of Local Authorities and Regions] 2010). During the years of national support being provided, one person with lived experience was appointed to support
the total number of new user organizations. This person was presumed to have extensive knowledge in the field of substance use treatment and services. This ‘change agent’, sometimes called a ‘key person’, could also help to identify and solve any problems that arose (Couros 2013). A defined task of this agent was to remain informed about local user organizations, in order to establish contacts between these entities and treatment centres. The role included providing initial and ongoing support to user organizations while they defined their position and explored their opportunities to influence substance use treatment in their regions. The long-term goal was to routinize these efforts, thus eliminating the need for continuing dependence on a change agent.

Previous findings (Bunn et al. 2006) show that patients who are active in making decisions about their own treatment are inclined to make more rational decisions, an example of involvement on an individual level. Studies also indicate positive effects in the processes of users’ mental health rehabilitation; for example, in developing social skills (Peterson, Hounsgaard, and Nielsen 2008). On a structural level, state-centred conception and support of such a practice model can lead to excluded groups of patients being included in influencing their own treatment (Hernandez, Robson, and Sampson 2010).

The Socialstyrelsen [The Swedish National Board of Health and Welfare] (2011) has also implied that user participation may influence the development of care and treatment interventions from an organizational perspective.

**Users and their influence**

A ‘user’ can be defined as a final beneficiary of a public utility – the party who receives the service (Dahlberg and Vedung 2013). The term ‘user’ here includes patients, clients, and ordinary citizens utilizing societal resources, and seems to be commonly used in many countries to refer to persons in treatment for substance use disorders (SUDs) (American Psychiatric Association 2013).

The Socialstyrelsen [The Swedish National Board of Health and Welfare] (2007, 2011) recommends *user* as a collective consensus concept to represent all patients who are receiving individual treatment in the form of social, somatic, and psychiatric care. The term has been accepted following consensus across municipalities and several user organizations.

**Levels of users’ influence**

There are three different levels at which patients and users can exert influence on health care and social services:

- **User participation at a structural level**, which may include participation in policy programmes. (It should be noted that user participation at a structural level is not part of this study, because the primary focus was on users’ development of their user organizations.)
- **User influence at an organizational level**, which involves representatives from user organizations or individuals participating in the development and decision-making processes of operational availability or care content.
- **User influence at an individual level**, which implies that the individual is expected to take part in the planning of their own care or treatment. At this level, users can influence the alignment of their own care and the social support that is provided; hence, they can influence their own life situation. User influence at the individual level is mandatory according to the Swedish Social Services Act (SFS 2001:453). Broadly, the Act states that the social organization efforts of the individual must be designed and implemented in collaboration with said individual and, if necessary, with other community agencies and organizations, as well as other associations (SFS 2001:453).
Implementation

To define implementation the six phases in the implementation process described by Fixsen et al. (2005) is useful. The process starts with 1) an initial phase of exploration and testing are the first step in deciding to use a method, then 2) installing programs or methods. This phase involves various practical issues in resources and structures to start working with the programme or method. After this installation 3) an initial phase of implementation begins. If this works this phase evolves into 4) a form of operational phase or institutionalization where the programme/method becomes an established part of the business and where it may become relevant 5) innovation and development. In the long term perspective, it is also important that the programme/method achieves 6) sustainability in order to be able to function for several years despite changes in the environment.

Governments sometimes create policies that rely on implementation by organizations, and which require practice changes on the part of different areas of the health care system, with little understanding of the differences between and complexities of these agencies. Barriers may be in place when it comes to practical changes (Watt, Sword, and Kreuger 2005). Kleintjes et al.’s (2010) research study describes specific strategies for improving user participation in mental health care, in order to support the development and implementation of relevant policies. Only a small number of studies have been conducted regarding national support for the development of user influence at an organizational level (Rosenberg and Hillborg 2016).

Swedish national support for the development of user organizations in the field of substance use treatment began in 2009. At this time, only five among Sweden’s twenty-one regions had an active user organization in this area. During the period 2009 to 2014, with the help of national support, an increase in the number of user organizations was achieved. One specific support programme involved educating the user organizations in how to conduct user audits in health care and social services. These audits consist of a form of questionnaire regarding patients’ experiences of treatment and care. Several studies of user involvement in psychiatric care in London indicate that user surveys are useful for describing a patient’s situation and their experience of treatment (Crawford et al. 2003). When national financial support ceased in 2014, there were still active regional user organizations in twenty of the twenty-one Swedish regions.

