FEDERAL RESEARCH PROGRAMME ON DRUGS

SUMMARY

SUMHIT

Substance use and mental health care integration

A study of service network in mental health and substance use disorders in Belgium, their accessibility, and user's needs

AUTHORS:

Mégane CHANTRY (UCLouvain) Jürgen MAGERMAN (HOGENT/UGent) Kim FERNANDEZ (Sciensano) Clara DE RUYSSCHER (UGent) Deborah Louise SINCLAIR (UGent) Ilse GOETHALS (HOGENT) Jérôme ANTOINE (Sciensano)

PROMOTORS:

Pablo NICAISE (Coord) – Institute of Health and Society (IRSS), UCLouvain
Jessica DE MAEYER – EQUALITY//ResearchCollective, HOGENT
Lies GREMAUX – Sciensano
Wouter VANDERPLASSCHEN – Department of Special Needs Education, UGent
Freya VANDER LAENEN[†] – Department of Law and Criminology, UGent
Philippe DELESPAUL – Department of Psychiatry and Neuropsychology and School for Mental Health and Neuro Science, Maastricht University



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EXECUTIVE SUMMARY

- PROMOTORS:
 Pablo NICAISE (UCLouvain)

 Jessica DE MAEYER (HOGENT)

 Lies GREMAUX (Sciensano)

 Wouter VANDERPLASSCHEN (Ugent)

 Freya VANDER LAENEN[†] (UGent)

 Philippe DELESPAUL (Maastricht University)
- AUTHORS: Mégane CHANTRY (UCLouvain) Jürgen MAGERMAN (HoGent/UGent) Kim FERNANDEZ (Sciensano) Clara DE RUYSSCHER (UGent) Deborah Louise SINCLAIR (UGent) Ilse GOETHALS (HOGENT) Jérôme ANTOINE (Sciensano)









Published in 2024 by the Belgian Science Policy Office (BELSPO) WTCIII Simon Bolivarlaan 30 Boulevard Simon Bolivar 30 B-1000 Brussels Belgium Tel: +32 (0)2 238 34 11 - Fax: +32 (0)2 230 59 12 http://www.belspo.be http://www.belspo.be/drugs

Contact person: Aziz Naji Tel: +32 (0)2 238 36 46

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I. PRELIMINARY NOTE

Drug addiction and mental illness are sensitive topics with different interpretations depending on the terminology used. Across the different sections of the present report, we tend to refer to substance use disorders (SUD), whatever the substance is, including alcohol, and to mental disorders or mental illness (MI). We also refer to "care" as any type of support, either medical, psychological, social, or other, and to people utilising care services or in need of care as "care users" or sometimes "users". We, therefore, distinguish people who use drugs without specific needs from people who have substance use disorders, and from care users, i.e. people utilising services or in need of care. We are using these terms in a generic sense, without any specific, normative orientation that would underlie these concepts. The conceptual framework underpinning the whole research is the personal recovery approach ⁽¹⁻⁴⁾, key aspects of which we expound upon in the following pages. Although the concept is also subject to different interpretations, we understand it as an approach to SUD and MI that supports the autonomy, social inclusion, empowerment, and personal resources of people in need of care in order to develop a meaningful life despite the possible problems related to illness ⁽¹⁾.

II. GENERAL BACKGROUND

A. Introduction

This is the executive summary of the final report of the research project "Substance Use and Mental Health care Integration, a study of service networks in mental health and substance use disorders in Belgium, their accessibility, and users' needs" (SUMHIT). The research addressed several aspects of the divide that exist between the organisation of care in mental health, which we refer to as "generic" in this report (e.g. based in community mental health services or psychiatric wards), and in substance use disorders, which we refer to as "specialised" in this report.

It is well established in the scientific literature that many people who have a substance use related disorder (SUD) also have concomitant mental disorders, while many people with mental illness (MI) also use drugs. However, care in the specialised SUD sector and in the generic mental health care sector (MHC) have been developed separately. Professionals and services from both sectors do not always collaborate efficiently, and users cared for in the two sectors may have different profiles of needs. In addition, there might be care needs that are unmet because of the divide. In this context, the main objective of SUMHIT was to examine and assess the place of people who use drugs in the field of generic mental health care. The project also examined the availability of generic mental health care for people with SUD and the capacity of both generic mental health care and specialised SUD care sectors to collaborate within the regulation framework of the mental health service networks that have been established in Belgium since 2010. Using both quantitative and qualitative data, SUMHIT addressed three levels of study: care users, care professionals and services, and the whole care system. In particular, the research examined (1) the met and unmet needs of people with SUD in terms of mental health care and their care pathways, (2) experiences of professionals (clinicians and service managers from the full range of generic and specialised services, network coordinators...), and (3) structural care system features (e.g. networks) that frame practicing collaboration. Key findings and suggestions for organisational mechanisms were discussed with key stakeholders from the two main linguistic communities as to provide authorities and professionals with evidence-based policy and care recommendations in order to improve the continuity of care between sectors, the tailoring of care pathways to specific profiles, and to support a global approach of care users' personal recovery.

B. State-of-art

Many people who have a substance use disorder (SUD) suffer from concomitant mental disorders, while many people with mental illness (MI) also use drugs. Estimates of drug use among people with MI usually range from 20 to more than 50%^(5, 6). In Belgium, within the evaluation of the 'Title 107' reform of mental health care delivery (2014-2015), among the 1,200 service users with severe MI recruited across all service types from the mental health service networks, 18.5% had a concomitant diagnosis of SUD⁽⁷⁾. People with co-occurring SUD and MI have more severe adverse outcomes than people with either condition alone, in terms of accessibility to services, unmet needs, adherence to treatment and relapse, social integration, and personal recovery⁽⁸⁾. However, in most countries, including Belgium, the specific care and assistance sector dedicated to people with SUD (hereafter, "specialised drug-addiction sector") has been developed separately from the generic mental health care (MHC) sector. Most people using either generic MHC or specialised SUD services are facing, however, similar complex and long-term problems, both in nature and extent. Their medical, psychological, and social needs require comprehensiveness from the part of the care providers, in particular in terms of care continuity and personalised care ^(1, 3, 4, 9-12).

The divide is on the side of clinician and care system practices, not on the side of users ⁽¹³⁾. Specifically in Belgium, the lack of capacity of services to address the issues of people with multiple needs, in particular regarding people with SUD, was outraised as an important weakness of the mental health care reform ⁽¹⁴⁾. Moreover, fragmentation is amplified by the complex distribution of health policy responsibilities between the Federal State and the several overlapping federated entities (Regions and Communities) ⁽¹⁵⁾. However, during the first two decades of the 21st century, both the SUD and MHC sectors have undergone major changes. Regarding MHC, at the beginning of the 2000s, the Belgian generic MHC sector was still heavily hospital-centred, with one the highest rates of hospital beds per inhabitant in OECD countries, and lengthy stays in psychiatric inpatient services (16, 17). The nation-wide reform policy of mental health care delivery, known as 'Title 107', started in 2010. It established networks of services with four main aims: (1) to strengthen the supply of care in the community, (2) to improve continuity of care within and across care sectors, (3) to reduce and intensify the resort of hospital stays, and (4) to favour the social rehabilitation of care users (15, 18). Regarding the specialised care for people with SUD, a new drug policy framework, calling for a comprehensive and integrated drug policy, was established in 2001⁽¹⁹⁾. It shifted the main priority of the Belgian drug policy from enforcement to prevention and assistance. This policy framework, combined with the devolution of health policy responsibilities to federated entities, prevention and assistance supply sectors (including harm reduction and rehabilitation) grew importantly, with a variety of novel interventions and service types embedded in multiple approaches. Alike in the generic MHC sector, the priority in the specific SUD sector was given to community services and a strong emphasis was placed on social rehabilitation over more traditional, residential drug-free treatment - though the latter remained on the continuum of existing assistance options. Therefore, the conditions aligned with a renewed model of collaboration or integration between the two sectors. The main objective of SUMHIT was the examination and assessment of the current situation and opportunities for improved comprehensiveness of the care supply in MH and SUD care.

More particularly, one key weakness of the Belgian healthcare system, both in SUD and MHC care, is its low capacity for continuity of care ^(20, 21). Continuity of care encompasses three main dimensions: cross-sectional continuity, i.e. the capacity for multiple clinicians and services to offer comprehensive care and support within one care episode; longitudinal continuity, i.e. the capacity of the care system to maintain contact with chronic users across episodes of care; and relational continuity, i.e. appropriate therapeutic alliance ⁽²²⁾. Whilst relational continuity of care is mainly related to elements at the individual level, longitudinal and cross-sectional continuity are strongly affected by organisational and system dimensions. For example, research has indicated that collaboration within service networks was driven by interpersonal and informal relationships rather than by formal and organisational mechanisms⁽²³⁾. However, little is known about how to effectively organise care within service networks ⁽²⁴⁾.

In other respects, for some years, literature on both SUD and MHC has strongly emphasised personal recovery as overarching principle ^(1, 3, 9-11, 25-28). Personal recovery is widely evidenced in the literature and sustained by several evidence-based interventions (4, 12, 25, 27-41). Personal recovery is an approach to psycho-social rehabilitation of people with mental or substance-related impairments that aim to support them regain their autonomy despite illness ^(1, 2). Therefore, services and interventions working within this approach consider social integration (housing, activity, participation in social life, and personal goals) as a priority over the management of illness and symptoms. This implies the people's involvement in decisions regarding their own health and care and the use of people's preferences and own resources in defining care objectives and outcomes, social inclusion being the priority ^(28, 35, 40-42). Because of its potential overarching nature, the framework of personal recovery is likely to help care professionals of both sectors to set shared objectives between them and with users. Therefore, the adoption of a personal recovery approach is expected to reduce issues in continuity of care, and consequently, to reduce the risks of adverse events and crises episodes, as well as to strengthen the user's autonomy and right to choose what they consider to be the most appropriate and suitable treatment. Moreover, at the level of services and the whole care system, the personal recovery approach is likely to reduce the key issues of care continuity and fragmentation that delays the system capacity to respond to care users' needs. Therefore, it should result in a reduction of the use of crisis and emergency care, reduce the overload of most services (and reduce the waiting time to access services), and eventually reduce system costs while increasing system effectiveness. It is expected to be especially impactful for the most vulnerable subgroups. Despite evidence and the availability of evidence-based tools and interventions, however, the approach is only gaining interest from many care professionals in Belgium⁽⁴³⁾. In this research, we argue that the personal recovery approach is likely to favour an optimal integration of the SUD and MHC sectors ⁽¹⁰⁾.

C. Research questions and content of the report

SUMHIT addressed three levels of study: (1) care users, (2) care professionals and services, and (3) service networks and the care system. The main research question has been "what is the current level of collaboration/integration between the (generic) MH and (specialised) SUD care sectors and how can it be effectively improved?"

To address this main research question, several work packages were carried out with specific actions at the three levels of study. The study used a mixed-methods approach, as both quantitative and qualitative data was collected at these three levels, and different methodologies were used to analyse them, including statistics, social network analysis, inductive and deductive thematic analyses, and

document and literature reviews. When composing the final report, it seemed more consistent to present the results according to several research sub questions at the three study levels, instead of reporting results per work package. Indeed, most of these research subquestions are addressed with findings from multiple analyses. Therefore, the full report is structured around five sections.

The first section is an *introduction and general background of the study*. In the second section, we addressed the *users' needs and access to services*. A self-reported survey was carried out with users of diverse service types across the country in order to assess the users' met and unmet needs, and the predictors of these needs. Findings obtained during the course of the project allowed us recruiting care users with specific profiles for a deeper exploration of these needs during qualitative interviews. We examined the access and use of care by users and intended to unveil whether users of generic MH and specialised SUD services had different needs and what the determinants of accessing and using these two sectors were. We also examined the lived experience of users in their contacts with both sectors, including the barriers and facilitators encountered. Users with no (more) contacts with the care system were also included in this part of the study.