This four-year follow-up study was designed with the intention of examining whether national support programmes can stimulate implementation of user influence in health care and social services. There is a need for further evaluation studies focused on describing the implementation process of such support (Bhattacharyya, Reeves, and Zwarenstein 2009).

The national implementation project was tax-financed; therefore, it was important to follow the implementation process to discover the results and determine whether the implementation methods used were successful (SKL – Sveriges kommuner och landsting [Swedish Association of Local Authorities and Regions] 2010). Both politicians and taxpayers could take an interest in whether the national financial support was a worthwhile expenditure.

Aim

The aim of this four-year follow-up study was to assess whether user organizations continued their work following the end of the national support programme, and whether their influence in social services and health care for persons with substance use disorders, at both organizational and individual levels, had been successfully implemented.

Method and materials

Participants

The participants in this study comprised members from 14 Swedish user organizations supporting persons with substance use disorders. Emails and postal addresses for each local user organization
were obtained through an initial web search and from referrals from the change agent, who had been selected to support users in the development of regional user organizations (SKL – Sveriges kommuner och landsting [Swedish Association of Local Authorities and Regions] 2010). The researchers contacted each user organization’s office and asked if the members would be interested in taking part in this follow-up study by completing a questionnaire about their organization’s contacts, and about participation in health care units and social services in their region.

**Data collection**

A questionnaire was developed, inspired by questions raised to user organizations between 2009 and 2015, when they were supported and financed by the SNBHW. The questionnaire was formulated on the basis of Fixsen et al.’s (2009) implementation perspective. Some questions focused on the termination of the national support, how this had affected the user organizations, and how (or if) termination of this support had affected the success of user involvement. Most questions focused on the user organizations’ contacts and participation in social services and health care for persons with substance use disorders, while another theme addressed whether the organizations’ goals had been successfully implemented, and if so, how this had been achieved (see Appendix).

**Data analysis**

Content analysis was applied to analyse, describe and group the answers and narratives from the questionnaires. There are two types of content analysis at two different abstraction levels: the manifest consists more of what is directly narrated in a text, while the latent requires researchers to interpret what is meant by a text (Graneheim and Lundman 2004). It has been stated that any content analysis involves some kind of interpretation, but this can be more or less deep (Graneheim, Lindgren, and Lundman 2017).

In order to analyse this study’s data, the authors had to apply manifest content analysis for some answers and a more interpretive, latent analysis to gain a deeper understanding of other responses to the questionnaires. The first step of reading through the whole text was conducted by each author, followed by an initial and independent analysis of the answers by comparing the two authors’ assessments, and finally arriving at a consensus evaluation. Some analyses use descriptive statistics; however, due to the small number of organizations and subjects, the results of the current study are presented in numbers, rather than percentages.

**Ethics**

All participants responded to the questionnaires confidentially as representatives of their user organizations, not as identified individuals. No personal data were requested. All participants were informed about confidentiality and their right to withdraw from the study at any time. Ethics consent for conducting this study was approved in 2017 by the Regional Ethical Review Board in Linköping, Sweden.

**Results**

The results from this four-year follow-up (Table 1) study show that fourteen user organizations were still active in 2018, four years after the national support ended. The results also show that the influence of user organizations in social services and health care for persons with substance use disorders, at both organizational and individual levels, has been developed over time.
Termination of national support

Some user organizations reported that the long-term perspective had been undermined when national support ceased. They also reported that, without national support, a range of resources and opportunities were no longer available to them. Examples of the most common narratives include a decrease in educational possibilities, and in the ability to meet with colleagues in other user organizations to make plans and discuss shared issues.

Involvement in care activities

Some user organizations noted having weekly contact with inpatients and outpatients in active treatment, while others stated that they visited patients on a more irregular basis. The purpose of supporting patients in their social situations, and in maintaining their abstinence from substance use, was consistent across the responses. This is an example of user organizations’ influence on an individual level. To evaluate user influence at an individual level in social services and health care, the user organizations have developed user audits in the form of questionnaires to evaluate patients’ experiences of, and participation in, their own treatment and care. There seemed to be an overall trend in each region of increases in the development and implementation of user audits over time during the period relevant to the current study.

Supporting and maintaining users’ influence

The responses indicate that, when national support ended, about half of the user organizations identified new ways to regularly finance their continuing work. This work included participation in treatment planning with social services and health care authorities at organizational and individual levels. The other half of the responding user organizations reported temporary economical support when participating in their regions different activities, such as education for staff or conducting user audits. There were also significant differences between the regions: some organizations were regularly financed by foundations and some obtained financing from their regions’ municipalities.