The third section reports the *professionals' experiences*. These experiences encompass the relationships of professionals with care users, but also the perceived barriers and facilitators in the collaboration process with other professionals and services, in particular within the service networks. This section also reports experiences of collaboration and interventions developed elsewhere and good practices retrieved from the literature. The forth section addressed the *level of networks and the care system*. In particular, we examined the specificities of the care supply and the structure of networks, with a specific view on the positioning of specialised SUD services in the broader context of MHC service networks.

Finally, the fifth section is a *general discussion* of the findings obtained at the three levels of study and includes the study *recommendations for both policy and practice* in order to improve the collaboration capacity of both sectors. These recommendations were elaborated upon through co-construction with managers and decision-making stakeholders. The general discussion and recommendations are included in this executive summary.

D. General methodology and study setting

SUMHIT addresses the capacity of the Belgian mental healthcare system to encompass the needs of people with SUD therein. Therefore, the research is framed, at the organisational level, within the mental-health policy that established networks of services in 2010 in order to cover the mental health needs of the population ^(15, 18). More specifically, the reform policy established 20 network areas across the country (12 in Flanders, 1 in the Brussels-Capital Region, and 7 in Wallonia). Five areas were selected for the study. The selection was made based on several criteria: (1) we wanted to include the three regions, (2) we wanted to include large urban areas, where people with SUD and mental comorbidity are usually found more easily and the provision of services is more important, but we also wanted to include semi-urban areas where the provision of services may be scarcer. In addition, (3) previous research on mental health service networks indicated that these networks may vary considerably in terms of size, i.e. number of services included, as well as in composition, i.e. proportion of service types ^(44, 45). Based on these criteria, we selected five network areas: Antwerpen (SaRA), Aalst-Dendermonde-St-Niklaas (GGZ ADS), and Zuid-West Vlaanderen (GGZ ZWVI) in Flanders; Brumenta (the Brussels

network, which is composed of 4 subnetworks: Brussels-East, Hermes+, Rézone, and Norwest); and the "Réseau Santé Namur" in Wallonia (See map).

In the five areas selected, several research actions were carried out. At the level of users, a survey on care needs and contacts with services was organised. The survey was based on a self-reported guestionnaire that was composed with different scales validated in the literature. In particular, it included the Camberwell Assessment of Needs-Short Appraisal Scale for Patients (CANSAS-P) in order to assess the needs for care in 23 domains ⁽⁴⁶⁾. For the survey, we aimed to obtain information from at least 500 users, half of them recruited from the Dutch-speaking area and the other half from the French-speaking area. In addition, we aimed to recruit half of the sample from generic MHC services and the other half from specialised SUD services. 53 qualitative interviews with users were also conducted (34 in Dutch and 19 in French) with users of services as well as with people who dropped out of care. At the level of care professionals and services, a service survey was also carried out with the help of tools used in previous research (47, 48). The survey was based on an online guestionnaire filled out by service team members and addressing the organisation of the services, staffing, funding, targetgroup of users, accessibility, care supply, orientation towards recovery, and contacts with other services in the network. Focus groups were also organised with professionals and peer-workers. These data were complemented by literature reviews. Finally, two focus groups (one per linguistic group) were carried out with managers, coordinators, and decision-makers, in order to co-elaborate the final recommendations. Detailed methods are presented in each section of the report.



Source: www.psy107.be

III. MAIN FINDINGS AND RECOMMENDATIONS

A. Main findings

The research question underlying SUMHIT addressed the current level of collaboration and integration between the generic mental health and the specialised substance use disorder care sectors. It examined how integration could be improved effectively. To this end, we assessed various aspects of the phenomenon at the level of care users, the level of professionals and services, and the level of the service networks and the care system, using both quantitative and qualitative methods.

The study confirmed the high prevalence of the **comorbidity that associates substance use related disorders and other mental disorders** in relative terms. The study was not designed to assess the prevalence of comorbidity in absolute terms, i.e. the estimation of the rate of comorbidity in the general population. However, several findings of SUMHIT clearly confirmed the strength of the association between mental disorders and substance use. The examination of the care needs of service users who are using substances, both in the generic mental health care and the specialised addiction care sectors, indicated that <u>users having an unmet care need in mental health were five times more likely to also</u> <u>have an unmet need regarding substance use</u>, and vice-versa. When <u>the need of mental health care</u> was met, however, the need of care related to substance use was significantly three to four times lower.

The experience reported by these care users indicated the extent to which this comorbidity raised specific **barriers to care access** in both generic mental health and specialised addiction care sectors. Not only did the study confirm the high prevalence of this comorbidity, it also highlighted **the numerous care needs** that are associated with it, such as socio-economic, daily activity, and relationship needs. The latter, particularly, appeared to be an unmet care need domain for the majority of users, including for a class of care users who reported less care needs. This finding indicates the extent to which this population suffers from **social isolation**. It is clearly evidenced in the scientific literature that <u>social isolation and connectedness have a major impact on mental health</u> ⁽⁴⁹⁻⁵¹⁾ as well as on the capacity of individuals to access appropriate support ⁽⁵²⁾.

The study also indicates that the care needs of people with mental and substance-related comorbidity do not affect both genders similarly. Women were significantly associated with the class of care users reporting mainly met care needs compared to the two other classes, i.e. users with few needs and users with many unmet needs. Therefore, women tended to report more care needs, although they did not report a higher number of unmet care needs. It is known, in the literature, that women tend to have less access to specialised addiction services and inpatient psychiatric services, although they would access more outpatient mental health services than men ⁽⁵³⁻⁵⁵⁾. Further research should investigate this phenomenon in more detail, but these findings indicate that **gender is a factor that requires specific attention** and different care access mechanisms ⁽⁵⁶⁾.