Among the user organizations in the sample, ten were able to gain representation in their regional health services’ user committees and eight also participated in dialogue meetings with managers from their regional psychiatric departments and substance use treatment centres. This is an example of user organizations participating on an organizational level. Four of them, also

<table>
<thead>
<tr>
<th>Themes arising from results</th>
<th>Citations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Termination of national support</td>
<td>When national support ceased, the long-term perspective was undermined. Resources were no longer available and educational support ceased. It is economically much more difficult to operate without support.</td>
</tr>
<tr>
<td>Supporting and maintaining user influence</td>
<td>Our user organization is financed by our regional culture department. Our organization is represented in the regional health service’s user committee. We participate in dialogue meetings with managers from psychiatric departments, the substance use treatment centre, and social services.</td>
</tr>
<tr>
<td>Involvement in care activities</td>
<td>We have regular meetings with outpatients regarding active treatment and sometimes also with their relatives. Members from our user organization visit inpatients at the local substance use disorders treatment centre every week. Many members in our organization are trained in conducting user audits.</td>
</tr>
<tr>
<td>The impact at both organizational and individual level increased</td>
<td>We are involved in steering groups in our regional substance use treatment centres. Nowadays, we also participate in conferences in both healthcare and social services. In recent years we have developed user audits aimed at increasing knowledge of patient situations in treatment. Currently, our user organization is involved in the development of individual treatment plans.</td>
</tr>
</tbody>
</table>
established regular contact with social service units for providing support to relatives of persons with substance use disorders.

Among the fourteen responding user organizations, the majority noted that their members experienced ongoing and stable contact at an individual level with substance use treatment units in social services and health care systems. Additionally, twelve of the fourteen user organizations considered their most important task to be establishing and maintaining contact with users in active treatment provided by health care bodies or social services. Other stated goals included representing users, maintaining user commitment, increasing user influence in health care, and ensuring that users received the treatment they were entitled to. A minority (three) of the user organizations considered their main task to be carrying out user audits, because of the potential for documenting user experiences and using these accounts as background information for developing treatment and care plans for patients with substance use disorders. These user organizations were also working actively to support users at an individual level.

**Influence at the organizational and individual level**

During this four-year follow-up period, user influence increased at both organizational and individual levels. This included eight user organizations becoming more involved in steering groups responsible for treatment development. Recently, user organizations have also participated in educational conferences for staff and user organizations in the field of substance use disorders. At these conferences, they have been able to inform staff working in health care and social services about patients’ rights to participate in their own treatment planning. Some differences between regions were identified, but they did not seem to be influenced by the regions’ geographical locations or their population densities.

While the current study was in progress, the user organizations were developing user audits aimed at increasing knowledge of patients’ experiences of treatment. By 2018, all fourteen responding user organizations reported having at least one member who had been trained to carry out user audits. The majority of the organizations had conducted a user audit and provided feedback to patients and staff at treatment units about their results.

**Discussion**

The response rate for this four-year follow-up study was fourteen among twenty possible responding organizations, fifteen of which were still active in 2018. The researchers perceive this response rate as being high, and possibly contingent on the researchers’ participation in informational meetings within users’ organizations in different regions. During the time when national support was being provided to the user organizations, the researchers attempted to establish a personal contact with their representatives. This was achieved by participating in national meetings where the problems facing user organizations were discussed. During one of these initial meetings, the researchers introduced themselves and presented their interest in the development of user organizations.

National support to user organizations was supplied annually from 2009 to 2014, and the organizations were initially not aware of when this financial support would end. They had to re-apply for support at the beginning of each year, which they reported to be a burdensome task. It may have been better for the user organizations’ continuity if this support had been part of the intervention from the beginning. Support was supplied at a national level, but may have been more effective if local health care and social services had got that national support in cooperation with the user organizations. The change agent was employed and active at a national level, which made it possible for all user organizations to get equal support.

It appears as if financial support was vital for the development of user organizations. In Sweden, the influence of user organizations has been a factor in somatic and psychiatric treatment in social services and health care for a long time.
The user organizations appear to have reached the fourth phase of implementation (Fixsen et al. 2005), where their participation had become an established part of the business. The results of this study indicate that user organizations have been invited to discuss treatment development issues in health care and social service settings. Previous studies indicate that state-centred conception as a practice model can lead to excluded groups of patients being included at the level of everyday participation in their own treatment (Hernandez, Robson, and Sampson 2010).

Manual-based user audits aimed at describing patients’ treatment situations were, during the period of this study, carried out in a rigorous and qualified manner. User audits were also perceived by user organizations as an important tool for influencing treatment, aimed at individual users. Several studies regarding psychiatric care in London have shown that the most common way to study user influence at an individual level is through questionnaires/user audits (Crawford et al. 2003). A recommendation is that Swedish regional social and health services’ support user organizations by requesting user audits as an evaluation of patients/users experience of treatment and care.