SUMHIT also indicated that, according to services, **31% of care users in generic mental health services were identified as having a substance use related disorder.** This rate might be somewhat overestimated in relation with participation in the survey, but remains significant. A majority of service users, recruited either in generic mental health or specialised addiction services, had their needs met in the specific domain of the service, i.e. mental health or addiction. However, <u>users recruited in generic mental health</u> services were more likely to report unmet needs regarding substance use, while users recruited in specialised addiction services were more likely to report unmet needs in mental health as well as socioeconomic needs. The study identified several determinants of care needs and indicated that access to services was not only driven by such needs. We observed that the number of care needs, in particular **the number of unmet care needs, was associated with lower social integration and lower quality of life**. We also noted that having more unmet care needs was associated **with the use of multiple substances**. Care users who use illicit drugs, in particular opiates, were more likely to be treated in specialised addiction rather than in generic mental health care services, despite also being more likely to report unmet needs related to their mental health. However, results show that care users who had **contacts with generic social services had a significantly lower number of unmet needs.** The most deprived population likely has limited access to generic mental health care, in particular people who use opiates and multiple substances, and even less to the most generic types of services, e.g. social services.

Barriers to care are clearly experienced and reported by care users. <u>The results can be put in perspective</u> with the high number of services (41%) that declared **substance use as an exclusion criterion to start treatment**. Whilst it can be understandable that the use of substances can be an adverse condition for several therapeutic programmes at the individual level, this criterion is a barrier to care at the population level and affects other needs and conditions of care users. At the level of networks, <u>the full</u> range of care supply should be available to care users within a determined catchment area. We used an adapted version of the ESMS classification tree ^(57, 58) in order to describe with more detail the care supply in the five study areas. From a population point of view, the presence of drug-free services, i.e. services supplying therapeutic programmes in which the use of substances is not allowed, either generic or specific, should be complemented in the care supply with **other services that are available to people who use drugs** and who follow another pathway to recovery. We, therefore, recommend that network coordinators look more closely at the range of care supply available in their area and within the network so that there is sufficient care supply available for people who use drugs.

In the qualitative interviews, care users also reported experiences of stigma, particularly regarding substance use in the generic services. Care users described how stigma could be a barrier accessing appropriate information on care options and treatment. They specifically pointed to insufficient attention to the trauma that many of them experienced in their life or care trajectory, and the feeling of not being really listened to. This feeling strengthens their global impression of care fragmentation, with care professionals and services being unable to communicate information with each other and unable to adapt care to the individual needs and situations. A textbook example of such incapacity is reflected in the phenomenon of waiting lists. Most services manage their caseload with such waiting lists, which may have a significant impact on the global care trajectory of care users with substance use disorders, perhaps more so than on other care users given the importance of motivation for behaviour change. Whilst waiting lists are mainly the consequence of organisational features, they are perceived by care users as a mark of fragmentation and silo working, as many services apply lengthy admission processes. Care users still point to the importance of some individual care providers who can also have a great impact on the care trajectory. Trust towards professionals is of utmost importance and care users report good practice examples of key professionals that were "really listening" and caring, although these encounters tended to occur by chance. Care users felt the importance of such encounters in their care trajectory and claimed for some form of case management that would be based on principles of mutual trust (e.g. strengths-based case management ⁽⁵⁹⁾). Care users also pointed to the importance of peer workers for the establishment of such mutual trusting relationships. In the survey of services, we found that across service types and networks, about 30% of services reported having at least one peer-worker.

Other results from the survey on services, however, only confirmed partially the users' experience. On the one hand, waiting lists and the experience of restricted access to some services is consistent with the results of the survey on services indicating that generic mental health care services, in particular inpatient services and rehabilitation services have significantly more restrictive access conditions. While it is also understandable that inpatient services have more restrictive access conditions, this appears to be counterproductive for rehabilitation and generic outpatient mental health care services in general. On the other hand, however, silos, i.e. the tendency to favour collaboration with other services in the same sector, were not clearly reflected in the structure of contacts existing between services. Homophily, which is the measure of such tendency of services to refer care users to services of the same type (i.e. within generic mental health or within specialised addiction services) was low in many networks, and tended to be more noticeable across specialised addiction services than across generic mental health care services, with the exception of some sub-networks in Brussels. This result has to be interpreted with caution, however, given the specific characteristics of the network in Brussels in terms of size and subnetworks. Nor do specialised addiction services appear to be more peripheral in the network than generic mental health services. We must admit, however, that participation in the service survey may have been driven by the topic of the study and, hence, that the services that were more involved in care for people with substance use disorders may have been more actively participating in the survey.

Nevertheless, the structure of contacts between services may not sufficiently capture the content of the care process for users. It remains interesting to note, however, that **the existing structure of contacts between services allows for collaboration and possible coordination.** In several networks, there exist many contacts and referrals between services and across service types. In many cases, however, the structural model of integration that emerged from contacts is **favourable to** *linkage*, i.e. numerous links between all services in a network, which allows for primary integrated operations and responds to the milder needs of care users. In several networks, the services with higher centrality were hospital units. Within a personal recovery approach, however, a higher centrality of outpatient services would be expected. Likewise, more complex needs and formalised operations of integration might require more *coordination*, which is found in networks with higher centralisation.

Results from the literature review indicate that **most of the issues identified in SUMHIT are also topics of debate elsewhere.** Several studies point to the <u>need for more recovery-oriented policies</u>, appropriate training of professionals, and adapted organisational frameworks. In addition, studies highlight the necessity for professionals to support care users' recovery capital, i.e. not only providing medical and psychological treatment but also addressing elements related to their social inclusion, like housing and employment. While it is not possible to provide a global recommendation for networks, as the structural features of a network need to be tailored to the local needs and situation, we can recommend that network coordinators examine their local context and service supply more carefully based on the findings emanating from SUMHIT.

All studies have their limitations, and SUMHIT is no exception. One of the main limitations of the study was that we only had limited access to office-based care providers, such as GPs, psychiatrists, and psychologists. These care professionals, however, take on an important role in care delivery for the target group of people with mental and substance use disorders in Belgium. For instance, SUMHIT found that most care users recruited into the study reported at least one contact with a GP during the year before the survey. In other respects, recent policy measures allowed for the reimbursement of up

to twenty yearly visits to a psychologist who is registered with a mental health network. It is possible, therefore, that some specific care users' profiles were not covered in the study. Likewise, it is possible that we missed a part of the care supply. In the qualitative interviews, we also tried to include people who had no access to care services, although even people who had least contacts with the care system were, to some extent, in contact with some type of care provider, e.g. with low-threshold programmes, outreach teams, or the so-called *'lieux de liens'*, i.e. peer-run services aiming at socialisation, as found in Brussels and Wallonia. We cannot rule out the fact that some severely deprived populations with the highest level of needs were missed.

Other limitations are related to the participation rates in the surveys. We know that some care sectors were highly reluctant to participate, either because they did not feel concerned about the topic, or because they considered that they had insufficient resources to participate. Regarding the latter limitation, we recommend that more support is given to services so that they can be fully involved in research projects that aim to improve care effectiveness.

B. Recommendations

Based on SUMHIT findings, we formulate several recommendations for policy authorities as well as for local care providers and network coordinators. Several of these recommendations were discussed during two focus groups, one in each linguistic community. For each recommendation, we briefly outline the supporting key findings and how these findings may relate to other parts of the study. We also indicate the stakeholders for whom the recommendation has implications and provide examples and avenues of how to operationalise it in practice. Recommendations are presented at the macro-(networks and care system) and meso- (services and care professionals) levels.

1. Recommendations at the macro level

Recommendation 1: Personal recovery is an evidence-based approach to mental health care and care for substance use disorders. Principles of personal recovery should be considered in the general organisation of care in mental health and in specialised care for people who have substance use disorders, as well at the level of organisational mechanisms (funding, provision, governance) as at the level of services, individual care professionals, and interventions.

<u>Stakeholders involved</u>: All policy authorities with competence in health care (Federal and federated entities), network coordinators and service managers, individual care professionals

<u>Examples and avenues for action</u>: This is an overarching recommendation. See the following recommendations for examples and avenues for action.

Personal recovery principles are evidenced and implemented in the organisation and delivery of care in most high-income countries ⁽¹⁻⁴⁾. These principles have also been suggested as the guiding framework for better coordination and integration of care in mental health and care for substance use disorders ^(28, 35, 40-43). The main features of the personal recovery approach are the support for the person's strengths and own preferences for recovery, with an emphasis on social integration, opportunity for maximum social participation, and rehabilitation as the priority objectives of each individual's journey to recovery. It is, therefore, based on sense of self, social connection and supportive relationships, continuous support of hope for change, empowerment, and support of coping skills. People with mental or substance use disorders have the capacity to develop a meaningful life despite the possible impairments engendered by illness. It requires reducing stigma and actively creating meaningful perceived positions from the side of the society. Recovery, sometimes designated as 'clinical recovery',

i.e. in the limited sense of decreasing symptoms of mental illness or change in substance consumption behaviour, is only one possible pathway to care and can be a consequence of personal recovery rather than a precondition for personal recovery to occur⁽⁶⁰⁾.

Personal recovery was also the theoretical postulate underpinning SUMHIT and, therefore, the support for the personal recovery approach is not a result of the study per se. However, several findings of the study are consistent with the need to strengthen this approach in the organisation of care supply in Belgium. It supposes giving priority to objectives of social inclusion and quality of life, working with the care users' preferences, providing users with all the information required so that they can chose their preferred care options and reducing barriers to care access. Several interventions at the micro-level can be envisaged, such as working with peer-workers or providing flexible care-management based on care users' preferences. At the meso-level, service managers and network coordinators need to organise themselves to provide the full range of care supply at the network level so that all care options, including for instance harm-reduction oriented services, are available and users are provided with the information required. At the macro level, provision and funding schemes are expected to facilitate contacts and information exchange across services. For instance, findings from SUMHIT indicated that accessibility was significantly more restrictive in services that apply out-of-pocket payments. Several suggestions are further developed in the following recommendations.

Recommendation 2: Personal recovery is a novel approach that should ground care and social support for people with mental and substance use disorders. As such, principles of the personal recovery approach should be included in the basic education and training of social and care professionals. In addition, continuous training in the personal recovery approach should be made available to social and care professionals.

<u>Stakeholders involved</u>: Policy authorities with competence in health care (Federal and federated entities), policy authorities in the federated entities with competence in education, authorities responsible for university and high school teaching programmes, network coordinators and service managers, organisations providing continuous training to social and care professionals.

Examples and avenues for action: Inclusion of lectures and course modules on personal recovery and rehabilitation in university programmes in medicine, particularly in specialisation programmes for general medicine and psychiatry; inclusion of lectures and course modules on personal recovery and rehabilitation in university programmes in clinical psychology and orthopedagogy; Inclusion of lectures and course modules on personal recovery and rehabilitation in high school programmes in social work, nursing, special needs education, and any other professional training oriented towards care and social support; organisation of continuous training modules centred on personal recovery and rehabilitation; providing financial incentives for the organisation of such programmes; providing incentives (e.g. in the form of accreditation points) to professionals attending lectures and course programmes on personal recovery and rehabilitation.

Although care professionals reported being supportive of interventions that are in line with personal recovery principles, results of SUMHIT indicate that there are some misunderstandings about what personal recovery means and about how to implement it in everyday practice. These arguments are also found elsewhere, as reported in the literature ⁽⁴⁾, and professionals identify the need for more training. Changes in the current care practice and organisation have not led to sufficient updates of education and training programmes. Personal recovery skills should be integrated in the most generic education programmes, and not only in modules for specialisation.

Recommendation 3: The inclusion of peer-workers in care teams is an evidence-based method that facilitates the personal recovery approach, both in generic mental health care and specialised care for people with substance use disorders. In line with the previous recommendation, more training programmes for peer-workers are required.

<u>Stakeholders involved</u>: Policy authorities with competence in health care (Federal and federated entities), policy authorities in the federated entities with competence in education, network coordinators and service managers, organisations providing continuous training to social and care professionals.

Examples and avenues for action: Establishment of training programmes for peer-workers at professional and academic level.