Individual support to inpatients and outpatients has been implemented, and may be important for the future success of patients’ abstinence. This support can also strengthen patients’ motivation and compliance to treatment. It can be defined as the process of giving and receiving non-professional assistance from individuals with similar conditions or circumstances to achieve long-term recovery from substance-related problems (Tracy and Wallace 2016). It seems that a combination of support from professionals and the interest of user organizations may lead to a more permanent model of user influence (El Enany, Currie, and Lockett 2013).

Narratives from the respondents mentioned that they were involved in steering groups and conferences in the fields of health care and social services. This could indicate the progress of user influence in treatment development at an organizational level.

It is known from other research results that, despite a supportive policy context, progress towards achieving greater user involvement can be slow and often concentrates on lower levels of involvement (Ocloo and Matthews 2016). This could be due to current models of patient and public involvement (PPI) being too narrow, indicating that organizations who can present more equal involvement strategies that could lead to user/patient empowerment should receive greater attention (Ocloo and Matthews 2016).

It may be particularly interesting to evaluate, on a more detailed level, the specific themes or subjects adopted by the user organizations. There appears to be limited empirical research demonstrating successful implementation in this field (Arnett 2016).

Since user audits have been developed and implemented in most regions in Sweden, their impact at an individual level has increased. Future research may wish to follow the user organizations when they present the results from the user audit to staff. This may provide information as to whether these audits have been used to improve the treatment and care delivered to patients.

As mentioned above, the National Guidelines for Substance Abuse Treatment (Socialstyrelsen [The Swedish National Board of Health and Welfare] 2007) provided new recommendations for the integration of a user perspective within treatment (Socialstyrelsen [The Swedish National Board of Health and Welfare] 2007). More detailed recommendations on how to implement user involvement in the national guidelines may be helpful in the future. Studies indicate that practice guidelines may be important tools for improving the delivery of evidence-based practice, which includes an integration of user perspective, research results, and professionals’ experiences of treatment (Perron et al. 2010).

Some members of user organizations’ have full-time jobs elsewhere, which implies that even if they receive compensation for work trips and lost income, their commitment to engaging in work with these organizations must be carried out in their spare time. This may impede the sustainable development of user organizations. To overcome this situation the recommendation is that user organizations’ members will get some kind of part time permanent employment for the commitment in the user organization.

Some of the respondents described difficulties in terms of reaching out to treatment services, due to negative attitudes from staff towards people with addiction problems. This is probably caused by
the fact that many health care staff members are not used to cooperating with users regarding treatment issues.

A Swedish doctoral thesis (Eriksson 2015) presents the conclusion that, when society supports the participation of user organizations, the potential for users to influence their own treatment on an individual level increases. The study also states that, when society supports the involvement of user organizations, most treatment staff are very supportive, and that such organizations have developed strong controls and regulations.

**Strengths and limitations**

The strength of this study lies in the fact that all fifteen existing and active user organizations were contacted and fourteen responded. The sample was thus the most representative example of users that could be included.

Limitations in this study are partly that members of the user organizations responded to the questionnaires confidentially, as representatives of those organizations; however, despite this confidentiality measure, they were in the beginning of the study somewhat reluctant to respond. This was probably caused by their not being accustomed to participating in research studies. The eventual advantage appeared to be that they could be fairly open in their answers.

In studies of organizations, the information provided may be influenced by several factors. In this study, the respondents’ sense of exclusion, and how they had previously been treated in health care and social services contexts, may have been of importance. Patients who have had negative experiences of treatment may tend to give a more negative view regarding their user influence, while those with more positive experiences may give more positive responses, as well as being more open to collaborative activities.

Another limitation of this study may be that the responders from each user organization might not entirely reflect all the members’ experiences of user influence at organizational and individual levels. This study describes how members of user organizations have experienced their influence in the context of substance use treatment, but does not extend to how substance use treatment professionals experience the degree of user influence on treatment units, or how inpatients and outpatients view their opportunities to influence their situations. The results from this study are based on responses from the user organization we have studied, and if user influence has increased in the other regions are not known.

The authors’ experience in this field was partly established on more than 20 years’ work in health care and social services with persons with substance use disorders. Both authors were involved in the evaluation team for the National Guidelines for Treatment of Substance Use Disorders (The Socialstyrelsen [The Swedish National Board of Health and Welfare] 2007, 2015).