The inclusion of peer-workers in the staff of services is one of the evidence-based interventions in support of the personal recovery approach ⁽⁶¹⁻⁷⁰⁾. Peer-work is a twofold intervention, as it supports care delivery and also has a positive influence on the own recovery journey of peers ⁽⁷¹⁾. Findings from SUMHIT indicate that peer-workers are active in about one third of the services. The value of employing peer-workers is recognised by most professionals with experience of working with them, and they are also in demand by service users. It is not always easy, however, to find and include peer-workers in care staff. Whilst working with peer-workers can be included in training programmes for professionals, there is also a need to prepare, support, and supervise peer-workers. A few training programmes for peer-workers exist and were praised by professionals in SUMHIT. Therefore, these programmes should be extended and made available to a larger number of care users.

Recommendation 4: Network coordinators and service managers should establish specific care circuits for people with support needs related to substance use disorders, as care circuits could be established for other multiple and complex needs. Care circuits for people with support needs related to substance use disorders should not be limited to generic mental health and specialised addiction services, but include any type of health and social care and act in stepped-care logic, i.e. providing the most generic care as first option.

<u>Stakeholders involved</u>: All policy authorities with competence in health care (Federal and federated entities), with a particular attention to the Federal authorities managing mental health networks; network coordinators and service managers.

<u>Examples and avenues for action</u>: (a) At the macro-level: facilitating mechanisms for pooled funding; (b) at the meso-level: establishment of central primary care entry points (e.g. *Kruispunten*), personalrecovery-oriented case-management for care users without sufficient capacity for navigating the care system; (c) at the micro-level: access priority to accommodation or crisis services for users who registered for a care plan, financial incentives for services that collaborate with other services in the network based on a care plan for a care user (pay-for-performance).

The mental-health reform policy that has been implemented since 2010 ('Article 107') was based on the establishment of service networks and care circuits. While service networks were implemented, care circuits have been disregarded. Care circuits are not specific to people with mental illness and substance use disorders. There could be care circuits for any complex need. A care circuit is a bundled care package defined for a specific target group of care users, with the objective to improve care coordination and continuity of care ⁽⁷²⁾. It may include specific access criteria to services, dedicated information exchange tools, and specific mechanisms for allocating resources and financing interventions and services. Several examples of forms of care circuits exist in other care systems abroad, either public (e.g. clustering, or Payment by Results in the UK ^(73, 74)) or private (e.g. within managed care

in the USA ^(75, 76)). A care circuit does not imply a defined care trajectory nor any predefined care objective. The suggestion is based on organisational arrangements for people and services participating voluntarily. For such a group of care users and services, specific mechanisms may apply, e.g. at the micro-level, the definition of a care plan for participants, access to specific interventions such as case-management; at the meso-level, priority access rules to specific services, such as crisis centres, for participants; and at the macro-level, specific funding mechanisms (pooled funding or pay-for-performance incentives) supporting the care circuit. There are many options that can be included in the care circuit, and it is up to stakeholders to discuss and agree on the most appropriate interventions and mechanisms to be included. Yet, care organisation needs to be considered at the area and population level, and not only at the individual level.

Findings from SUMHIT indicate that the structure of contacts between services makes it possible to develop more linkage and coordination options. However, there is a slight trend towards homophily, more particularly from the part of specialised addiction services. Nonetheless, even when a specific care circuit is not defined, as far as people with substance use disorders are concerned, there should be more collaboration mechanisms that associate both generic mental health care and specialised addiction services and that aim to provide care beyond substance management.

Recommendation 5: Personal recovery requires higher social inclusion and social support to tackle stigma regarding people who have needs with mental health and substance-related issues. Actions are therefore needed to decrease stigmatisation towards people with care needs in mental health and substance use disorders in the general society as well as among care professionals and services.

<u>Stakeholders involved</u>: All policy authorities, with a specific attention to authorities with competence in health care (Federal and federated entities); network coordinators and service managers.

<u>Examples and avenues for action</u>: Information and prevention actions against stigma, information diffusion about positive mental health; inclusion of the topic of stigma in education and training for care professionals, in particular towards professionals who are not specialised in mental health and in addiction, such as primary care and social support professionals.

The main finding supporting this recommendation stem from qualitative interviews with care users, who repeatedly reported how they felt stigmatised in society and services and experienced the consequences of stigma, particularly people using substances in generic services. A textbook example of stigma, reported by care users, was the lack of capacity of professionals to cope with trauma. Stigma was, to some extent, also reflected in the high proportion of services (41%) who reported substance use as an exclusion criterion to start treatment. This proportion was high in services delivering rehabilitation programmes. A sizable proportion of services apply this exclusion criterion in line with a drug-free therapeutic programme, i.e. not allowing substance use in order to follow their care programme, particularly inpatient services. Globally, however, this criterion constitutes an organisational barrier to care access, in particular when no alternative service is available in the catchment area of the network. Therefore, the recommendation is twofold: on the one hand, network coordinators and service managers are invited to reconsider the rationale behind this exclusion criterion; on the other hand, network coordinators and services are also invited to consider the care supply available at the area level, so that alternative services are made available.

Stigma may also result from limited knowledge about specific disorders and needs. Therefore, network coordinators, service managers, and individual care professionals are encouraged to develop awareness about stigma mechanisms and consider tackling stigma in their everyday, routine practice.

It is worth noting that hope for change and mobilising the care user's resources are key principles of personal recovery ^(3, 60). Stigma may result from a priori, unconscious beliefs that care users have no chance to progress in their recovery journey or that they do not have sufficient resources and capacity to apply for some intervention or care option. These attitudes are not consistent with evidence indicating that recovery is possible, and should be avoided.

2. Recommendations at the meso level

Recommendation 6: Care supply and availability of services and interventions should be examined at the area level, i.e. network, so that the full range of services and interventions is made available to care users. Therefore, the role and mission of generic mental health and specialised addiction services should be clarified at the network-level.

<u>Stakeholders involved</u>: Policy authorities regulating services (Federal and federated entities); network coordinators and service managers.

<u>Examples and avenues for action</u>: Update of care directories that include a refined typology of service types, collaborative setting of inclusion and exclusion criteria in services, any initiative aiming to improve mutual knowledge, trust, and information exchange across services within the network.

Findings in SUMHIT indicate that the care supply is spread unevenly across catchment areas, i.e. service networks. Several barriers reported by care users are related to waiting lists, long and burdensome processes for accessing care, and lack of information exchange across services. The survey on services also indicated that networks were very different in size and composition, with several service types and interventions being unevenly distributed. Each service defines its own inclusion and exclusion criteria. In order to avoid these barriers, the care supply should be considered at the area and population levels, so that individual service rules and therapeutic programmes can be compensated by alternative services available elsewhere in the network. A clarification of the care supply that is available should be considered at the network level, including more efficient tools for referral and information exchange, including with primary care, self-help, and low threshold services that can enhance social connection and continuity of care ⁽⁷⁷⁾.

Recommendation 7: In line with the previous recommendation, information exchange between services in networks should be improved.

<u>Stakeholders involved</u>: Policy authorities regulating services (Federal and federated entities); network coordinators and service managers.

Examples and avenues for action: Implementation of shared information systems across services.

This recommendation has been repeatedly formulated in care evaluation research. Yet, lack of information exchange is still an issue at both the micro-level, i.e. between professionals involved in the care delivery of individuals with multiple care needs, and at the meso-level, i.e. across services concerning their care supply and target groups. Several tools for data collection and information exchange exist at both levels. Several authorities in Belgium have recommended the implementation of the Bel-RAI suite of assessment tools (See: <u>https://belrai.org</u>). Since the use of the Bel-RAI was not examined within SUMHIT, we are unable to determine whether this tool is helpful to address the issue of information exchange between services. Other tools also exist or are being tested. Yet, shared tools and instruments are surely required. Tools should also contribute to assess user-reported information and experience (PROMs and PREMs)⁽⁷⁸⁾, particularly at the local level. Authorities should also offer support to services in order to test and assess the tool's implementation. Support can take the form of

training and financial or material resources, but can also consist in more coherence in the tools used for information sharing. For example, several services and professionals are requested to collect administrative information with different tools making data collection a burdensome task to carry out, resulting in data that can be hardly compared.

Recommendation 8: Network-level interventions should be considered and implemented more systematically to support care users navigating services according to their care needs and preferences. This may include, but is not limited to, case management, central primary care points, outreaching, and peer-support.

<u>Stakeholders involved</u>: Policy authorities regulating services (Federal and federated entities); network coordinators and service managers.

<u>Examples and avenues for action</u>: Establishment of central primary care points (e.g. *Kruispunten*) where any type of care need can be assessed and where information about appropriate care options is found; care users are oriented and supported to access appropriate care resources. Implementation of recovery-oriented case-management, i.e. an intervention for people who are unable to navigate the care system, in which a case manager can help orienting the user according to care needs, preferences, and strengths, in collaboration with usual social and care professionals; inclusion of the identification of any type of care need as part of the tasks of outreach workers and adequate referral; broader inclusion of peers within services.

Several network-level interventions were considered in SUMHIT. In particular, case-management was discussed on several occasions. There were, however, different views on the objectives and principles of case-management. For instance, case-management in addiction has sometimes been implemented with a view to orient care users with substance use disorders in a care pathway towards abstinence. In mental health care, there are different variants of case-management, e.g. with case-managers being one of the professionals caring for the care user, or being a broker between different professionals. Case-management is also sometimes seen as a long-term intervention while, in other forms it is offered as a crisis or time-limited intervention (e.g. Critical Time Intervention)⁽⁵⁹⁾. In the Netherlands, the model of Flexible Assertive Community Treatment (F-ACT) tries to combine several models ⁽⁷⁹⁻⁸³⁾. While within SUMHIT, we cannot conclude whether a case-management model is more appropriate to care users and services involved in networks, it appears that the interest of a case-management intervention is deemed useful for people who are, temporarily or more definitely, unable to find their way in the care system and across available resources. Relational continuity was reported as a priority. Therefore, case management needs to be implemented at the network-level, in support to the care supply. Some local care providers warned against an overly instrumental, brokerage interpretation of case management, and argued that case-managers should explicitly focus on further developing the clients' natural network and context. Such form of case-management can also contribute to counteract social isolation (See Recommendation 10). Evidence supports the interest of the F-ACT model (84, 85). Nonetheless, in line with other recommendations, case-management should be carried out according to personal recovery principles (59, 86).

Other interventions aiming to support collaboration within networks can be envisaged. Another intervention that was supported during focus groups with professionals and decision-makers were central primary care points, e.g. *Kruispunten* (i.e. Crossroads). The role of outreach teams can be strengthened to support navigating the network, in combination with case-management. The role of peer-support has also been emphasized earlier. Still other interventions can be mentioned. Authorities are recommended to facilitate and support the implementation of such interventions, for instance by

providing the appropriate funding and governance mechanisms. Indeed, individual service funding and Fee-For-Service (i.e. funding according to the number of care acts provided), which are the most utilised funding mechanisms in the Belgian care system, do not favour collaboration and referrals across services ^(20, 87), nor do they facilitate interventions that are not related to an individual service. As recommended earlier, pooled funding, episode-based funding, and incentives related to the registration to a care circuits or elements of Pay-For-Performance (i.e. funding based on the achievement of determined objectives) based on objectives of social integration of care users might be preferable. Funding mechanisms in care systems are, however, a complex and sensitive topic. The recommendation is not pointing to a specific mechanism, but rather reconsidering funding mechanisms alongside care provision and innovative interventions.

Recommendation 9: In line with the previous recommendation, interventions and organisational mechanisms should be implemented to reduce and avoid the resort to waiting lists.

<u>Stakeholders involved</u>: Policy authorities regulating services (Federal and federated entities); network coordinators and service managers.