**Conclusions**

Users’ influence in social services and health care increased during the period when the user organizations were receiving financial support from the Swedish government. The conclusions are based on a four-year follow-up study, conducted in 2018 and is based on the responding user organizations.

According to the majority of the responding user organizations, user influence has increased during the past four years. There have also been improvements in responses from the social services and health care sectors, and an increased number of invitations from consultation groups to user organizations.

Despite four years without receiving financial support from the Swedish Government, user organizations have nonetheless been implemented, and they remain active in fifteen out of Sweden’s twenty-one regions.
The responses described users becoming more involved at an individual level, since the organizations have started to carry out user audits in the social services and health care systems. Evaluations by user organizations using user audits were developed successively between 2014 and 2018, and took place more frequently in 2018 than in 2014.

One difficulty for user organizations has been organizational cohesion. Problems such as financial support and finding people who are able and willing to devote their time to this type of work are two factors that have had an impact in this regard.

Future research

To increase knowledge of common effects and results in terms of substance use treatment in Swedish social services and health care systems, the following studies need to be carried out.

- Continued follow-up of user organizations’ experiences of influence on treatment, success factors, and obstacles within substance use treatment in health care and social services.
- Qualitative interviews with user organization staff, representatives of user organizations within steering groups, and inpatients and outpatients who are in attendance.
- A questionnaire focused on users’ influence, provided to staff at various treatment units in social services and health care institutions, which may include participation in locally developed policy programmes.
- Qualitative interviews with heads of steering groups and local politicians in health care and social services about their attitudes and future goals in terms of including user representatives as participants in policy programmes.
- Quantitative studies, national or regional, conducted in both social service and health care. The data collection could be conducted by using a survey distributed to as many users as possible. Example of questions to the users:
  - Are you a member of a user organization?
  - Do you participate in decisions concerning your own treatment?
  - Have you participated in the development of clinical guidelines?
  - Have you been working as a peer support specialist in health care?
  - Have you participated in education for professionals?
  - Have you been involved in evaluations like user audits?

Disclosure statement

No potential conflict of interest was reported by the authors.

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Appendix

Hello!

We, Ylva Benderix and Johan Billsten, are currently conducting a follow-up study regarding user influence in substance use treatment in health care and social services.

This questionnaire has been sent to all user organizations in all regions in Sweden. The questions address the development of user organizations at an organizational and at an individual level. It would be valuable to us should you be inclined to discuss and answer the questions collectively during your next meeting.

Participation in this study is voluntary and confidential. You should not provide any personal information. You can consider your answers as representative of your user organization.

If you want more information about this follow-up, please contact us by email: ylva.benderix@lnu.se or johan.billsten@lnu.se.

Please complete the questionnaire with support from your colleagues within your user organization.

QUESTIONS

1. Which region’s user organization do you represent?
2. When was your user organization founded?
3. How long have you (the person/persons who is answering the questionnaire) been a member of your user organization?
4. How many members are there in your user organization?
5. How has your user organization been affected by the fact that the national support has expired?
6. Has your user organization received any financial support for the past four years? (If so, please give details.)
7. Does your user organization receive any other form of support (e.g. education, access to meeting rooms, or other)?
8. Are members of your user organization represented in any steering groups or other groups (local and regional) in your region? (If so, please state which ones.)
9. Which occupational groups does your user organization meet with (politicians, managers, health professionals)?
10. Does your user organization also encounter users who have ongoing treatment contact?
11. What are your organization’s main tasks in collaboration with health care?
12. Does your user organization also have contact with the substance use treatment branch of social services in your region?

- If so, what influence does your user organization have there?
13. Which issues are relevant to your user organization at present?
14. What has been your experience of the development of user influence in the health care system in your region during the last four years (accessibility, treatment and care planning, involvement in implementation plans, etc.)?
15. What has been your experience of the development of user influence in social services in your region during the last four years (accessibility, treatment and care planning, involvement in implementation plans, etc.)?
16. How do you perceive the status of user influence in your region?
- Individually (i.e. the user’s involvement in their own care planning)?
- Organizationally (for example, planning of care locations, outpatient care, treatment focus)?

17. Has anyone in your user organization been trained in how to carry out user audits? If so, how many people?
18. Have you carried out any user audits in your region? If so, how many, when, and what kind of treatment service?
19. Have you presented the results of the user audit to the staff at the treatment centre where the audit was conducted?
20. Have the results led to any active changes in treatment within the treatment centre where the user audit took place?
21. Please add any other important information that was not asked for directly in the survey, but which you consider important to provide.

Thank you for participating!

The researchers’ email addresses:

ylva.benderix@lnu.se and johan.billsten@lnu.se