<u>Examples and avenues for action</u>: The examples provided for recommendation 8 also apply to recommendation 9: establishment of central primary care points (e.g. *Kruispunten*) where any type of care need can be assessed and where information about appropriate care options is found; care users are oriented and supported to access appropriate care resources. Implementation of recovery-oriented case-management, i.e. an intervention for people who are unable to navigate the care system, in which a case manager can help orienting the user according to care needs, preferences, and strengths, in collaboration with usual social and care professionals; inclusion of the identification of any type of care need as part of the tasks of outreach workers and adequate referral; broader inclusion of peers within services.

Waiting lists to access services have repeatedly been identified as a counterproductive mechanism. In SUMHIT, care users also emphasised the extent to which waiting lists were detrimental to an effective journey towards recovery. Perhaps waiting lists are even more detrimental for people with substance use disorders as motivation for change plays a key role in the recovery journey of these care users. Waiting lists are usually related to a lack of sufficient resources to address all the care demands. However, waiting lists may also be related to the lengthy, sometimes burdensome, process of admission applied in many services. Findings in SUMHIT indicated that this type of admission process was more frequent in generic mental health and inpatient services. Some admission processes could be avoided or substantially reduced if they were conducted at the network-level (See previous recommendation) or if there was more accurate information exchange across services at the time of referral. All network-level interventions are supposed to reduce the adverse effect of admission procedures, including the resort to waiting lists.

Recommendation 10: Trauma-informed care is an important approach for people with substance use disorders, both in generic mental health care and in specialised care settings. Additional knowledge training and structural embedding of trauma-informed principles are suggested.

<u>Stakeholders</u> involved: network coordinators and service managers, individual caregivers and therapists, organisations providing specific training to social and care professionals.

Examples and avenues for action: Establishment of specific training programmes for reference workers.

Evidence shows that coping with traumatic experiences is an essential part of the recovery journey of many people with SUD^(88, 89). In SUMHIT, care users reported needs that can be addressed with more trauma-sensitive care. Many service users experienced that care professionals too often focused on here-and-now issues, whereby working with a traumatic past may remain under the radar. Trauma-informed care requires focus on mutual connection, safety, and attention to the impact of profound childhood experiences and their effects on the brain, emotions, thought patterns, and eventual behaviour. An important prerequisite is acknowledging and resisting stigma⁽⁹⁰⁾.

Because trauma-informed care requires a systematic approach, it is important that it is embedded in a supported vision of services. In the focus groups with professionals and peer workers, participants acknowledged the lack of trauma-informed care, even if they did not clearly suggest how to operationalise this approach in the existing care supply. Training of professionals and attention to this topic from peer workers, however, are indicated. We recommend that stakeholders reflect further on this topic. Qualified and mandated reference persons can play a pivotal role here.

Recommendation 11: Social isolation and loneliness should receive higher priority in care interventions for the target population.

<u>Stakeholders involved</u>: Network coordinators and service managers, individual care professionals.

<u>Examples and avenues for action</u>: Assess and adress the social support (network) of care users; inclusion of peers, friends, relatives, and carers in interventions as a standard practice; establishing social integration as a priority objective when working with care users with mental illness and substance use disorders.

One of the major findings of the SUMHIT study on users' care needs was the high level of unmet needs regarding care users' social relationships in terms of intimate relationships, friendship, sexual relationships, and company. On the one hand, this finding is consistent with results reported in the literature⁽⁹¹⁾. On the other hand, this finding is also highly consistent with the general recommendation to support connectedness and the social integration of care users in a personal recovery approach⁽³⁾. It is likely that care professionals insufficiently address issues related to all levels of social contacts (from generic social support to intimate and sexual relationships) because they tend to address issues at the individual level, somewhat disregarding the social context in which these issues arise. It is also likely that they may lack tools and interventions to address the most intimate needs. Yet, the literature clearly indicates that loneliness is a powerful predictor and determinant of mental illness, in particular regarding psychosis^(92, 93), mood⁽⁹⁴⁻⁹⁶⁾, and substance use disorders⁽⁹⁷⁻¹⁰¹⁾. Effects of loneliness on mental health were strongly exacerbated during the COVID-19 pandemic^(102, 103). Therefore, tackling loneliness and social isolation is simultaneously a clinical and public health priority. Professionals and experts by experience in Brussels reported an interest in better understanding the social support network of care users. While further research and initiatives are needed regarding this specific aspect, various methods

and interventions do exist and may be of interest to care professionals ⁽¹⁰⁴⁻¹⁰⁸⁾, with peer-support as a key feature ⁽¹⁰⁹⁾. Other examples include drop-in centres where people can go for coffee or a meal, nonclinical settings where they can go for (day) activities and social contacts (e.g. *lieux de liens*), recovery houses for having a drug-free home and engagement in self-help and mutual aid groups ⁽⁷⁷⁾.

Recommendation 12: Accessibility to services, improved coordination, and integration should not be limited to health care. Reliance on the most generic services should be possible for anyone, and integration concerns the full range of health and social services.

<u>Stakeholders involved</u>: All policy authorities, with a specific attention to athorities with competence in health care and social welfare (Federal and federated entities); network coordinators and service managers, individual care professionals.

Examples and avenues for action: Create and adapt organisational mechanisms for funding, provision, and governance of social and care service supply.

Findings from SUMHIT indicate that the care users who accessed generic social services, i.e. social services accessible to the general population, had significantly more care needs met than other care users. This finding is consistent with previous studies on users of the mental health networks in Belgium ⁽¹¹⁰⁾. This finding is also highly consistent with our recurrent recommendation to put forward social integration objectives at the forefront of interventions. The federal government and several federated entities have recently promoted plans to support a higher integration of care and social support (See the Interfederal Plan on Integrated Care and Support https://www.inami.fgov.be/SiteCollectionDocuments/plan interfederal soins integres rapport final interfederaal plan geintegreerde zorg protocole 08112023.pdf). For some unexplained reason, however, the Interfederal Care Plan was not developed within the same organisational framework as the mental health reform. While "closer links between mental health care networks and primary care are sought wherever possible", both policy initiatives were developed separately. It is recommended, therefore, that mental health networks, which include specialised addiction care supply, be considered in future developments of funding, provision, and governance mechanisms that facilitate the integration and continuity of social and health care.

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